

# PARALYSIS RESOURCE GUIDE



CHRISTOPHER & DANA REEVE FOUNDATION

PARALYSIS RESOURCE CENTER®





# PARALYSIS RESOURCE GUIDE

FIFTH EDITION

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*by Sam Maddox*

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Cover photograph by Timothy Greenfield-Sanders

The material contained in this book is presented for the purpose of educating and informing readers about paralysis and its effects. Nothing contained herein should be construed as medical diagnosis or treatment advice. This information should not be used in place of the advice of a physician or other qualified healthcare provider. If any questions arise while reading this book, the PRC strongly recommends contacting a physician or the appropriate healthcare provider.

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## ACKNOWLEDGEMENTS

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*Welcome to the Fifth Edition of the Paralysis Resource Guide. We hope you find its content educational, practical and in some cases, life-changing.*

*This publication would not have been possible without the vision of Sam Maddox and the steadfast leadership of the PRC Senior Director Sheila Fitzgibbon who produced, edited, indexed and fact-checked this edition. Special thanks to my colleagues, Reeve Foundation staff members Rebecca Sultzbaugh, Killeen Marzella, Christopher Bontempo, James Howard, and Bea Torre as well as Jenn Hatfield, Beth Eisenbud, Chris Lambraia, and Maria Fonseca of the Information Specialist team, all of whom contributed to the editing and proofreading of this revision. Very special thanks to Bernadette Mauro for her thorough bulletproofing and editing skills and Patricia Correa for her editing, design and production work. Sincere appreciation to Liz Leyden for writing and refreshing sections of this edition. I'd like to acknowledge Sherman Gillums Jr. of AMVETS and MVP Advisory Council member Janet Andersen for assisting us with updates to our chapter on military and veterans, and Sara Struwe and the staff of the Spina Bifida Association for help with our section on spina bifida.*

*This book is made possible by the support of the Department of Health and Human Services (HHS), Administration for Community Living (ACL). Many organizations in the disability community provided resources as we reach for the highest standards of verisimilitude.*

*The Paralysis Resource Guide is dedicated to the memories of Christopher Reeve and Dana Morosini Reeve. They lived life fully and fearlessly, with purpose and passion. The spirit of Christopher and Dana is embodied in the pages of this book.*

***“Look for ways to let your light shine, but don't be afraid to occasionally be in the dark.” - Dana Reeve***

***Maggie Goldberg***  
*Chief Operating Officer*  
*Short Hills, NJ*





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**HELLO AND WELCOME** to the Paralysis Resource Guide. This book, created by the Christopher & Dana Reeve Foundation Paralysis Resource Center (PRC), offers comprehensive information and connections. Our goal is to help you find what you need to stay as healthy, as active and as independent as possible. The book serves the full community of people affected by paralysis, including loved ones and caregivers—people who know how paralysis can be a family issue.

Our founders, Christopher and Dana, understood how frightening it is to suddenly become paralyzed. Being active one day and immobile the next thrusts you into an entirely new existence. The changes are enormous and often overwhelming.

First, let us assure you that you are not alone. In the United States, there are 1.4 million people living with paralysis caused by spinal cord injury, and hundreds of thousands of others with paralysis caused by other types of trauma or disease. Although it's a club no one would choose to join, there are people who have gone through similar situations who are eager to help you maximize your health and well-being.

The PRC was created to provide information services and resources on the full range of topics related to paralysis, including specific health and clinical information on the various conditions that cause paralysis, whether by stroke, trauma or disease. We have strong ties with many national organizations to make sure you get the most relevant and reliable information.

Paralysis is much more than a medical issue, of course. The PRC hopes to encourage you to be active and to participate in your community as much on your own terms as possible. We have resources available on travel and recreation, specialized assistive equipment and automobiles, and key information to help navigate the healthcare and insurance systems.

You'll also find information on a multitude of organizations around the country that offer programs to promote independent living for children and adults with paralysis. You will find numerous listings in this book devoted to accessibility, health promotion, advocacy, research, and more. We have funded thousands of Quality of Life grants through the PRC and the Christopher & Dana Reeve Foundation to support such organizations around the country.



KEN REGAN/CAMERA 5

If you don't find what you need here in the book, be sure and visit the website, [www.ChristopherReeve.org](http://www.ChristopherReeve.org). If you prefer to speak to a trained Information Specialist, please contact us by phone (toll-free 1-800-539-7309) or email ([infospecialist@ChristopherReeve.org](mailto:infospecialist@ChristopherReeve.org)) and we will research your question for you.

Finally, and perhaps most importantly, we want you to know that paralysis is not a hopeless condition. Scientists are making steady progress in deciphering the complexities of diseases and injuries to the brain and spinal cord; we are convinced that they will succeed in developing treatments for acute and chronic paralysis. To learn even more about promising research, and how to support the Foundation's mission, visit the website [www.ChristopherReeve.org](http://www.ChristopherReeve.org)

— **The PRC Staff**



## Message from the President & CEO

Welcome to the Paralysis Resource Guide, a one-stop handbook to help you and your loved ones through the often bewildering world of paralysis. The goals of this book and of the Christopher & Dana Reeve Foundation Paralysis Resource Center are to improve the lives of millions of people living with paralysis. We offer information you can trust in order to make the best choices for a fulfilling and active life. The Reeve Foundation has over the years invested millions of dollars to support research to

restore function in the damaged spinal cord. While we expect the long-term payoff of treatments and cures, we understand the day-to-day challenges of living with paralysis. That's why we offer tools, services and resources, here and now, through our Quality of Life grants and the Paralysis Resource Center. We also advocate for the rights of people with disabilities; we want you to be armed with the information and knowledge you need to face the world of paralysis with the fierce determination and courage of our namesakes. We have a wonderful, dedicated team here at the Foundation carrying on Christopher and Dana's vision and keeping their legacy of hope and perseverance alive. But we all know there is much work ahead of us; we have yet to reach our goal of mobility, full participation and independence for all citizens. Until that day, we will continue to pursue today's care and tomorrow's cure.

**Peter Wilderotter**

*President and CEO*

*Christopher & Dana Reeve Foundation*

## Message from the PRC Director

The Paralysis Resource Center was created to provide a comprehensive, national resource to promote health, foster community involvement and improve quality of life for people living with paralysis, their caregivers and loved ones. Our staff is dedicated to providing a roadmap to navigate the inevitable chaos of paralysis.

Our message, like that of our founders, Christopher and Dana, is full of hope. It is upbeat and encouraging, credible and realistic. Paralysis can be a devastating occurrence—for the affected individual, of course, but also for families and friends.

The Paralysis Resource Center, formed through a cooperative agreement with the Centers for Disease Control and Prevention in 2002, offers information (in English, Spanish and other languages on demand) directly by telephone from our team of Information Specialists (toll-free 1-800-539-7309), by e-mail ([infospecialist@ChristopherReeve.org](mailto:infospecialist@ChristopherReeve.org)) or online at [www.ChristopherReeve.org/Ask](http://www.ChristopherReeve.org/Ask), and in print here in the Paralysis Resource Guide. The Reeve Foundation's Resource Center offers a variety of services and programs including:

**Peer & Family Support:** This is a national peer-to-peer mentoring program providing emotional support as well as local and national information and resources to people living with paralysis, their families, and caregivers. The program was created to enable people living with paralysis and those who care for them to come together for answers, hope and a way forward. For more information see page 139.

**Information Specialist Services:** Our seasoned specialists, several of whom live with spinal cord injury, answer questions regarding paralysis by providing



WINFIELD WETHERBEE



reliable information and referral to local, state, and national resources. We answer questions on all topics from insurance reimbursement and equipment needs to health information and home modifications. Through interpreter services, our team can provide free information in over 240 languages.

**Quality of Life Grants:** The Quality of Life Grants Program impacts and empowers people living with paralysis, their families and caregivers by providing grants to nonprofit organizations whose projects and initiatives foster inclusion, involvement and community engagement, while promoting health and wellness for those affected by paralysis in all 50 states and U.S. territories. Please visit [www.ChristopherReeve.org/QOL](http://www.ChristopherReeve.org/QOL) for more information on how to apply and to learn about past grantees.

**Military and Veterans:** This Reeve Foundation initiative addresses the needs of service members, whether they are paralyzed through combat-related, service-related, or non-service related events. We help with navigating the military and veterans systems and also with the transition back to the community. See Chapter 8, page 315. [www.ChristopherReeve.org/MVP](http://www.ChristopherReeve.org/MVP)

**Underserved Populations Outreach:** This program serves diverse populations across the United States and partners with organizations to improve the quality of life for people living with paralysis in underserved communities.

**Reeve Connect - Online Community:** Talk about anything and everything. Reeve Connect is a place where distance is not an obstacle when you need to connect with peers and experts on navigating the short and long-term realities of living with paralysis. Whether you're living with paralysis or are a caregiver, this is your community. Make yourself at home, ask questions, share your experiences and feel empowered to be open about the aspects of life that you believe should be talked about in a secure and private forum. Additionally, there are Community Groups for caregivers, veterans, LGBTQ+ identifiers, parents, and advocates where you can connect with others who share similar interests and experiences. [www.ChristopherReeve.org/community](http://www.ChristopherReeve.org/community)

We hope you find this book, and our other information services, to be beneficial. Remember, the Paralysis Resource Center is here for you.

**Maggie Goldberg**  
Chief Operating Officer



JUAN GARIBAY AND ERIC GIBSON BY CHRISTOPHER VOELKER

# 1

## BASICS BY CONDITIONS

Paralysis is the result of nerve damage in the brain or spinal cord due to trauma, disease, or birth condition. This chapter characterizes the primary causes.



The World Health Organization defines paralysis as a central nervous system disorder that results in difficulty or inability to move the upper or lower extremities. According to a study of over 70,000 households initiated by the Christopher & Dana Reeve Foundation, there are nearly 1 in 50 people living with paralysis— over 5.3 million people. That means we all know someone living with paralysis.

### ACUTE FLACCID MYELITIS (AFM)

Acute flaccid myelitis (AFM) is a rare, recently discovered neurologic condition affecting the gray matter of the spinal cord that causes the body's muscles and reflexes to weaken. The Centers for Disease Control and Prevention (CDC) began tracking AFM in 2014. Since then, there have been 633 confirmed cases, with more than 90 percent occurring in young children. Main symptoms include sudden weakness in the arms or legs and loss of muscle tone and reflexes. Additionally, some people might also experience drooping eyelids, difficulty swallowing, slurred speech, numbness, an inability to urinate and pain in the arms, legs, back or neck. Respiratory failure and neurologic symptoms, such as body temperature changes and blood pressure instability, are potentially life-threatening.

The cause of AFM remains unknown, but researchers at the CDC believe that viruses play a role. In data gathered starting in 2014, more than 90% of patients reported a mild respiratory illness or fever before developing AFM. Most cases developed between August and October, correlating with the period each year when many viruses, including enteroviruses, circulate.

#### SOURCES

Centers for Disease Control and Prevention

#### AFM RESOURCES

**Acute Flaccid Myelitis Association (AFMA)** is a non-profit organization

created by parents of children with AFM. It offers information, support, grants and advocacy. [www.afmanow.org](http://www.afmanow.org)

**Siegel Rare Neuroimmune Association (SRNA)** offers information about AFM. 855-380-3330; <https://wearesrna.org>

## ALS

Amyotrophic lateral sclerosis (ALS), also known as Lou Gehrig's disease after the New York Yankee baseball player who was diagnosed with it, is a rapidly progressive neurological disease that affects at least 16,000 Americans with a little over 5,000 new cases occurring each year.

ALS belongs to a group of disorders known as motor neuron diseases. Motor neurons are nerve cells located in the brain, brainstem, and spinal cord that serve as control units and communication links between the nervous system and the voluntary muscles of the body. The loss of these cells causes the muscles under their control to weaken and waste away, leading to paralysis. ALS is often fatal within five years of diagnosis, mainly due to respiratory failure. People who opt for permanent use of a feeding tube and a ventilator after failure of swallowing and respiratory muscles can generally be kept alive for many more years.

ALS symptoms may include frequent tripping and falling; loss of control in hands and arms; difficulty speaking, swallowing, and/or breathing; persistent fatigue; and twitching and cramping. Typically, ALS strikes in midlife. For reasons unknown, ALS is 20 percent more common in men than in women.

Because ALS affects motor neurons, the disease does not usually impair a person's mind, personality, or intelligence. It does not affect the ability to see, smell, taste, hear, or recognize touch. People with ALS usually maintain control of eye muscles and bladder and bowel function.

There is no known cure for ALS, nor is there a therapy to prevent or reverse its course. Riluzole is the only FDA-approved drug shown to prolong the survival of people with ALS—but only for a few extra months. Riluzole is believed to minimize damage to motor neurons due to the release of the neurotransmitter glutamate. ALS patients have raised levels of glutamate in the fluid bathing the brain and spinal cord. Riluzole may also extend the time before a person needs ventilation support. Riluzole does not reverse the damage already done to motor neurons however, and people taking the drug must be monitored for liver damage and other possible side effects.

In 2011, the FDA approved the NeuRx Diaphragm Pacing System (DPS) for ALS patients experiencing breathing issues. Clinical trials demonstrated that DPS neurostimulation helped ALS patients live longer and sleep better than with standard care. [www.synapsebiomedical.com](http://www.synapsebiomedical.com) (see pages 114-115 for more).

ALS experts have identified numerous compounds that show promise for treating the disease. Several drugs and cell therapies are currently being tested in patients.

There is strong evidence that trophic factors, molecules that nurture and protect cells, can rescue dying neurons in animal models of ALS. Indeed, targeted delivery to a vulnerable cell may be beneficial. So far, human trials have failed to follow up on success in animals. This work is still in progress.

A drug called arimoclomol, originally developed to treat diabetic complications, inhibited progression of ALS in a mouse model of the disease. Arimoclomol is thought to amplify “molecular chaperone” proteins, normally found in all cells of the body; these cells may protect a motor nerve cell against toxic proteins, repairing those that are believed to cause diseases such as ALS. Arimoclomol appears to accelerate the regeneration of previously damaged nerves in animals. Early phase clinical trials have shown the drug to be safe in humans; more tests are ongoing for dose and treatment.

**Drug cocktails:** Recent mouse model studies of ALS showed dramatic benefits using a combination of drugs, including Riluzole, nimodipine (a calcium channel blocker used in the treatment of acute stroke and migraine headache) and minocycline (an antibiotic that may block inflammation). The compounds given together appear to delay cell death, prevent nerve cell loss, and reduce inflammation. For more on ALS clinical trials, see [www.clinicaltrials.gov](http://www.clinicaltrials.gov).

Physical or occupational therapy and special equipment can enhance independence and safety throughout the course of ALS. Low-impact aerobic exercise such as walking, swimming, and stationary bicycling can strengthen unaffected muscles, prevent deconditioning, improve cardiovascular health, and help patients fight fatigue and depression. Range-of-motion and stretching exercises can help prevent painful spasticity and muscle contractures (shortening of muscles, limits joint movement). Occupational therapists can suggest devices such as ramps, braces, walkers, and wheelchairs that help people conserve energy and remain mobile, while making it easier to perform activities of daily living.

**Respiratory weakness:** People with ALS are at risk for pneumonia and



pulmonary embolism. Indicators of deteriorating respiratory status can include difficulty breathing, especially when lying down or after meals; lethargy; drowsiness; confusion; anxiety; irritability; loss of appetite; fatigue; morning headaches; and depression. When the muscles that assist in breathing weaken, use of ventilatory assistance (intermittent positive pressure ventilation, IPPV; or bi-level positive airway pressure, BiPAP) may be used to aid breathing during sleep. When muscles are no longer able to maintain oxygen and carbon dioxide levels, these devices may be required full-time.

Another problem common to many people with ALS is the inability to cough forcefully enough to clear away even normal amounts of mucus. People are advised to make sure their fluid intake is sufficient to keep the secretions thin; some take an over-the-counter cough medicine containing the expectorant guaifenesin, a mucus thinner. A weak cough can be made more effective by quad coughing (assisting a cough by applying a sort of Heimlich-like maneuver as the patient coughs), supplying fuller breaths with an ambu-bag to improve the cough, or using a device such as a “cofflator” or “in-exsufflator” (delivers deep breaths through a mask and then quickly reverses to negative pressure to simulate a cough).

**Drooling:** While people with ALS do not overproduce saliva, their swallowing problems can create sialorrhea, or excess salivation and drooling. Sialorrhea can be undertreated—it may take trials of several medications until one provides relief without undesirable side effects.

**Muscle problems:** Spasticity is present in some people with ALS. It causes a tightening of muscles and a stiffening of the arms, legs, back, abdomen, or neck. It can be triggered by a simple touch and can be painful especially if it sets off muscle cramps, common in ALS because of muscle fatigue. Cramps can be very painful but become less severe with time—weakening muscles can’t tighten into a cramp anymore. Fasciculation (muscle twitching) is common, too, though these are not painful so much as annoying.

**Loss of communication:** While the loss of the ability to communicate is not life-threatening or painful, it is a very frustrating aspect of ALS. Although assistive technology offers many solutions, it may be underutilized because people lack information about their options. Assistive devices range from simple call buttons and sensitive switches to small communication boards that speak pre-recorded words and messages. Also, equipment is available to magnify a weak whisper into audible speech. If a person can move nearly any body part, there is potential for some basic communication. Numerous

communication devices are on the market and can be found in many home health dealers or Internet shopping sites. See [www.alsa.org](http://www.alsa.org) for a list of products and vendors.

In experiments using brain waves, people who are locked-in due to ALS have learned to communicate by way of a computer using only their thoughts. For example, trials of the BrainGate System, which implants a sensor in the brain to transmit, have shown that neural signals associated with the intent to move a limb can be “decoded” by a computer in real-time and used to operate external devices, including robot arms. Trials are ongoing; see [www.braingate.org](http://www.braingate.org).

There are other ways that computers can be used by people who are almost totally paralyzed. See pages 296-302 for more information on hands-free control of cursors for communication, entertainment, and even work. Research holds great promise for treatments for ALS, including drugs, cell transplants, gene therapy, and immune system modulation.

### **SOURCES**

National Institute on Neurological Disorders and Stroke, ALS Association

### **ALS RESOURCES**

**ALS Association (ALSA)** features news, research support, and resources; it offers a national network of support groups, clinics, and specialty hospitals. Since 2014, ALSA has funded over \$111 million in research to identify the cause and a cure for ALS. 202-407-8580; [www.alsa.org](http://www.alsa.org)

**The ALS Therapy Development Institute** is a nonprofit biotechnology company working to discover treatments. 617-441-7200; [www.als.net](http://www.als.net)

**Project ALS** focuses on research in ALS. 212-420-7382, 855-900-2ALS (toll-free); [www.projectals.org](http://www.projectals.org)

**Team Gleason** provides adventure, technology, equipment, and care services to people living with ALS; <https://teamageason.org>

## **ARTERIOVENOUS MALFORMATIONS**

Arteriovenous malformations (AVMs) are defects of the circulatory system that are believed to arise during fetal development or soon after birth.

They

comprise snarled tangles of arteries and veins, disrupting the vital cycle that would normally carry oxygen-saturated blood in arteries away from the heart to the body's cells and return oxygen-depleted blood by way of veins to the lungs and heart. An AVM directly connects arteries and veins, and thereby reduces oxygen to nervous system tissue and increases the risk of bleeding.

Arteriovenous malformations can form wherever arteries and veins exist. They occur most often without symptoms. However, AVMs that form in the brain or spinal cord can be especially problematic. Even in the absence of bleeding or significant oxygen loss, large AVMs can damage the brain or spinal cord by their presence. They can range in size from a fraction of an inch to more than 2.5 inches in diameter. The larger the lesion, the greater the amount of pressure there is on surrounding brain or spinal cord structures.

AVMs of the brain or spinal cord (neurological AVMs) affect approximately 30,000 Americans. They occur in males and females of all racial or ethnic backgrounds at roughly equal rates.

Common symptoms of AVMs are seizures and headaches. Other neurological symptoms may include muscle weakness or paralysis in one part of the body or loss of coordination (ataxia). Also, AVMs can cause pain or disturbances of vision or speech. Mental confusion or hallucination is also possible. There is evidence that AVMs may also cause subtle learning or behavioral disorders during childhood.

Diagnosis of AVM is by either computed axial tomography (CT) or magnetic resonance imaging (MRI) scans. Angiography is an accurate way to get the exact location of the malformation. A thin tube is inserted in a leg artery, threaded toward the brain, and then injected with a dye. The scans reveal the AVM tangle.

Arteriovenous malformations can put veins under great pressure since there are no capillaries to slow blood flow. Over time, the AVM may rupture and cause a hemorrhage. While the risk of hemorrhage is small, the risk increases over time; treatment is usually recommended.

**Treatment:** Advances in technique have made surgical treatment of most cases of AVM safe and effective. Surgery inside the skull may attempt to cut out or burn away the AVM with a laser. Another option for smaller AVMs is stereotactic radiosurgery, which focuses radiation on AVM blood vessels to slowly obliterate them. It may take from one to three years to remove the AVM.

A third treatment option is endovascular embolization, which is similar to an

angiogram. A catheter is inserted into a leg artery and threaded through the body toward the affected arteries. A glue-like substance is injected to block key blood vessels leading to the AVM, thus reducing its size so radiosurgery or conventional surgery may treat it.

Surgery is a decision that must be made with full understanding of risks. Untreated, AVMs may lead to serious neurological deficits or death. Surgery on the central nervous system, however, has known risks as well; AVM surgery is invasive and can be quite complex.

### **SOURCES**

National Institute of Neurological Disorders and Stroke, Mayo Clinic, National Organization for Rare Disorders

### **AVM RESOURCES**

**Mayo Clinic** offers many educational materials about arteriovenous malformation and provides treatment at three centers. 507-284-2511; [www.mayoclinic.org](http://www.mayoclinic.org), search arteriovenous malformation.

**National Institute of Neurological Disorders and Stroke (NINDS)** offers clinical detail and resources on AVM. 301-496-5751, toll-free 1-800-352-9424; [www.ninds.nih.gov/Disorders/All-Disorders/Arteriovenous-Malformation-Information-Page](http://www.ninds.nih.gov/Disorders/All-Disorders/Arteriovenous-Malformation-Information-Page)

**National Organization for Rare Disorders (NORD)** includes AVM in its materials. 203-744-0100, toll-free 1-800-999-6673; <http://rarediseases.org>

## **BRACHIAL PLEXUS INJURY**

Brachial plexus injuries are caused by excessive stretching, tearing, or other trauma to a network of nerves located between the spine and the shoulder, arm, and hand. Symptoms may include a limp or paralyzed arm and loss of muscle control or sensation in the arm, hand, or wrist. Chronic pain is often a concern. Injuries often occur due to vehicular accidents, sports mishaps, gunshot wounds, or surgeries; these injuries can also happen during the birth process if a baby's shoulders become impacted, causing the brachial plexus nerves to stretch or tear.

Some brachial plexus injuries may heal without treatment; many babies improve or recover by three to four months of age. Treatment for these injuries

includes occupational or physical therapy and, in some cases, surgery. For avulsion (tears) and rupture injuries there is no potential for recovery unless surgical reconnection is made in a timely manner. For neuroma (scarring) and neuropraxia (stretching) injuries, the potential for recovery is encouraging; most people with neuropraxia injuries recover.

### **SOURCES**

United Brachial Plexus Network, National Institute of Neurological Disorders and Stroke

### **BRACHIAL PLEXUS RESOURCES**

**United Brachial Plexus Network** provides support related to brachial plexus injuries. Toll-free 781-315-6161; [www.ubpn.org](http://www.ubpn.org)

## **BRAIN INJURY**

The brain is the control center for all of the body's functions, including conscious activities (walking, talking) and unconscious ones (breathing, digestion). The brain also controls thought, comprehension, speech, and emotion. Injury to the brain, whether the result of severe trauma to the skull or a closed injury in which there is no fracture or penetration, can disrupt some or all of these functions.

Traumatic brain injury (TBI) is mainly the result of motor vehicle accidents, falls, acts of violence, and sports injuries. It is more than twice as likely to occur in males than in females. The estimated incidence rate is 100 in 100,000 people. The Centers for Disease Control and Prevention estimates that 5.3 million Americans are living with disabilities from brain trauma. The highest incidence is among persons 15 to 24 years of age and 75 years and older. Alcohol is associated with half of all brain injuries, either in the person causing the injury or in the injured person.

People with spinal cord injury often have accompanying brain injury; this is especially true for higher cervical injuries, close to the brain.

Enclosed within the bony framework of the skull, the brain is a gelatinous material that floats in cerebrospinal fluid, which acts as a shock absorber in rapid head movements. Injury to the brain can be caused by a fracture or penetration of the skull (such as a vehicle accident, fall, or gunshot wound),



a disease process (including neurotoxins, infection, tumors, or metabolic abnormalities), or a closed head injury such as shaken baby syndrome or rapid acceleration/deceleration of the head. The outer surface of the skull is smooth, but the inner surface is jagged—this is the cause of significant damage in closed head injuries, as the brain tissue rebounds inside the skull over rough bony structures. With trauma, brain

damage may occur at the time of impact or may develop later due to swelling (cerebral edema) and bleeding into the brain (intracerebral hemorrhage) or bleeding around the brain (epidural or subdural hemorrhage).

If the head is hit with sufficient force, the brain turns and twists on its axis (the brainstem), interrupting normal nerve pathways and causing a loss of consciousness. If this unconsciousness persists over a long period of time, the injured person is considered to be in a coma, a disruption of nerve messages going from the brainstem to the cortex.

A closed head injury often occurs without leaving obvious external signs, however other differences between closed and penetrating injuries can be significant. A bullet wound to the head, for example, might destroy a large area of the brain but the injury may be minor if the area is not a critical one. Closed head injuries often result in more damage and extensive neurologic deficits, including partial to complete paralysis; cognitive, behavioral, and memory problems; and persistent vegetative state.

Injured brain tissue can recover over time. However, once brain tissue is dead or destroyed, there is no evidence that new brain cells form. The process of recovery usually continues even without new cells, perhaps as other parts of the brain take over the function of the destroyed tissue.

A concussion is a type of closed head injury; while most people fully recover from a concussion, there is evidence that accumulated injury to the brain, even moderate injury, causes long-term effects.

Brain injury can have serious and lifelong effects on physical and mental functioning, including loss of consciousness, altered memory and/or personality, and partial or complete paralysis. Common behavioral problems include verbal and physical aggression, agitation, learning difficulties, poor self-awareness, altered sexual functioning, impulsivity, and social disinhibition. Social consequences of mild, moderate, and severe TBI are numerous, including higher risk of suicide, divorce, chronic unemployment, and substance abuse. The annual cost of acute care and rehabilitation in the United States for new cases of TBI is enormous: \$9 billion to \$10 billion. Estimates for average lifetime cost of care for a person with severe TBI range from \$600,000 to \$2 million.

The rehabilitation process begins immediately after injury. Once memory begins to be restored, the rate of recovery often increases. However, many problems may persist, including those related to movement, memory, attention, complex thinking, speech and language, and behavioral changes; survivors often cope with depression, anxiety, loss of self-esteem, altered personality, and, in some cases, a lack of self-awareness of their deficits.

Rehab may include cognitive exercises to improve attention, memory, and executive skills. These programs are structured, systematic, goal-directed, and individualized; they involve learning, practice, and social contact. Sometimes memory books and electronic paging systems are used to improve particular functions and to compensate for deficits. Psychotherapy, an important component of a comprehensive rehabilitation program, treats depression and loss of self-esteem. Rehab may also include medications for behavioral disturbances associated with TBI. Some of these drugs have significant side effects in persons with TBI and are used only in compelling circumstances.

Behavior modification has been used to reduce personality and behavioral effects of TBI and to retrain social skills. Vocational training is also common to many rehab programs. According to a consensus statement on brain injury from the National Institutes of Health, persons with TBI and their families should play an integral role in the planning and design of their individualized rehabilitation programs.

### **SOURCES**

National Institute of Neurological Disorders and Stroke, Brain Injury Resource Center

### **BRAIN INJURY RESOURCES**

**Brain Injury Association of America (BIAA)** features resources on living with brain injury, treatment, rehabilitation, research, prevention, etc. It also has state-by-state affiliates. 703-761-0750 or 1-800-444-6443; [www.biausa.org](http://www.biausa.org)

**Brain Injury Resource Center (BIRC)** operates a resource center “to empower you to have your needs met and avoid exploitation.” 206-621-8558; [www.headinjury.com](http://www.headinjury.com)

**Defense and Veterans Brain Injury Center (DVBIC)** serves active duty military, their dependents and veterans with traumatic brain injury. [www.dvbic.org](http://www.dvbic.org)

**Traumatic Brain Injury (TBI) Model Systems of Care** are specialty head injury clinics with federal grants for developing and demonstrating expertise with traumatic brain injury. The centers create and disseminate new knowledge about the course, treatment, and outcomes of these types of injuries, and demonstrate the benefits of a coordinated system of care. <https://msktc.org/tbi/model-system-centers>

**Baylor Scott & White Institute for Rehabilitation, Dallas, TX**  
**Craig Hospital, Englewood, CO**

**Icahn School of Medicine at Mount Sinai, New York, NY**  
**Indiana University School of Medicine, Indianapolis, IN**

**JFK Johnson Rehabilitation Institute, Edison, NJ**

**Kessler Foundation, West Orange, NJ**

**Mayo Clinic, Rochester, MN**

**Moss Rehabilitation Research Institute, Philadelphia, PA**

**Rehabilitation Institute of Michigan, Detroit, MI**

**Rusk Rehabilitation, New York, NY**

**Spaulding Rehabilitation Hospital, Boston, MA**

**TIRR Memorial Hermann, Houston, TX**

**University of Alabama at Birmingham, Birmingham, AL**

**University of Washington, Seattle, WA**

**Virginia Commonwealth University, Richmond, VA**

**Wexner Medical Center at Ohio State University, Columbus, OH**



**Traumatic brain injury research:** The brain is quite fragile, though it is protected by hair, skin, and skull, and a cushion of fluid. In the past, this protection was mostly adequate, until we developed more lethal weapons and new ways of hurtling along at high speeds.

Brain injuries vary, depending on which part of the brain is injured. A blow to the hippocampus causes memory loss. A brainstem injury is similar to a high spinal cord injury. Injury to the basal ganglia affects movement, and damage to the frontal lobes can lead to emotional problems. Injury to certain parts of the cortex affects speech and understanding. Each symptom may require specialized care and treatment.

A brain injury also involves many physiological processes, including nerve cell (axon) injury, contusions (bruises), hematomas (clots), and swelling. As in stroke, spinal cord injury, and other types of nerve trauma, brain injury is not an isolated process, it is a continuous event. Waves of destruction can last days and even weeks after the initial damage. With currently available treatments, doctors are unable to fully repair the original injury, which may include massive loss of nerve cells.

The spread of secondary damage to the brain can be limited, however. Scientists have targeted some of these secondary factors, including cerebral ischemia (loss of blood), low cerebral blood flow, low oxygen levels, and the release of excitatory amino acid (e.g., glutamate). Edema, once thought to be the result of blood vessel leakage, is now believed to be due to continuing cell death in the injured tissue.

There have been numerous drug trials to control a wide range of secondary effects of brain trauma, including glutamate toxicity (selfotel, cerestat, dexanabinol), calcium damage (nimodipine), and cell membrane breakdown (tirilazad, PEG-SOD). Smaller clinical studies have investigated application of growth hormones, anticonvulsants, bradykinin (increases blood vessel permeability), and cerebral perfusion pressure (increases blood flow to the brain). Several trials have tested the effect of acute hypothermia (cooling) after brain trauma; while there are intensive care units that apply cooling, there are no specific recommendations for its use. Clinical trials of potential neuroprotective agents have generally not been successful, even though the various therapies seemed to work well in animals. Scientists say this is because the gap between animal models and human clinical practice is huge—human injury is widely variable and poorly demonstrated in a small lab animal. Also, it is often difficult to initiate treatment in humans within the proper therapeutic

time frame. Animals don't always experience the same intolerable side effects to drugs as humans do, and animal models can't address the complicated and sometimes lifelong effects of brain trauma on human mind, memory, and behavior.

To be sure, the injured brain does have some capacity to recover. As scientists put it, the brain is “plastic”—that is, using nerve growth factors, tissue transplantation, or other techniques, the brain can be encouraged to remodel itself and thus restore function. Because different mechanisms are active at different times during recovery, interventions may work better at certain times. A series of timed medications might be used, each addressing specific biochemical processes in the wake of brain damage. While cell replacement (including stem cells) is theoretically possible, much research remains before application in humans.

## CEREBRAL PALSY

Cerebral palsy (CP) refers to a group of conditions that affect control of movement and posture. CP disorders are not caused by problems in the muscles or nerves. Instead, faulty development or damage to areas in the brain cause inadequate control of movement and posture. Symptoms range from mild to severe, including forms of paralysis.

Cerebral palsy does not always cause profound disability. While a child with severe CP might be unable to walk and may require extensive care, a child with mild cerebral palsy might only be slightly off-balance and require no special assistance. CP is not contagious, nor is it usually inherited. With treatment, most children significantly improve their abilities. While symptoms may change over time, cerebral palsy by definition is not progressive; if impairment does increase, it's usually due to a disease or condition other than CP.

Children with cerebral palsy often require treatment for intellectual disabilities, learning disabilities, and seizures, as well as vision, hearing and speech difficulties. Cerebral palsy is not usually diagnosed until a child is about two to three years old. It affects about 1.5 to more than 4 children out of 1,000 over the age of three. Globally, over 17 million people have cerebral palsy.

There are three major types:

**Spastic cerebral palsy:** About 70 to 80 percent of those affected have spastic cerebral palsy, in which muscles are stiff, making movement difficult. When both legs are affected (spastic diplegia), a child may have difficulty walking

because tight muscles in the hips and legs cause the legs to turn inward and scissor at the knees. In other cases, only one side of the body is affected (spastic hemiplegia), often with the arm more severely affected than the leg. Most severe is spastic quadriplegia, in which all four limbs and the trunk are affected, often along with the muscles of the mouth and tongue.

**Dyskinetic (athetoid) cerebral palsy:** About 10 to 20 percent of people with CP have the dyskinetic form, which affects the entire body. It is characterized by fluctuations in muscle tone from too tight to too loose; dyskinetic CP is sometimes associated with uncontrolled movements (slow and writhing or rapid and jerky). Children often have trouble learning to control their bodies well enough to sit and walk. Because muscles of the face and tongue can be affected, swallowing and speech may be difficult.

**Ataxic cerebral palsy:** About 5 to 10 percent of people with CP have the ataxic form, which affects balance and coordination; they may walk with an unsteady gait and have difficulty with motions that require coordination, such as writing.

In the United States, about 10 to 20 percent of children who have CP acquired the disorder after birth, the result of brain damage in the first few months or years of life; brain infections, such as bacterial meningitis or viral encephalitis; or head injury. Cerebral palsy present at birth may not be detected for months. In most cases, the cause of congenital cerebral palsy is unknown. Scientists have pinpointed some specific events during pregnancy or around the time of birth that can damage motor centers in the developing brain. Until recently, doctors believed that a lack of oxygen during delivery was the primary cause of cerebral palsy. Studies show that this causes only about 10 percent of cases.

Hyperbaric oxygen continues to be explored for treatment of CP, stroke, or brain injury. Some clinics and manufacturers promote its use for CP but there is no consensus that it is effective.

A child with CP usually begins physical therapy to increase motor skills (sitting and walking), improve muscle strength, and help prevent contractures (shortening of muscles that limit joint movement). Sometimes braces, splints, or casts are used to improve function of the hands or legs. If contractures are severe, surgery may be recommended to lengthen affected muscles.

A newer technique called constraint-induced therapy (CIT) is a type of physical therapy used successfully with adult stroke survivors with a weak arm on one side of the body. The therapy restrains the stronger arm in a cast,

forcing the weaker arm to perform activities. In a randomized, controlled study of children with cerebral palsy, one group of children went through conventional physical therapy and another group went through 21 consecutive days of CIT. Researchers looked for evidence of improvement in the function of the disabled arm, whether the improvement lasted after the end of treatment, and if it was associated with significant gains in other areas, such as trunk control, mobility, communication, and self-help skills. Children receiving CIT outperformed the children receiving conventional physical therapy across all measures, and six months later they still had better control of their arm.

Researchers are developing new ways to target and strengthen spastic muscles. For example, with functional electrical stimulation (FES), a microscopic wireless device is inserted into specific muscles or nerves and is powered by remote control. This technique has been used to activate and strengthen muscles in the hand, shoulder, and ankle in people with cerebral palsy, as well as in stroke survivors. For more information on FES, see pages 147-148.

Drugs may ease spasticity or reduce abnormal movement. In some cases, a small pump is implanted under the skin to continuously deliver an anti-spasm drug, such as baclofen. Success has been reported using Botox injections to quiet selective muscles. For younger children with spasticity affecting both legs, dorsal rhizotomy may permanently reduce spasticity and improve the ability to sit, stand, and walk. In this procedure, doctors cut some of the nerve fibers that contribute to spasticity.

As a child with CP grows older, therapy and other support services will change. Physical therapy is supplemented by vocational training, recreation and leisure programs, and special education, when necessary. Counseling for emotional and psychological issues is important during adolescence.

### **SOURCES**

United Cerebral Palsy, March of Dimes, Centers for Disease Control and Prevention, National Institute of Neurological Disorders and Stroke, Cerebral Palsy Foundation.

### **CEREBRAL PALSY RESOURCES**

**Cerebral Palsy Foundation** funds research to discover the cause, cure and care for those with CP and related developmental disabilities. 212-520-1686; [www.yourcpf.org](http://www.yourcpf.org)



**March of Dimes Birth Defects Foundation** features resources and connections to address birth defects, infant mortality, low birth weight and lack of prenatal care. Toll-free 1-888-663-4637; [www.marchofdimes.org](http://www.marchofdimes.org)

**United Cerebral Palsy (UCP)** offers resources on CP health and wellness, plus lifestyle, education and advocacy resources. UCP advances full inclusion of people with disabilities; two-thirds of people served by UCP have disabilities other than cerebral palsy. UCP, toll-free 1-800-872-5827; [www.ucp.org](http://www.ucp.org)

## FRIEDREICH'S ATAXIA

Friedreich's ataxia (FA) is an inherited disease that causes progressive damage to the nervous system. It can result in muscle weakness, speech difficulties, or heart disease. The first symptom is usually difficulty with walking; this gradually worsens and can spread to the arms and the trunk. Loss of sensation in the extremities may spread to other parts of the body. Other features include loss of tendon reflexes, especially in the knees and ankles. Most people with Friedreich's ataxia develop scoliosis (a curving of the spine to one side), which may require surgical intervention.

Other symptoms may include chest pain, shortness of breath, and heart palpitations. These symptoms are the result of various forms of heart disease that often accompany Friedreich's ataxia, such as hypertrophic cardiomyopathy (enlargement of the heart), myocardial fibrosis (formation of fiber-like material in the muscles of the heart), and cardiac failure.

Friedreich's ataxia is named after the physician Nicholas Friedreich, who first described the condition in the 1860s. "Ataxia" refers to coordination problems and unsteadiness and occurs in many diseases and conditions. Friedreich's ataxia is marked by degeneration of nerve tissue in the spinal cord and of nerves that control arm and leg movement. The spinal cord becomes thinner and nerve cells lose some of the myelin insulation that helps them conduct impulses.

Friedreich's ataxia is rare; it affects about 1 in 50,000 people in the United States. Males and females are affected equally. Symptoms usually begin between the ages of five and fifteen, but can appear as early as eighteen months or as late as age thirty.

There is currently no effective cure or treatment for Friedreich's ataxia. However, many of the symptoms and accompanying complications can be treated. Studies show that frataxin is an important mitochondrial protein for proper function of several organs. Yet in people with FA, the amount

of frataxin in affected cells is severely reduced. This loss of frataxin may make the nervous system, heart, and pancreas particularly susceptible to damage from free radicals (produced when excess iron reacts with oxygen). Researchers have tried to reduce the levels of free radicals using treatment with antioxidants. Initial clinical studies in Europe suggested that antioxidants like coenzyme Q10, vitamin E, and idebenone may offer limited benefit. However, clinical trials in the United States have not revealed effectiveness of idebenone in people with Friedreich's ataxia; more powerful modified forms of this agent and other antioxidants are in trials at this time. Meanwhile, scientists also are exploring ways to increase frataxin levels and manage iron metabolism through drug treatments, genetic engineering, and protein delivery systems.

### SOURCES

National Institute of Neurological Disorders and Stroke, National Organization for Rare Disorders, Friedreich's Ataxia Research Alliance, Muscular Dystrophy Association

### FRIEDREICH'S ATAXIA RESOURCES

**Friedreich's Ataxia Research Alliance (FARA)** offers information on Friedreich's ataxia and the related ataxias, including current research, as well as information for researchers, patients, families and caregivers. FARA also offers support and information for the newly diagnosed. 484-879-6160; [www.curefa.org](http://www.curefa.org)

**Muscular Dystrophy Association (MDA)** offers news and information about neuromuscular diseases, including ataxias. Toll-free 1-800-572-1717; [www.mda.org](http://www.mda.org)

**National Ataxia Foundation (NAF)** supports research into hereditary ataxia, with numerous affiliated chapters and support groups in the United States and Canada. 763-553-0020; [www.ataxia.org](http://www.ataxia.org)

**National Organization for Rare Disorders (NORD)** is committed to the identification and treatment of more than 6,000 rare disorders, including Friedreich's ataxia, through education, advocacy, research and service. [www.rarediseases.org](http://www.rarediseases.org)

## GUILLAIN-BARRÉ SYNDROME

Guillain-Barré (ghee-yan bah-ray) syndrome is a disorder in which the body's immune system attacks part of the peripheral nervous system. The first symptoms include varying degrees of weakness or tingling sensations in the legs, often spreading to the arms and upper body; these can increase in intensity until a person is totally paralyzed. Many people require intensive care during the early course of their illness, especially if a ventilator is required.

Guillain-Barré syndrome is rare. It usually occurs a few days or weeks after a person has had symptoms of a respiratory or gastrointestinal viral infection; while the most common related infection is bacterial, 60 percent of cases do not have a known cause. Some cases may be triggered by the influenza virus or by an immune reaction to the influenza virus. Occasionally, surgery or vaccinations will trigger it. The disorder can develop over the course of hours or days, or it may take three to four weeks. It is not known why Guillain-Barré strikes some people and not others. Most people recover from even the most severe cases of Guillain-Barré, although some continue to have a degree of weakness. There is no known cure for this syndrome, but therapies can reduce its severity and accelerate recovery. There are a number of ways to treat the complications. Plasmapheresis (also known as plasma exchange) mechanically removes autoantibodies from the bloodstream. High-dose immunoglobulin therapy is also used to boost the immune system. Researchers hope to understand the workings of the immune system to identify which cells are responsible for carrying out the attack on the nervous system.

According to the CDC, "Current research suggests that Guillain-Barre syndrome (GBS), an uncommon sickness of the nervous system, is strongly associated with Zika; however, only a small proportion of people with recent Zika virus infection get GBS."

### SOURCE

National Institute of Neurological Disorders and Stroke

## GUILLAIN-BARRÉ SYNDROME RESOURCES

**GBS/CIDP Foundation International** offers information on Guillain-Barré and Chronic Inflammatory Demyelinating Polyneuropathy. 610-667-0131 or toll-free 1-866-224-3301; [www.gbs-cidp.org](http://www.gbs-cidp.org)

## THE LEUKODYSTROPHIES

The leukodystrophies are progressive, hereditary disorders that affect the brain, spinal cord, and peripheral nerves. Specific leukodystrophies include metachromatic leukodystrophy, Krabbe disease, adrenoleukodystrophy, Canavan disease, Alexander disease, Zellweger syndrome, Refsum disease, and cerebrotendinous xanthomatosis. Pelizaeus-Merzbacher disease can also lead to paralysis.

Adrenoleukodystrophy (ALD) affected the young boy Lorenzo Odone, whose story is told in the 1992 film "Lorenzo's Oil." In this disease, the fatty covering (myelin sheath) on nerve fibers in the brain is lost, and the adrenal gland degenerates, leading to progressive neurological disability. (See <https://adrenoleukodystrophy.info/treatment-options/lorenzo-odone> for more information.)



## LEUKODYSTROPHY RESOURCES

**United Leukodystrophy Foundation (ULF)** raises funds, offers resources and clinical detail on the leukodystrophies. Toll-free 1-800-728-5483 or 815-748-3211; [www.ulf.org](http://www.ulf.org)

## LYME DISEASE

Lyme disease is a bacterial (*Borrelia burgdorferi*) infection transmitted to humans by the bite of certain black-legged ticks, although fewer than 50 percent of all Lyme disease patients recall a tick bite. Typical symptoms include fever, headache, and fatigue. Lyme disease, which can lead to neurological symptoms including loss of function in arms and legs, is often misdiagnosed as amyotrophic lateral sclerosis or multiple sclerosis. According to some Lyme disease experts, standard diagnostic methods fail to discover as many as 40 percent of cases. Most cases of Lyme disease can be treated



*Borrelia burgdorferi*

successfully with antibiotics over several weeks. While some people with long-term Lyme disease take antibiotics over an extended course of time, most physicians do not consider Lyme to be a chronic infection. According to published medical literature, many patients diagnosed as having chronic Lyme disease demonstrate no evidence of prior infection; only 37 percent of patients in one referral center had current or previous infection with *B. burgdorferi* as the explanation for their symptoms. There are reports that

hyperbaric oxygen and bee venom have been effective for some in treating symptoms of the disease. A number of people with chronic Lyme disease have traveled abroad for expensive, unauthorized stem cell therapies.

### **LYME DISEASE RESOURCES**

**American Lyme Disease Foundation** offers resources and treatment information. [www.aldf.com](http://www.aldf.com)

**International Lyme and Associated Diseases Society** offers educational materials. <http://ilads.org>

**Lyme Disease Association** offers information and referral. [www.lymediseaseassociation.org](http://www.lymediseaseassociation.org)

### **MULTIPLE SCLEROSIS**

Multiple sclerosis (MS) is a chronic and often disabling disease of the central nervous system. A study funded by the National MS Society has confirmed that nearly 1 million people are living with MS in the United States. Symptoms may be episodic and mild, such as numbness in a limb, or severe, including paralysis, cognitive loss, or loss of vision. MS involves decreased nerve function associated with scar formation on myelin, the covering of nerve cells. Repeated episodes of inflammation destroy myelin, leaving multiple areas of scar tissue (sclerosis) along the covering of the nerve cells. This results in slowing or blockage of nerve impulse transmission in that area. Multiple sclerosis often progresses with episodes (called “exacerbations”) that last days, weeks, or months. Exacerbations may alternate with times of reduced or no symptoms (remission). Recurrence (relapse) is common.

Symptoms of MS include weakness, tremor, or paralysis of one or more extremities; spasticity (uncontrollable spasms); movement problems; numbness; tingling; pain; loss of vision; loss of coordination and balance; incontinence; loss of memory or judgment; and, most commonly, fatigue.

Fatigue, occurring in about 80 percent of people with MS, can significantly interfere with a person’s ability to work and function. It may be the most prominent symptom in a person who has otherwise been minimally affected by the disease. MS-related fatigue generally occurs on a daily basis and tends to worsen as the day progresses. It tends to be aggravated by heat and humidity. MS-related fatigue does not appear to be correlated with depression or the degree of physical impairment.

Multiple sclerosis varies greatly from person to person and in the severity and the course of the disease. A relapsing-remitting course, the most common form of MS, is characterized by partial or total recovery after attacks; about 75 percent of people with MS begin with a relapsing-remitting course.

Relapsing-remitting MS may become steadily progressive. Attacks and partial recoveries may continue to occur. This is called secondary-progressive MS. Of those who start with relapsing-remitting, more than half will develop secondary-progressive MS within ten years; 90 percent within 25 years.

A progressive course from onset of the disease is called primary-progressive MS. In this case, symptoms generally do not remit.

The exact cause of MS is unknown. Studies indicate an environmental factor may be involved. There is a higher incidence in northern Europe, northern United States, southern Australia, and New Zealand than in other areas of the world. Because people in sunnier climates are less likely to get MS, research has targeted vitamin D levels; indeed, there is some link between lower levels of vitamin D and MS. Vitamin D is synthesized naturally by the skin as it is exposed to sunlight. Studies show that people in northern climates often have reduced vitamin D levels; babies born in less sunny April have the highest risk of developing multiple sclerosis later in life while those born in sunnier October have the lowest risk.

There may also be a familial tendency toward the disorder. Most people with MS are diagnosed between the ages of 20 and 40. Women are more commonly affected than men. The progress, severity, and symptoms of MS in any individual cannot yet be predicted.

Multiple sclerosis is believed to be an abnormal immune response directed

against the central nervous system (CNS). The cells and proteins of the body's immune system, which normally defend the body against infections, leave the blood vessels serving the CNS and turn against the brain and spinal cord, destroying myelin. The specific triggering mechanism that causes the immune system to attack its own myelin remains unknown, although a viral infection combined with an inherited genetic susceptibility is a leading suspect. While many different viruses have been thought to cause MS, there has been no definitive evidence linking its cause to any one virus.

Multiple sclerosis was among the first diseases to be described scientifically. Nineteenth-century doctors did not fully understand what they saw and recorded, but drawings from autopsies done as early as 1838 clearly show what is known today as MS. In 1868, Jean-Martin Charcot, a neurologist at the University of Paris, carefully examined a young woman with a tremor of a sort he had never seen before. He noted her other neurological problems, including slurred speech and abnormal eye movements, and compared them to other patients he had seen. When she died, he examined her brain and found the characteristic scars or "plaques" of MS.

Dr. Charcot wrote a complete description of the disease and the changes in the brain that accompany it. He was baffled by its cause and frustrated by its resistance to all of his treatments, including electrical stimulation and strychnine (a nerve stimulant and poison). He also tried injections of gold and silver (somewhat helpful in the treatment of the other major nerve disorder common at that time, syphilis).

One century later, in 1969, the first successful scientific clinical trial was completed for a treatment of MS. A group of patients who were having multiple sclerosis exacerbations were given a steroid drug; steroids remain in use today for acute exacerbations.

Clinical trials since then have led to the approvals of more than a dozen medications shown to affect immune response, and thus the course of MS. Injectable treatments include: Betaseron, which helps reduce the severity and frequency of attacks; Avonex, approved in 1996, known to slow the development of disability and reduce the severity and frequency of attacks, Copaxone, which treats relapsing-remitting MS; Rebif, for reducing the number and frequency of relapses and slowing the progression of disability; and Plegridy, approved for the treatment of relapsing forms of MS and administered in less frequent doses. Novantrone treats advanced or chronic MS and reduces the number of relapses.

Tysabri is a monoclonal antibody administered by infusion and approved to treat relapsing-remitting multiple sclerosis. The drug hampers the movement of potentially damaging immune cells from the bloodstream, across the blood-brain barrier, and into the brain and spinal cord. FDA prescribing information about Tysabri includes a "black box" warning about the risk of progressive multifocal leukoencephalopathy (PML), an infection of the brain that usually leads to death or severe disability. Known factors that increase the risk of PML in Tysabri-treated patients are previous treatment with an immunosuppressant and the length of time Tysabri is taken.

Other intravenous infusions approved to treat MS include Ocrevus, shown to reduce relapse rates and slow disability progression in relapsing forms of multiple sclerosis and primary progressive multiple sclerosis, and Novantrone, which reduces neurologic disability and frequency of clinical relapses in secondary progressive MS, progressive-relapsing MS and worsening relapsing-remitting MS. Lemtrada, shown to reduce relapses, is prescribed only when other treatments have proven unsuccessful; a "black box" warning reports that the medication can cause serious or fatal autoimmune conditions and life-threatening infusion reactions and that strokes have occurred within three days of receiving the treatment.

Oral medications approved for treating MS include: Gilenya, for reducing the frequency of relapses and delaying physical disability in relapsing forms of MS; Aubagio, which inhibits the function of specific immune cells implicated in MS; Tecfidera, shown to reduce relapses and development of brain lesions and to slow disability progression over time; Vumerity, similar to Tecfidera but with fewer reported gastrointestinal side effects, treats relapsing forms of MS by reducing relapses and slowing progression of disability; and Mayzent, shown to reduce relapses and slow progression of disability for relapsing forms of MS. Mavenclad, which decreases relapses and reduces progression of disability in relapsing forms of multiple sclerosis carries a "black box" warning for increased risk of malignancy and fetal harm, and is recommended only for patients who have had an inadequate response to an alternative drug.

Ampyra, an extended release form of 4 aminopyridine, is approved to improve walking speed in people with MS. This oral medication is available by prescription from compounding pharmacies.

#### **There are many research efforts underway to treat MS:**

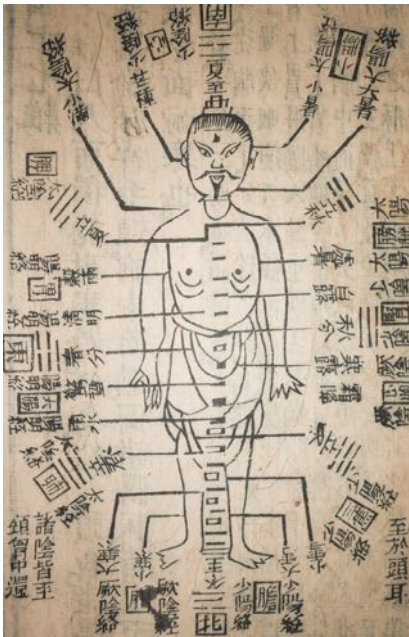
- Antibiotics that fight infection may decrease MS disease activity. Various



infectious agents have been proposed as potential causes for MS, including Epstein-Barr virus, herpes virus, and coronaviruses. Minocycline (an antibiotic) has showed promising results as an anti-inflammatory agent in trials with relapsing-remitting MS.

- Plasmapheresis is a procedure in which a person's blood is removed to separate plasma from other blood substances that may contain antibodies and other immune-sensitive products. The purified plasma is then transfused back into the patient. Plasmapheresis is used to treat myasthenia gravis, Guillain-Barré, and other demyelinating diseases. Studies of plasmapheresis

## ACUPUNCTURE



*While there is no evidence that the ancient Chinese practice of acupuncture can reduce the number of flareups or slow the progress of disability, it may help relieve some MS-related symptoms. Acupuncture is a traditional Chinese medicine based on a theory of body functioning that involves the flow of energy through 14 pathways (called meridians) throughout the body. Disease, as the theory goes, results from an imbalance or disruption in the flow of energy. There have been no large-scale controlled clinical trials assessing the effectiveness of acupuncture on MS patients, though there are currently small sample studies underway.*

*Though not clinical trials, two large self-assessment surveys conducted in the United States and Canada showed that one in four respondents with MS had tried acupuncture for symptom relief. About 10 to 15 percent said they planned to continue using acupuncture. A National Institutes of Health panel evaluating studies done of acupuncture treating other diseases concluded it is a safe treatment without side effects. More MS-specific research is needed. See National Multiple Sclerosis Society, [www.nationalmssociety.org](http://www.nationalmssociety.org)*

in people with primary and secondary progressive MS have had mixed results.

- Bone marrow transplantation is being studied in MS. By wiping out the immune cells in a patient's bone marrow with chemotherapy and then repopulating it with healthy mesenchymal stem cells, researchers hope the rebuilt immune system will stop attacking its own nerves.
- Studies and trials exploring the effectiveness of treating MS using other types of stem cells, including embryonic stem cells, olfactory ensheathing glia and umbilical cord blood stem cells, are currently underway. A number of clinics outside the United States offer treatments with various cell lines; no data exists to evaluate these clinics and they should be approached with caution.
- Therapies to repair damage to myelin coating on nerve fibers, which can lead to disrupted nerve signaling and nerve loss, are also being studied in several clinical trials.

**Symptom management options:** Medicines commonly used for MS symptoms include baclofen, tizanidine, or diazepam, often used to reduce muscle spasticity. Doctors prescribe anti-cholinergic medications to reduce urinary problems and antidepressants to improve mood or behavior symptoms. Amantadine (an antiviral drug) is sometimes used to treat fatigue. To stay current on MS drug information, visit the National Multiple Sclerosis Society's webpage ([www.nationalmssociety.org/Treating-MS/Medications](http://www.nationalmssociety.org/Treating-MS/Medications)) which provides an overview of drugs used to modify the disease, manage symptoms and manage relapse.

Physical therapy, speech therapy, or occupational therapy may improve a person's outlook, reduce depression, maximize function, and improve coping skills. Exercise can help maintain muscle tone and bone density and may also improve energy level, bowel and bladder function, mood, and flexibility. MS is chronic, unpredictable, and at this time incurable, but life expectancy can be normal or nearly so.

## SOURCES

National Institute of Neurological Disorders and Stroke, National Multiple Sclerosis Society, Consortium of MS Centers, Multiple Sclerosis Complementary and Alternative Medicine/Rocky Mountain MS Center

## **MULTIPLE SCLEROSIS RESOURCES**

**Consortium of Multiple Sclerosis Centers** is a rich repository of clinical and research information for people with MS. Publishes the International Journal of MS Care. [www.ms-care.org](http://www.ms-care.org)

**Multiple Sclerosis Association of America** features free services that help improve lives. Programs include a Helpline with trained specialists; educational videos and publications, including MSAA's magazine, The Motivator; safety and mobility equipment distribution; cooling accessories for heat-sensitive individuals; educational programs held across the country; and a Lending Library. 1-800-532-7667; [www.mymyasa.com](http://www.mymyasa.com)

**Multiple Sclerosis Complementary Care**, a section of the Rocky Mountain MS Center, provides information and discussion of complementary and alternative medicine therapies commonly used by people with MS, such as acupuncture, herbal medicine, and homeopathy. [www.mscenter.org/education/patient-resources/complementary-care](http://www.mscenter.org/education/patient-resources/complementary-care)

**Multiple Sclerosis Society of Canada** has information about the disease, progress in MS research and services as well as details about fundraising events, and donation opportunities. [www.mssociety.ca](http://www.mssociety.ca)

**National Multiple Sclerosis Society** provides information on living with MS, treatment, scientific progress, MS specialty centers, clinical research funding, local chapters, and resources for healthcare professionals. Toll-free 1-800-344-4867; [www.nationalmssociety.org](http://www.nationalmssociety.org)

## **NEUROFIBROMATOSIS**

Neurofibromatosis (NF) is a genetic, progressive and unpredictable disorder of the nervous system which causes tumors to form on the nerves anywhere in the body at any time. Although most NF-related tumors are not cancerous, they may cause problems by compressing the spinal cord and surrounding nerves; this can lead to paralysis. The most common tumors are neurofibromas, which develop in the tissue surrounding peripheral nerves. There are three types of neurofibromatosis. Type 1 causes skin changes and deformed bones, can affect the spinal cord and brain, often contributes to learning disabilities, and usually starts at birth. Type 2 causes hearing loss, ringing in the ears, and poor balance; it often starts in the teen years. Schwannomatosis, the rarest form, causes intense pain. As a group, the neurofibromatoses affect more than 100,000 Americans. There is no known

cure for any form of NF, although the genes for both NF-1 and NF-2 have been identified.

### **SOURCES**

National Institute of Neurological Disorders and Stroke, Neurofibromatosis Network

## **NEUROFIBROMATOSIS RESOURCES**

**Children's Tumor Foundation** supports research and the development of treatments for neurofibromatosis, provides information, and helps in the development of clinical centers, best practices, and patient support mechanisms. [www.ctf.org](http://www.ctf.org)

**Neurofibromatosis Inc. California** offers medical symposiums, family support and patient advocacy, and supports NF research. [www.nfcalifornia.org](http://www.nfcalifornia.org)

**Neurofibromatosis Network** advocates for NF research, disseminates medical and scientific information about NF, offers a national referral database for clinical care, and promotes awareness of NF. [www.nfnetwork.org](http://www.nfnetwork.org)

## **POST-POLIO SYNDROME**

Poliomyelitis is a disease caused by a virus that attacks nerves that control motor function. Polio (infantile paralysis) has nearly been eradicated from almost every country in the world since the approval of the Salk (1955) and Sabin (1962) vaccines. In 2020, only three countries (Afghanistan, Nigeria, and Pakistan) remained polio-endemic, down from more than 125 in 1988.

The World Health Organization (WHO) estimates that 12 million people worldwide live with some degree of disability caused by poliomyelitis.

The National Center for Health Statistics estimates about one million polio survivors in the United States, with almost half reporting paralysis resulting in some form of impairment. The last major outbreaks of polio in the United States were in the early 1950s.

For years, most polio survivors lived active lives, their memory of polio mainly forgotten and their health status stable. But by the late 1970s, survivors who were 20 or more years past their diagnosis began noting new problems, including fatigue, pain, breathing or swallowing problems, and additional weakness—medical professionals called this post-polio syndrome (PPS).



Some people experience PPS-related fatigue as a flu-like exhaustion that worsens as the day progresses. This type of fatigue can also increase during physical activity, and it may cause difficulty with concentration and memory. Others experience muscle weakness that increases with exercise and improves with rest.

Research indicates that the time one has lived with the residuals of polio is as much of a risk factor as age. It also appears that individuals who experienced the most severe original paralysis with the greatest functional recovery have more problems with PPS than others with less severe original involvement.

Post-polio syndrome appears to be related to physical overuse and, perhaps, nerve stress. When the poliovirus destroyed or injured motor neurons, muscle fibers were orphaned and paralysis resulted. Polio survivors who regained movement did so because non-affected neighboring nerve cells began to “sprout” and reconnect to what might be considered orphaned muscles.

Survivors who have lived for years with this restructured neuromuscular system are now experiencing the consequences including overworked surviving nerve cells, muscles, and joints, compounded by the effects of growing older. There is no conclusive evidence to support the idea that post-polio syndrome is a reinfection of the poliovirus.

Polio survivors are urged to take care of their health in all the usual ways—by seeking periodic medical attention, being nutrition-wise, avoiding excessive weight gain, and by stopping smoking or overindulging in alcohol. Survivors are advised to listen to their body’s warning signals, avoid activities that cause pain, prevent overuse of muscles, and conserve energy by avoiding tasks that are nonessential, and by using adaptive equipment when needed.

Post-polio syndrome is not typically a life-threatening condition, but it may cause significant discomfort and disability. The most common disability caused by PPS is deterioration of mobility. People with PPS may also experience difficulties performing daily activities such as cooking, cleaning, shopping, and driving. Energy-conserving assistive devices such as canes, crutches, walkers, wheelchairs, or electric scooters may be necessary for some people.

Living with post-polio syndrome often means adjusting to new disabilities; for some, reliving childhood experiences of coming to terms with polio can be difficult. For example, moving from a manual to a power chair can be tough. Fortunately, PPS is gaining increasing attention in the medical community, and there are many professionals who understand it and can provide appropriate



*Franklin D. Roosevelt, seldom seen as a polio survivor, with Ruthie Bye and Fala, 1941*

medical and psychological help. In addition, there are PPS support groups, newsletters, and educational networks that provide up-to-date information about PPS while assuring survivors that they are not alone in their struggle.

### **SOURCES**

International Polio Network, Montreal Neurological Hospital Post-Polio Clinic

### **POLIO RESOURCES**

**Global Polio Eradication Initiative** is a public-private partnership led by national governments and spearheaded by the World Health Organization (WHO), Rotary International, the US Centers for Disease Control and Prevention (CDC), and the United Nations Children’s Fund (UNICEF).

[www.polioeradication.org](http://www.polioeradication.org)

**Post-Polio Health International** offers information for polio survivors and promotes networking among the post-polio community. PPHI publishes numerous resources, including the quarterly Polio Network News, the annual Post-Polio Directory, and The Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors. PPHI is the evolution of the GINI organization, founded as a mimeograph newsletter by Gini Laurie in St. Louis over 60 years ago. 314-534-0475; [www.post-polio.org](http://www.post-polio.org)

## SPINA BIFIDA

Spina bifida is the most common permanently-disabling birth defect in the United States. One out of 1,500 newborns in the United States is born with spina bifida, and each year 4,000 pregnancies are affected by it. About 166,000 people are currently living with spina bifida.

A large percent of babies with spina bifida are born to parents with no family history of this birth defect. While spina bifida appears to run in certain families, it does not follow any particular pattern of inheritance.

Spina bifida, a type of neural tube defect (NTD), means “cleft spine,” or an incomplete closure of the spinal column. This birth defect occurs between the fourth and sixth weeks of pregnancy when the embryo is less than an inch long. Normally, a groove along the middle of the back of the embryo deepens, allowing the sides to meet and enclosing the tissue destined to be the spinal cord in a tube-like structure. In spina bifida, the sides of the embryo do not fully meet, resulting in defects in the future spinal column. These openings allow the spinal cord and nerves to be exposed to amniotic fluid and can be traumatized just by the baby moving around. These “lesions” often have functional consequences on movement and sensation.

The most serious form of spina bifida may include muscle weakness or paralysis below the level of lesion of the spinal column along with loss of sensation and loss of bowel and bladder control.

There are three general types of spina bifida (listed below from mild to severe).

**Spina bifida occulta:** This form of spina bifida occurs when one or more of the bones of the spine incompletely fuse or close which results in a small gap. The spinal cord is usually intact and there is no nerve or spinal cord damage. It is fairly common and found incidentally in around 12 percent of the population in the United States. People with this defect have intact skin and rarely have any symptoms.

**Meningocele:** The meninges, or the protective covering around the spinal cord, pushes out through the opening in the vertebrae in a sac called the meningocele. The spinal cord does not protrude into this sac and remains intact; this can be repaired with little or no damage to the nerve pathways. People with this defect rarely have symptoms.

**Myelomeningocele:** This is the most severe form of spina bifida, in which a portion of the meninges, spinal cord and nerves protrudes through the back defect. Because the spinal cord and nerves are not protected, they can be damaged which results in muscle and sensation problems. Often associated with myelomeningocele is hydrocephalus, an accumulation of fluid in the brain that can cause swelling of the ventricles and damaging pressure on the brain. A large percentage of children born with myelomeningocele has hydrocephalus. Increased pressure within the brain can be controlled by surgical procedures such as the more common shunting procedure. This relieves the fluid build-up in the brain and reduces the risk of damage, seizures, or blindness.

In some cases, children with spina bifida who also have a history of hydrocephalus experience learning problems. They may have difficulty paying attention, problem solving and grasping reading and math. Early intervention with children who experience learning problems can help considerably to prepare them for school and life.

Spina bifida not only has an impact on the nervous system but can cause problems in multiple body systems. Examples of these secondary conditions may include musculoskeletal problems, impaired bladder and bowel control, kidney failure, latex allergy, obesity, skin breakdown, and gastrointestinal disorders. In addition, learning disabilities and psychosocial issues such as anxiety, depression and sexual problems can occur. Spina bifida impacts muscle movement and sensation to varying degrees depending on which part of the spinal cord is involved. Mobility needs will depend on what muscles are weak or paralyzed. Some children may not require assistive devices whereas others may need braces, crutches or wheelchairs to get around home and in the community. Also, many children can independently manage their bowel and bladder problems.

According to the Spina Bifida Association (SBA), medical consensus indicates that, besides physical issues, it is equally important that attention be focused on the psychosocial development of children and young adults. Recent surveys of adults with spina bifida conducted by the Spina Bifida Association indicate that emotional problems can result from factors such as low self-esteem and lack of

social skills training.

Children with spina bifida are at risk for developing a tethered spinal cord where the spinal cord and the membranes that line it stick to local scar tissue. This typically occurs because of the initial back closure surgery. Tethering puts tension on the cord which may negatively impact spinal cord function. Tethered cord can occur throughout life, but it typically happens during periods of rapid growth.

Spina bifida is a relatively common birth defect, however until recent decades children born with a myelomeningocele died shortly after birth. What made the difference was the ability to surgically close the open spinal defect and use shunts to drain off spinal fluid that would cause hydrocephalus. These procedures are usually done within the first 24 hours after birth. With recent medical advances most of these infants typically go on to live full and active lives as adults.

Birth defects can happen in any family. Women with certain chronic health problems, including diabetes and seizure disorders needing treatment with anticonvulsants, have an increased risk (approximately 1 out of 100) of having a baby with spina bifida. Many things can affect a pregnancy, including family genes and things women may be exposed to during pregnancy. Recent studies have shown that folic acid is one factor that may reduce the risk of having a baby with an NTD. Taking folic acid before and during early pregnancy reduces the risk of spina bifida and other NTDs. Folic acid, a common water-soluble B vitamin, is essential for the functioning of the human body. During periods of rapid growth, such as fetal development, the body's requirement for this vitamin increases. The average diet in the United States does not supply the recommended level of folic acid; it can be found in multivitamins, fortified breakfast cereals, dark green leafy vegetables such as broccoli and spinach, egg yolks, and some fruits and fruit juices.

According to the Centers for Disease Control and Prevention (CDC), folic acid fortification of enriched grain products is an important way to help prevent NTDs. The CDC reports that researchers who used data from birth defects tracking systems found that ever since enriched grain products have been fortified with folic acid, about 1,300 babies are born each year without an NTD who might have otherwise been affected.

Additionally, CDC urges all women who are capable of becoming pregnant to get at least 400 mcg of folic acid every day. It is especially important for women

to get this amount of folic acid at least one month before becoming pregnant to help prevent NTDs. Women can get folic acid in these ways:

- Take a vitamin containing 400 mcg of folic acid every day.
- Eat a bowl of breakfast cereal every day that has 100 percent of the daily value of folic acid.

- Eat a diet with plenty of fortified grains and foods like beans, peas, and leafy greens, which are rich in folate, the natural form of folic acid in foods.

Folic acid supplementation must begin before conception, as the condition develops before women know they are pregnant. It is important to identify early in the pregnancy whether there is an NTD/spina bifida. Three prenatal tests are used to detect spina bifida: blood test for alpha-fetoprotein; ultrasound; and amniocentesis. Early identification allows families to explore options for prenatal surgery and delivery.

Researchers are looking for the genes linked specifically to spina bifida. They are also exploring the complex mechanisms of normal brain development to see how neural tube problems impact brain development. This will provide information that can influence how future clinical care and interventions can positively impact individuals with spina bifida.

Historically, treatment for spina bifida has only been to provide care after the baby is born. Since the 1930s, surgical closure of the back was performed within a few days of birth. Such interventions prevent further damage to the nervous tissue, but do not restore function to the already damaged nerves. A national research study compared two spine closure surgery methods for babies with spina bifida: 1) during pregnancy, also known as fetal surgery, and 2) standard surgeries performed after birth. Babies who had fetal surgery required less shunting for hydrocephalus and seemed to have improved mobility. Now, recipients of fetal surgeries are being followed to discover the long-term benefits of prenatal surgery.

Spina bifida is a common birth defect that can have many physical, emotional and psychosocial consequences. Nevertheless, most people with spina bifida who have the appropriate supports will live full and active lives, and there is ongoing and promising research about ways to improve their quality of life.

### **SOURCES**

Spina Bifida Association, National Institute of Neurological Disorders and



Stroke, March of Dimes Birth Defects Foundation

## **SPINA BIFIDA RESOURCES**

**March of Dimes Birth Defects Foundation** offers information about the four major problems that threaten the health of America’s babies: birth defects, infant mortality, low birth weight, and lack of prenatal care. Toll-free 1-888-663-4637; [www.marchofdimes.org](http://www.marchofdimes.org)

**Spina Bifida Association** builds a better and brighter future for those impacted by spina bifida. For more information call 202-559-2788 or toll-free 1-800-621-3141 or email [sbaa@sbaa.org](mailto:sbaa@sbaa.org). [www.spinabifidaassociation.org](http://www.spinabifidaassociation.org)

## **SPINAL CORD INJURY**

Spinal cord injury (SCI) involves damage to the nerves within the bony protection of the spinal canal. The most common cause of cord injury is trauma, although damage can occur from various diseases acquired at birth or later in life, tumors, electric shock, poisoning, or loss of oxygen related to surgical or underwater mishaps. The spinal cord does not have to be severed in order for a loss of function to occur. In fact, in most people with SCI, the spinal cord is damaged but some connections remain.

Since the spinal cord coordinates body movement and sensation, an injured cord loses the ability to send and receive messages from the brain to the body’s systems that control sensory, motor, and autonomic function below the level of injury; this often results in paralysis.

Spinal cord injury is an age-old problem, but it wasn’t until the 1940s that the prognosis for long-term survival was very optimistic. Prior to World War II, people routinely died of infections to the urinary tract, lungs, or skin; the advent of antibiotic drugs changed SCI from a death sentence to a manageable condition. Nowadays, people with spinal cord injury who endured the perilous first year approach the full life span of non-disabled individuals.

Spinal cord trauma is more than a single event. The initial blunt force damages or kills spinal nerve cells. But in the hours and days after injury a cascade of secondary events, including loss of oxygen and the release of toxic chemicals at the site of injury, further damage the cord.

Acute care may involve surgery if the spinal cord appears to be compressed by bone, a herniated disk, or a blood clot. Traditionally, surgeons waited

for several days to decompress the spinal cord, believing that operating immediately could worsen the outcome. More recently, many surgeons advocate immediate decompression surgery to minimize secondary damage.

Generally speaking, after the swelling of the spinal cord begins to subside, most people show some functional improvement after an injury. With many injuries, especially incomplete injuries (some motor or sensory function preserved below the lesion level), a person may recover function eighteen months or more after the injury. In some cases, people with SCI regain some function years after the injury.

### **Spinal cord biology:**

Nerve cells (neurons) of the peripheral nervous system, which carry signals to and from the limbs, torso, and other parts of the body, are able to repair themselves after injury. However, nerves in the brain and spinal cord, within the central nervous system (CNS), are not able to regenerate (see below for discussion of research to address this lack of spontaneous self-repair in the spinal cord).

The spinal cord includes nerve cells (neurons) and long nerve fibers (axons) that are covered by myelin, a type of electrical insulation substance. Loss of myelin, which can occur with cord trauma and is the hallmark of such diseases as multiple sclerosis, prevents effective transmission of nerve signals. The neurons themselves, with their tree-like branches called dendrites, receive signals from other neurons. As with the brain, the spinal cord is enclosed in three membranes (or meninges): the pia mater, the innermost layer; the arachnoid, the middle layer; and the dura mater, the leather-like outer layer (“dura mater,” Latin for tough mother).

Several types of cells carry out spinal cord functions. Large motor neurons, or efferents, have long axons that control skeletal muscles in the neck, torso, and limbs. Sensory neurons called dorsal root ganglion cells, or afferents, carry information from the body into the spinal cord and on to the brainstem. Projection neurons within the spinal cord and brainstem carry these sensory signals to the cortex. Spinal interneurons, which lie completely within the spinal cord and are the vast majority of neurons in the cord, help integrate sensory information and generate coordinated signals that control muscles. Autonomic motor neurons, or efferents that control function of our internal organs, also have their cell bodies in the spinal cord.

Glia, or supporting cells, far outnumber neurons in the brain and spinal

cord and perform many essential functions. One type of glial cell, the oligodendrocyte, creates the myelin sheaths that insulate axons and improve the speed and reliability of neuronal signal transmission. Astrocytes, large star-shaped glial cells, regulate the composition of the biochemical fluids that surround neurons. Smaller cells called microglia become activated in response to injury and help clean up waste products. All of these glial cells produce substances that support neuron survival and influence axon growth. However, these cells may also impede wound repair and recovery following injury; some glial cells become reactive and thereby contribute to formation of growth-blocking scar tissue after injury.

Neurons of the brain and spinal cord respond to trauma and damage differently than most other cells of the body, including those in the peripheral

### **PARALYSIS PREVALENCE: BIG NUMBER**

*The numbers are out and they are shockingly large: there are over 5.3 million Americans living with paralysis, roughly 1 in 50. A study from the Reeve Foundation estimates that 1.4 million Americans are living with paralysis resulting from spinal cord injuries — five times the previous commonly used estimate of 250,000. Stroke, which paralyzes 1.8 million Americans, was found to be the leading cause of paralysis; spinal cord injury was the second-leading cause, at 27 percent of cases.*

*The figures were gathered from a meticulously designed population-based telephone survey of about 70,000 households. It was developed by researchers at the University of New Mexico with input from top experts from around the country, including the Centers for Disease Control and Prevention as well as 14 leading universities and medical centers.*

*These findings have major implications for the treatment of spinal cord and paralysis-related diseases—not only for those living with these conditions, but also for their families, caregivers, healthcare providers, and employers. As the number of people living with paralysis and SCI increases, so do the costs associated with treating them. Each year, paralysis and spinal cord injuries cost the healthcare system billions of dollars. According to the National Spinal Cord Injury Statistical Center, health care costs and living expenses average over \$1.1 million for a high-level quadriplegic and about half a million for a paraplegic in the first year after injury. People living with paralysis and spinal cord injuries are also often unable to afford health insurance that adequately covers the complex secondary or chronic conditions that are commonly linked with these conditions.*

nervous system. The brain and spinal cord are confined within bony cavities that protect them, but this also renders them vulnerable to compression damage caused by swelling or forceful injury. Cells of the central nervous system have a very high rate of metabolism and rely upon blood glucose for energy—these cells require a full blood supply for healthy functioning; therefore, CNS cells are particularly vulnerable to reductions in blood flow (ischemia).

Other unique features of the CNS are the blood-brain barrier and the blood-spinal cord barrier. These barriers, formed by cells lining the blood vessels in the CNS, protect nerve cells by restricting entry of potentially harmful substances and cells of the immune system. Trauma may compromise these barriers, perhaps contributing to further damage in the brain and spinal cord. The blood-spinal cord barrier also prevents entry of some potentially therapeutic drugs.

**Complete vs. incomplete injury:** Those with an incomplete injury have some spared sensory or motor function below the level of injury—the spinal cord was not totally damaged or disrupted. In a complete injury, nerve damage obstructs all signals coming from the brain to the body, and the body to the brain, below the injury.

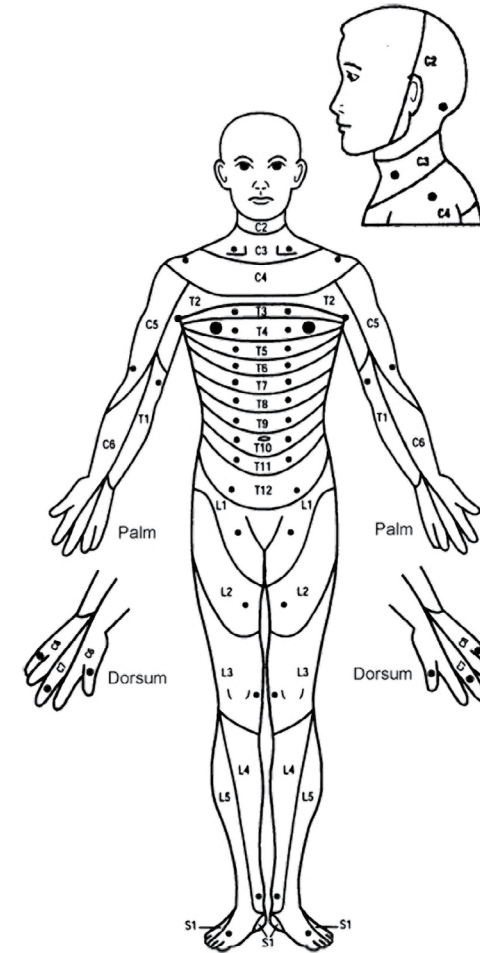
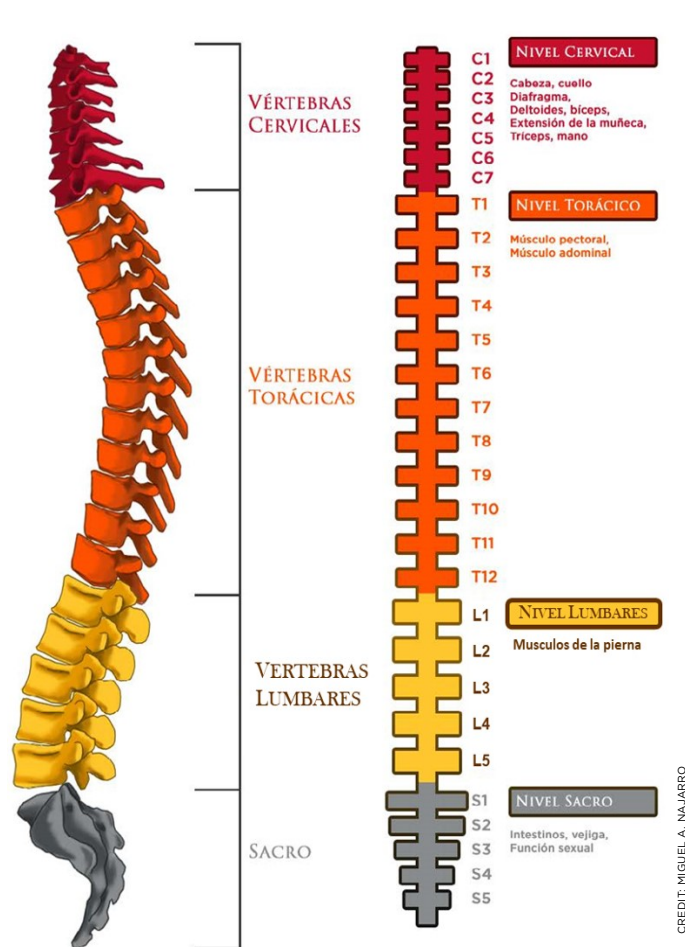
It is important to note that a clinically complete injury is not necessarily anatomically complete, so multiple researchers are looking at ways to increase output from spared connections, even in clinically complete injuries. While there's almost always hope of recovering some function after a spinal cord injury, it is generally true that people with incomplete injuries have a better chance of getting more return. The sooner muscles start working again, the better the chances are of additional recovery. When muscles come back later, after the first several weeks, they are more likely to be in the arms than in the legs. As long as there is some improvement and additional muscles recover function, the chances are better that more improvement is possible. The longer there is no improvement, the lower the odds it will start to happen on its own. The spinal cord is organized into segments along its length, noted by their position along the thirty-three vertebrae of the backbone. Nerves from each segment are responsible for motor and sensory functions for specific regions of the body (if you map this, it's called a dermatome). In general, the higher in the spinal column an injury occurs, the more function a person will lose. The segments in the neck, or cervical region, referred to as C1 through C8, control signals to the neck, arms, hands, and, in some cases the

diaphragm. Injuries to this area result in tetraplegia or, as it is more commonly called, quadriplegia.

Injury above the C3 level may require a ventilator for the person to breathe. Injury above the C4 level usually means loss of movement and sensation in all four limbs, although often shoulder and neck movement is available to facilitate sip-and-puff devices for mobility, environmental control, and communication. C5 injuries often spare the control of shoulder and biceps, but there is not much control at

the wrist or hand. Those at C5 can usually feed themselves and independently handle many activities of daily living. C6 injuries generally allow wrist control, enough to be able to drive adaptive vehicles and handle personal hygiene, but those affected at this level often lack fine hand function. Individuals with C7 and T1 injuries can straighten their arms and can typically handle most self-care activities, though they still may have dexterity problems with hands and fingers.

Nerves in the thoracic, or upper back region (T1 through T12), relay signals to the torso and some parts of the arms. Injuries from T1 to T8 usually affect control of the upper torso, limiting trunk movement as the result of a lack of



abdominal muscle control. Lower thoracic injuries (T9 to T12) allow good trunk control and good abdominal muscle control. Those injured in the lumbar, or mid-back region just below the ribs (L1 through L5), are able to control signals to the hips and legs. A person with an L4 injury can often extend the knees. The sacral segments (S1 through S5) lie just below the lumbar segments in the mid-back and control signals to the groin, toes, and some parts of the legs.

Besides a loss of sensation or motor function, injury to the spinal cord leads to other changes, including loss of bowel, bladder, and sexual function, low blood pressure, autonomic dysreflexia (for injuries above T6), immune dysfunction, deep vein

thrombosis, spasticity, and chronic pain. Other secondary issues related to injury include bone density loss, pressure injuries, respiratory complications, urinary tract infections, pain, obesity, and depression. See pages 90-125 for more on these conditions; they are mainly preventable with good healthcare, diet, and physical activity.

Research on aging with disability indicates that respiratory illnesses, diabetes, and thyroid disease occur more often in people with SCI than in the rest of the population. For example, people with SCI are more prone to lower respiratory infections, resulting in lost productivity, increased healthcare costs, and increased risk of early death. These problems are common not only in those with high cervical injuries, who have loss of respiratory muscle function, but



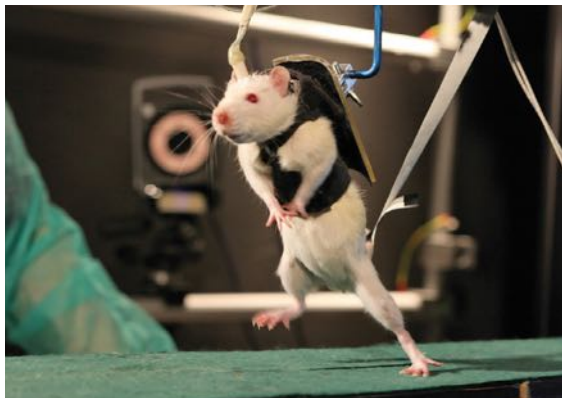
also in those with paraplegia.

Spinal cord injuries are most commonly caused by motor vehicle accidents, followed by sports-related injuries (more common in children and teenagers), falls and acts of violence. More work-related injuries (mainly construction work) occur with adults. According to the National Spinal Cord Injury Statistical Center, the average age at injury has increased from 29 years old during the 1970s to 43 in 2015. About four out of five people with spinal cord injuries are male. More than half of spinal cord injuries occur in the cervical area, a third occur in the thoracic area, and the remainder occur mostly in the lumbar region.

## SPINAL CORD INJURY RESEARCH

There are no definitive treatments yet for spinal cord injury. However, ongoing research to test new therapies is progressing rapidly. Drugs and biologics to limit injury progression, decompression surgery, nerve cell transplantation, therapies targeting neural regeneration, plasticity, remyelination, and neuromodulation are being examined as potential ways to minimize the effects of spinal cord injury and restore function. The biology of the injured spinal cord is enormously complex but clinical trials are underway with more coming; hope for restoring function after paralysis continues to rise, and for good reason. Still, paralysis from disease, stroke or trauma is considered one of the toughest of medical problems. In fact, just over a generation ago, any damage to the brain and spinal cord that severely limited motor and/or sensory function was thought to be untreatable. In recent years, though,

the word “cure” in this context has not only entered the vocabulary of the science community but also that of clinicians. Restorative neuroscience is bubbling with energy and expectation. To be sure, scientific progress is a slow but steady march. One day in the not-too-distant future, there will be a host of procedures or treatments



*Motivated mouse: epidural stimulation plus treadmill training equals function.*

GREGOIRE COURTINE LAB

to mitigate the effects of paralysis, but it is not reasonable to expect a one-size-fits-all “magic bullet” for restoring function. It is almost a certainty that these coming treatments will involve combinations of therapies, given at various time points in the injury process, including a significant rehabilitation component. Here is a snapshot of work being done in several research areas.

**Nerve protection:** As in the case of brain trauma or stroke, the initial damage to spinal cord cells is followed by a series of biochemical events that often knock out other nerve cells in the area of the injury. This secondary process is the body’s inflammatory response to trauma, which instead of being neuroprotective can cause more extensive damage than the initial trauma. The steroid drug methylprednisolone (MP) was FDA-approved in 1990 as a treatment to reduce inflammation in acute SCI; it is still the only approved acute treatment. Recent studies suggest that the steroid actually causes more damage than it helps. Meanwhile, research is underway in many labs around the world to find a better acute treatment.

Several therapeutics look promising, including Riluzole (protects nerves from further damage from excess glutamate), protein therapies targeting Nogo (anti-Nogo and Nogo Trap, which promote spinal cord neuron growth by blocking inhibition), and antibodies targeting RGMa (which block action of a powerful neural growth inhibitor). Cooling of the spinal cord is another possible acute therapy; hypothermia appears to not only reduce bleeding and edema and produce an analgesic effect but also limits cell loss. Ongoing research studies are being conducted to determine optimal cooling conditions and efficacy. For more information, see [www.themiamiproject.org](http://www.themiamiproject.org).

Stem cells have also been considered as an acute therapy: the biotech firm Geron began (then abandoned) human safety trials using human embryonic stem cells to treat acute spinal cord injuries. Several studies suggest stem cells, especially those derived from bone cells, might release a mix of chemicals and molecules that help protect injured neurons and help the spinal cord repair itself in the acute phase of injury. For discussion of what a stem cell is, see sidebar pages 69-71.

One method researchers have explored to avoid some of the complications of stem cells (e.g. survivability, immune rejection) is by way of exosomes. An exosome is a nano-sized lipid vesicle that cells use to transport chemicals and proteins to other cells. Think of these as fat-lined tiny packets of potentially useful molecules and proteins. While there is great promise in both stem cells and exosomes to promote repair in acute and subacute SCI,

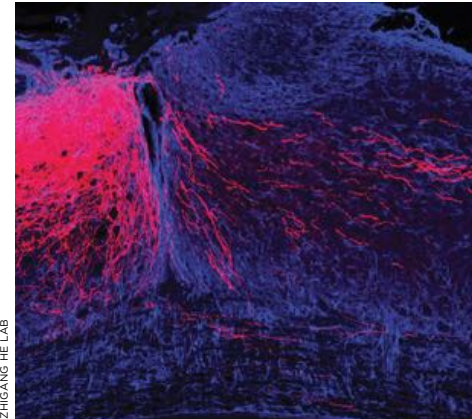
research is needed to identify how to engineer the ideal type of stem cell or exosome, safety profile, and dose for optimal functional improvement.

**Bridging and building a growth friendly environment:** The idea of a bridge is conceptually easy—transplanted nerves and/or a biomaterial scaffold to fill the damaged area of the cord (often a scar-lined cyst), and thus allow nerves of the spinal cord to cross through otherwise inhospitable terrain. In 1981, Canadian scientist Albert Aguayo showed that spinal cord axons could grow long distances using a bridge made of peripheral nerve, proving without a doubt that axons will grow if they have the right environment.

Biomaterial scaffolds used alone or in conjunction with stem cells have shown great promise in preclinical studies to decrease the lesion cavity size, promote neural growth, and produce functional improvements after SCI. Initial clinical studies with biomaterial implants (from InVivo Therapeutics and BioArctic) had difficulty replicating preclinical results, but the research team is excited to see what changes in techniques and substrates might make biomaterials or peripheral nerve grafts more successful in humans.

A variety of techniques has evolved through experiments to create a growth-enhancing environment, including the use of stem cells, nerve cells called olfactory ensheathing cells (support cells for olfactory neurons that come from the upper nose), Schwann cells (support cells of peripheral nerves that have been shown to help spinal cord and brain cells), and drugs that digest or interfere with growth inhibitors (e.g. chondroitinase ABC, an enzyme that breaks down inhibitory sugars associated with the scar tissue, or Nogo Trap, a protein that interferes with aptly named Nogo signals that block neuronal growth after injury). Clinical trials are currently underway to optimize and assess the efficacy of these growth-enhancing therapies, including two different ways of targeting Nogo signaling (NG-101 and AXER-204) and transplantation of supporting cell therapies either alone or in combination with other cell types (e.g. olfactory ensheathing cells). By making the spinal cord more amenable to neuronal growth, any remaining fibers can more easily strengthen existing connections and make new ones. This is often referred to as plasticity, or the ability of the nervous system to change its structure, and is necessary to get functional improvement.

**Regeneration:** The term regeneration, broadly speaking, refers to the ability of damaged or severed axons to regrow. Historically, it was believed that to restore function after SCI would require axons to regrow across the injury site to reconnect with their original targets. Scientifically, this is a huge feat



ZHIGANG HE LAB

*Nerve fibers (axons), labeled red, cross the lesion site of an injured spinal cord, coaxed by genetic manipulation to release growth potential.*

to accomplish, because this might mean neurons damaged at the cervical level regrowing 2-3 feet to reconnect to their original targets at the lumbar or sacral level.

In recent years, some researchers have also focused on other forms of regeneration that may involve shorter distance growth: (1) getting spared axons to make new connections above and below the injury, creating new and reorganizing old circuits that can be trained to accomplish new

tasks; and (2) enabling injured or severed axons to make new connections around or through the lesion to form new relay circuits. Whether or not the shorter distance growth can fully recover function is heavily debated within the scientific community, but there is no doubt that in preclinical models it can lead to significant functional improvement.

Regardless of type of regeneration, axons in the spinal cord cannot regenerate unless (a) their path is cleared of inhibitory signals stopping growth and (b) their internal growth program is reignited. Many researchers are also exploring chemicals that facilitate or guide growth. Longer distance axonal growth through the injury site will also likely require (c) a bridge or other substrate on which to grow and other external growth facilitators (see section above). Blocking the action of signals that inhibit growth (e.g. Nogo and its receptors, myelin associated molecules, and chondroitin sulfate proteoglycans) can facilitate axonal regrowth and circuit reorganization after injury in preclinical studies, and ongoing clinical research seeks to confirm this.

In order to reignite neuronal growth programs, scientists at several labs have used a molecular switch to target cells of interest after trauma. One such example is PTEN, a tumor suppressor gene that was discovered by cancer researchers fifteen years ago. This gene regulates cell proliferation and it turns out to be a molecular switch for axon growth. When scientists deleted PTEN in a complete spinal cord injury model, axons that connect the brain to the spinal cord—the ones needed for major movement function—regenerated at unprecedented rates. PTEN is complicated; you can't just get rid of it

throughout the body because it is the brake needed to stop certain kinds of cellular overgrowth (cancer). Modern technological advances (e.g. gene therapy with targeted delivery) have shown great promise in targeting subsets of cells and are currently being explored for human use. A number of labs are exploring PTEN and other molecular regulators of a neuron's internal growth program, either alone or in combination with blocking the inhibitors or making a more growth friendly environment.

**Cell replacement:** There are two main ways researchers are studying the use of stem cells to replace lost cells: (1) replacing lost myelin and (2) forming new spinal cord relay circuits.

Loss of myelin (the protective neuronal covering that allows for fast communication) occurs early after SCI. As mentioned in the introduction, myelin is made up of support cells called oligodendrocytes, which continue to die for weeks after injury. Transplanting cells that are precursors to oligodendrocytes has been explored as a way to restore myelin to the injured cord. The extent to which a loss of myelin contributes to functional impairments in chronic SCI, and the best recipe for “growing” stem cell oligodendrocyte precursors to sufficiently increase myelination, are still being explored.

While remyelination is dependent on replacing cells, the cells introduced are never intended to become neurons. The first stem cells explored for neurological research were embryonic stem cells, those derived from embryonic tissue, for their capacity to develop into multiple neuron types and connect to targets appropriately (remember, adult neurons do not divide and grow like other cell types). An alternative source of stem cells are those derived from adult skin, dental pulp, fat, or blood cells reprogrammed with chemical and environmental steps to become neural progenitor cells (NPCs). These induced pluripotent stem cells (iPSCs) have the ability to be created from a patient's own cells, i.e., autologous, thus avoiding the massive immune response generated when foreign cells are introduced. iPSCs are somewhat of a blank slate. They can become neurons, or heart cells, or skin cells, etc. so researchers may use the term human induced neural progenitor cells (hiNPCs), to describe iPSCs guided to a neural identity. Recent rodent studies have shown that both hiNPCs and embryonic NPCs can become neurons after transplantation after SCI, can grow for multiple segments, and lead to functional improvements. Notably, this use of stem cell transplantation ideally forms relay circuits, connecting neurons above and below the injury. This is

a promising therapeutic area, but critical questions about lasting functional recovery, safety, type of cell and growth conditions, scalability, and delivery remain.

A word of caution: stem cell therapy has not yet been approved for use for SCI; the only approved use in the United States is bone marrow transplantation. Also, it's important to keep in mind that the term “stem cell” can refer to many kinds of cells, those from embryonic tissue or derived from adult skin, dental pulp, fat, or blood cells, reprogrammed with different recipes. That's why, if you're going to enroll in a scientific study of stem cells or anything else, you want to make sure there is appropriate oversight of the study to ensure it's based on sound science. The FDA issues an Investigational New Drug Application (IND) number and requires a review board to oversee the study. When in doubt, ask about these and/or follow up with your personal health care provider before agreeing to participate.

**Rehabilitation:** Almost any treatment to restore function after paralysis will require a physical component to rebuild muscle, rebuild bone, and reactivate patterns of movement. Some form of rehabilitation training will be needed even after function comes back. Moreover, it appears that activity itself affects recovery: in 2002, seven years after his supposedly complete C2 injury, Christopher Reeve showed that he had regained limited function and sensation. His doctor credited his use of functional electrical stimulation, which may have kick-started the repair process, and a program of passive electrical stimulation, aqua therapy, and passive standing.

To a limited extent, Reeve also used weight-bearing treadmill training, a type of physical therapy that forces the legs to move in a pattern of walking as the body is suspended in a harness above a moving treadmill. Interestingly, the spinal cord can itself interpret incoming sensory signals, and some movements, known as reflexes, require no input from the brain. It can also generate certain patterns of movement commands by an internal network of neurons, known as a central pattern generator (or CPG). CPGs are found across many species and are capable of generating muscle activation patterns necessary for common behaviors such as swimming and walking.

Stepping during treadmill training sends sensory information to the locomotor CPG, adapting and reinforcing the circuits necessary for stepping. Scientists use the term plasticity to describe this reinforcement—the nervous system is not “hard wired” and appears to have the ability to change in response to new stimulation. Researchers are learning much more about the exact role

of sensory information within the CPG and ways to increase the ability of the spinal cord to learn (or relearn) new tasks.

While rehabilitation techniques are still improving, they evolved to the point that exercise and physical activity are an essential component of recovery. The amount and intensity of activity-based training seems to play a large role in the amount of functional recovery an individual experiences. For the person with a spinal cord injury, it's best to stay active and always strive for the maximum outcome. For more on activity-based recovery, and to learn about the Reeve Foundation NeuroRecovery Network, see pages 63-65.

**Spinal cord stimulation:** There are a few forms of electrical stimulation that are actively being pursued in scientific research: epidural electrical stimulation, transcutaneous stimulation, and magnetic stimulation, each with its own advantages and limitations.

Epidural stimulation is the application of an electrical current, at varying frequencies and intensities, to specific locations on the lumbar spinal cord using a microarray implanted over the dura. Epidural stimulation at the lumbar spinal cord has induced patterned leg movements and enabled voluntary control of paralyzed muscles in some people with complete injury. Scientists don't fully understand the mechanisms by which it works, but the current hypothesis is that epidural stimulation raises the level of excitability of the networks in the spinal cord and increases the functional output of the few spared connections from the brain. After long-term stimulation, many individuals see improvements even when the stimulator is off, suggesting reorganization of some circuits in the spinal cord. Human studies suggest that epidural stimulation may improve autonomic system function and ameliorate some of secondary dysfunctions (e.g. cardiovascular and respiratory function, bladder and sexual function) in addition to improved motor function. For more on epidural stimulation, see the Rob Summers story, page 68.

Non-invasive transcutaneous stimulation (or stimulation through the skin) has also been shown to promote functional recovery in humans with SCI. Depending on the stimulation parameters (frequency, intensity, location), studies have shown improvement in voluntary movement, muscle strength, spasticity, pain, and bladder control in individuals with SCI. This type of stimulation is thought to recruit large sensory neurons, those responsible for sensing touch and a limb's position in space, with secondary actions on spinal cord and supraspinal circuits. As with epidural stimulation, transcutaneous stimulation is often paired with intensive activity-based rehabilitation training to

maximize improved function.

**Acute intermittent hypoxia:** In recent years, a handful of clinical and preclinical researchers have explored acute intermittent hypoxia (AIH), or periodically providing an individual with brief bouts of low oxygen, as a way to jumpstart plasticity in the spinal cord. This can lead to functional improvements with task specific training, such as hand function, locomotion, and respiration. This may even enhance corticospinal plasticity in humans (the pathway thought to be crucial to voluntary control of movement).

While we're not sure all the ways AIH works, preclinical research suggests after chronic injury this is partially due to brainstem activation that leads to enhanced growth factor release in the spinal cord, which in turn leads to neuroprotection and activity-dependent plasticity in motor pathways. When given repeatedly, AIH can lead to long-lasting functional improvement, yet in rodents this effect is restricted to that task which the rodent was trained on after AIH (e.g. treadmill walking, ladder walking and, reach and grasp tasks).

More research is necessary to optimize AIH protocols, but so far results in humans appear very promising with relatively minor risks.

### SOURCES

American Association of Neurological Surgeons, Craig Hospital, Christopher & Dana Reeve Foundation, National Institute of Neurological Disorders and Stroke.

### SPINAL CORD INJURY RESOURCES

**Christopher & Dana Reeve Foundation** funds research to develop treatments for paralysis caused by spinal cord injury or other nervous system disorders. The Foundation also works to improve the quality of life for people living with paralysis through its grants program, Paralysis Resource Center, and advocacy efforts. For an overview of the Foundation's research and advocacy, details on the Quality of Life Grants Program, or to connect with an Information Specialist, visit [www.ChristopherReeve.org](http://www.ChristopherReeve.org) or write 636 Morris Turnpike, Suite 3A Short Hills, NJ 07078; toll-free 1-800-539-7309.

**Reeve Foundation Peer & Family Support Program** is a national peer-to-peer mentoring program providing emotional support as well as local and national information and resources to people living with paralysis and their families and caregivers. [www.ChristopherReeve.org/peer](http://www.ChristopherReeve.org/peer)



**Craig Hospital** supports a dedicated nurse to answer non-emergency calls from people with SCI, Monday-Friday. Toll-free 1-800-247-0257 or 303-789-8508. Educational materials are available online. [www.craighospital.org](http://www.craighospital.org)

**Facing Disability** While spinal cord injury affects the entire family, there are few resources for families. This website provides information and peer support for people with injuries and their families. Sharing life experiences—by way of over 1,000 videos—with others who have been down the same road helps people find their own strength and support. [www.FacingDisability.com](http://www.FacingDisability.com)

**International Spinal Cord Society**, with a membership of over 1,000 clinicians and scientists from 87 countries, promotes education, research and clinical excellence; produces the journal Spinal Cord. [www.iscos.org.uk](http://www.iscos.org.uk) They offer a free online education resource, **elearnSCI.org**, for spinal cord injury prevention and comprehensive clinical practice and rehabilitation. An initiative of the physician-based International Spinal Cord Society. Visit online [www.elearnsci.org](http://www.elearnsci.org)

**Paralyzed Veterans of America (PVA)** works toward quality healthcare, rehabilitation and civil rights for veterans and all citizens with spinal cord injuries and diseases. PVA offers numerous publications and fact sheets and supports the Consortium for Spinal Cord Medicine, which produces authoritative clinical guidelines for spinal cord injury. PVA supports research by way of its Spinal Cord Research Foundation. The organization sponsors the magazines PN/Paraplegia News and Sports 'N Spokes. Toll-free 1-800-424-8200; [www.pva.org](http://www.pva.org)

**Ralph's Riders Foundation** is a peer network in the Southern California area founded by Mayra Fornos in honor of her late husband, Ralph, an activist lawyer and quadriplegic. [www.ralphsriders.org](http://www.ralphsriders.org)

**SCI Information Network** offers



information about spinal cord injury, including new injuries, and is home to the National Spinal Cord Injury Statistical Center (NSCISC).

<https://www.uab.edu/medicine/sci/> or <https://www.nscisc.uab.edu/>

**Spinal Injury 101** is a video series from the Shepherd Center, with backing from the Reeve Foundation and the National Spinal Cord Injury Association. Tutorial videos on SCI, acute management, secondary conditions and more. [www.spinalinjury101.org](http://www.spinalinjury101.org)

**SPINALpedia** is an Internet social mentoring network and video archive “that allows the spinal cord injury community to motivate each other with the knowledge and triumphs gained from our individual experiences.” [www.spinalpedia.com](http://www.spinalpedia.com)

**United Spinal Association (USA)** provides expertise, connections and access to resources. It offers a toll-free help line, peer support, and information resources. 718-803-3782; [www.unitedspinal.org](http://www.unitedspinal.org)

## **SCI RESEARCH RESOURCES**

**Canadian/American Spinal Research Organization** is dedicated to physical improvement for persons with spinal cord injury or related neurological deficits through targeted medical research. 905-508-4000; [www.csro.com](http://www.csro.com)

**CatWalk Spinal Cord Injury Trust** was founded by New Zealander Catriona Williams, injured in a 2002 riding accident. The trust is dedicated to raising funds to support cure science. [www.catwalk.org.nz](http://www.catwalk.org.nz)

**CenterWatch** provides a list of approved clinical trials being conducted internationally. 866-219-3440; [www.centerwatch.com](http://www.centerwatch.com)

**ClinicalTrials** lists all federally supported clinical trials in the U.S., sorted by disease or condition, location, treatment or sponsor. Developed by the National Library of Medicine. [www.clinicaltrials.gov](http://www.clinicaltrials.gov)

**Coalition for the Advancement of Medical Research (CAMR)**, comprised of patient organizations, universities, scientific societies, foundations, and individuals with life-threatening disorders, advocates for the advancement of research in regenerative medicine - including stem cell research. [www.camradvocacy.org](http://www.camradvocacy.org)

**Craig H. Neilsen Foundation** was formed to improve the quality of life for those living with spinal cord injury and to support scientific exploration for therapies and treatments. The foundation is the largest non-profit funding

source for SCI research in the U.S. Neilsen, a casino executive, lived 21 years with paralysis before his death in 2006. <http://chnfoundation.org>

**Conquer Paralysis Now** (formerly known as the Sam Schmidt Paralysis Foundation) helps individuals with spinal cord injuries and other illnesses by funding research, medical treatment, rehabilitation and technology advances. The organization was originally named for Schmidt, a former race car driver living with quadriplegia. 702-463-2940; [www.conquerparalysisnow.org](http://www.conquerparalysisnow.org)

**Dana Foundation** provides reliable, accessible information on the brain and spinal cord, including research. The Foundation offers numerous books and publications and sponsors Brain Awareness Week every March. [www.dana.org](http://www.dana.org)

**International Research Consortium on Spinal Cord Injury** is a Reeve Foundation-funded collaboration of prominent neuroscience laboratories in the U.S. and Europe working toward treatments for spinal cord injury. [www.ChristopherReeve.org/research](http://www.ChristopherReeve.org/research)

**International Society for Stem Cell Research** is a source for reliable information about stem cell research and clinical advances. [www.isscr.org](http://www.isscr.org)

**International Spinal Research Trust** is the UK's leading charity funding medical research around the world to develop effective treatments for paralysis. [www.spinal-research.org](http://www.spinal-research.org)

**Miami Project to Cure Paralysis** is a research center at the University of Miami dedicated to finding treatments and, ultimately, cures for paralysis. Toll-free 1-800-STAND-UP; [www.themiamiproject.org](http://www.themiamiproject.org)

**Mike Utley Foundation** provides financial support to research, rehabilitation and education programs on spinal cord injury. Toll-free 1-800-294-4683; [www.mikeutley.org](http://www.mikeutley.org)

**National Institute of Neurological Disorders and Stroke** is the primary federal funding source for all research related to the brain and spinal cord and provides authoritative research overviews for all diseases and conditions related to paralysis. [www.ninds.nih.gov](http://www.ninds.nih.gov)

**Neil Sachse Foundation** was founded in Australia to support SCI research. Sachse had a sporting injury leading to quadriplegia. [www.spinalcordresearch.org.au](http://www.spinalcordresearch.org.au)

**PubMed**, a service of the National Library of Medicine, provides access to over 30 million citations in the medical literature back to the mid-1960s. It includes links to many sites providing full text articles and other related resources.

Search using key word, researcher name, or journal title.

[www.ncbi.nlm.nih.gov/pubmed](http://www.ncbi.nlm.nih.gov/pubmed)

**Reeve-Irvine Research Center** was formed by philanthropist Joan Irvine Smith in honor of Christopher Reeve to study injuries and diseases of the spinal cord that result in paralysis. Contact c/o University of California at Irvine; [www.reeve.uci.edu](http://www.reeve.uci.edu). The **Roman Reed Program** at the Reeve-Irvine Research Center is dedicated to finding cures for neurological disorders. The program is named for California advocate Roman Reed, injured in a college football game. [www.reeve.uci.edu/roman-reed.html](http://www.reeve.uci.edu/roman-reed.html)

**Rick Hansen Foundation** was created in Canada in 1988 to support spinal cord injury research as well as wheelchair sport, injury prevention and rehabilitation programs. 604-295-8149; [www.rickhansen.com](http://www.rickhansen.com)

**SCORE** is dedicated to finding a cure for paralysis and also helps with out-of-pocket costs for home modifications, vehicle adaptations, etc., for young people who are injured in sporting events; [www.scorefund.org](http://www.scorefund.org)

**Society for Neuroscience** is an organization of about 40,000 basic scientists and clinicians who study the brain and nervous system, including trauma and disease as well as brain development, sensation and perception, learning and memory, sleep, stress, aging and psychiatric disorders. 202-962-4000; [www.sfn.org](http://www.sfn.org)

**Spinal Cord Injury Project at Rutgers University** works to move therapies from laboratory to clinical trial and is home of the CareCure community. 732-445-2061; see online <https://keck.rutgers.edu/>

**Spinal Cord Injury Research Program, U.S. Department of Defense** was established by Congress in 2009 with a \$35 million appropriation to support research into regenerating or repairing damaged spinal cords and improving rehabilitation therapies. Congressionally Directed Medical Research Programs: 301-619-7071; <http://cdmrp.army.mil/scirp>

**Spinal Cord Research Foundation of the Paralyzed Veterans of America (PVA)** funds research to treat spinal cord dysfunction and to enhance the health of people who are paralyzed. Toll-free 1-800-424-8200; [www.pva.org](http://www.pva.org)

**Spinal Cord Society (SCS)** is a research advocacy organization that raises money to cure spinal cord injuries. 218-739-5252; [www.scsus.org](http://www.scsus.org)

**Spinal Cure Australia** (formerly Australasian Spinal Research Trust) was established in 1994 to fund scientific research to find cures for paralysis. [www.spinalcure.org.au](http://www.spinalcure.org.au)

**Travis Roy Foundation**, named for the injured Boston University hockey player, helps people with spinal cord injuries and funds cure research. The foundation has awarded grants for wheelchairs, van purchases, home modifications, and other adaptive gear; [www.travisroyfoundation.org](http://www.travisroyfoundation.org)

**Unite 2 Fight Paralysis (U2FP)** advocates as “cure warriors” for SCI research and sponsors the annual Working to Walk research science meeting. <http://u2fp.org>

**Veterans Affairs Rehabilitation Research and Development Service (RR&D)** supports the study of pain, bowel and bladder function, FES, nerve plasticity, prosthetics, and more. RR&D also publishes the *Journal of Rehabilitation R&D* and hosts the International Symposium on Neural Regeneration.

<https://www.rehab.research.va.gov>

**Wings for Life**, based in Austria, finances research projects worldwide aimed at healing the injured spinal cord; projects are picked by an international group of reviewers to ensure the best possible investment of donations.

[www.wingsforlife.com/en-us](http://www.wingsforlife.com/en-us)

**Yale Center for Neuroscience and Regeneration Research** works to develop new treatments, and ultimately a cure, for spinal cord injury and related disorders. The center is supported by the Paralyzed Veterans of America, the Department of Veterans Affairs and four other foundations. 203-937-3802;

<http://medicine.yale.edu/cnrr>

## SPINAL CORD MODEL SYSTEMS



*The Spinal Cord Injury Model Systems (SCIMS) Centers Program was established by the federal government in 1970; the goal of the program has been to improve care and outcomes for individuals with spinal cord injury, based on research showing the superiority of comprehensive versus fragmented care. The SCIMS Centers provide multidisciplinary care from emergency services through rehabilitation and re-entry into community life. The centers also conduct research, provide education and disseminate information to improve the health and quality of life for individuals living with spinal cord injury.*

*There are currently 14 SCI Model Systems centers sponsored by the National Institute on Disability, Independent Living, and Rehabilitation Research; Office of Special Education and Rehabilitative Services; and the U.S. Department of Education.*



**University of Alabama at Birmingham Spinal Cord Injury Model System**

University of Alabama at Birmingham, Birmingham, AL; 205-934-3283

**Southern California Spinal Cord Injury Model System**

Rancho Los Amigos National Rehabilitation Center, Downey, CA; 562-401-8111

**Rocky Mountain Regional Spinal Injury System**

Craig Hospital, Englewood, CO; 303-789-8306

**South Florida Spinal Cord Injury Model System**

University of Miami, Miami, FL; 305-243-9516

**Southeastern Regional Spinal Cord Injury Care System**

Shepherd Center, Inc., Atlanta, GA; 404-352-2020

**Midwest Regional Spinal Cord Injury Care System**

Shirley Ryan AbilityLab, Chicago, IL; 312-238-2920

**Spaulding New England Regional Spinal Cord Injury Center**

Rehabilitation Hospital/New England Regional SCI, Boston, MA; 617-952-6174

**Northern New Jersey Spinal Cord Injury System**

Kessler Foundation Research Center, West Orange, NJ; 973-324-3567

**Mount Sinai Hospital Spinal Cord Injury Model System**

Mount Sinai Hospital, New York, NY; 212-659-9369

**Ohio Regional Spinal Cord Injury Model System**

Ohio State University, Columbus, OH; 614-366-3877

**Northeast Ohio Regional Spinal Cord Injury Model System**

Case Western Reserve, Cleveland, OH; 216-778-8781

**Regional Spinal Cord Injury Center of the Delaware Valley**

Thomas Jefferson University, Philadelphia, PA; 215-955-6579

**University of Pittsburgh Model Center on Spinal Cord Injury**

UMPC Rehabilitation Institute, Pittsburgh, PA; 412-232-7949

**Texas Model Spinal Cord Injury System at TIRR**

Memorial Hermann, Houston, TX; 713-797-5972

**Source:** [www.msctc.org/sci/model-system-centers](http://www.msctc.org/sci/model-system-centers)

**LIVING A FEARLESS LIFE**

*by Christopher Reeve*

*I live a fearless life on a daily basis. I'm reminded of that every time I come into New York, because I'm put in the back of a van, strapped down by four straps, and driven around by a bunch of guys who just happen to be firefighters from Yonkers. These guys are used to driving fire trucks—at great speed—so when I get into the van, I have to give it up. As a self-confessed control freak from way back in my early childhood, being able to sit in the back, assume that we're going to safely reach our destination, and actually doze off has been big for me.*

*This one hour van trip is a good metaphor for the journey I'd like to talk about. For so many of us, the source of our fear is the loss of control. But the more we try to control what happens to us, the greater our fear that we're no longer empowered, that there's no safety net, and that dangerous, unexpected things may happen. Ironically, the act of trying to control what happens is what actually robs us of great experiences and diminishes us.*

*The lesson I had to learn when I had my injury was pretty drastic because my life before that as an actor had been one of self-sufficiency, perseverance, and discipline. I had been extremely self-sufficient from the time I finished high school, all the way through college and graduate school, and as I made my way to Off-Broadway, Broadway, television and film. I had done well and was used to being in charge.*

*My accident was a strange and very close call. If I had landed differently, even by a millimeter in one direction, I wouldn't have been injured; if I had landed a millimeter the other way, I wouldn't be here today. I had, at best, a 40 percent chance of surviving my surgery, during which my head was actually reattached to my neck. Also during the surgery, I nearly died as a result of a drug reaction. I was told I would never again move below my shoulders, that I would absolutely have no further recovery, and that my life expectancy at 42 years of age was, at best, six to seven more years.*

*I dealt with it with my wife Dana at my side, thank God. We just decided not to buy into the fear that people tried to instill in us. This decision was the most important of all. How many people are walking around today three years after they were told that they only had six months to live? How many of us are doing things now that we were told that we could never do? It happens all the time.*

*One of the keys to going ahead and conquering fear is to ignore your moods. Ignore it when you feel like you really don't want to do whatever it is today. Ignore it when you feel like you can't be bothered. Often you start the day feeling bad—feeling like*





HERBER RITTS

*you don't want to do something or you are treading water and getting nowhere or you can't keep going—and the day turns out to be one of the best you're ever going to have. You have to leave yourself open to possibility. By staying in the moment regardless of how you actually feel, you leave yourself open for surprises, both on a big scale and on a little scale.*

*I am proud of what I have achieved, but my path hasn't been without problems and difficulties. About a year ago, I was the second patient in the world to have diaphragm pacing implanted into my body. It's like a cardiac pacemaker, but it stimulates the diaphragm to create normal breathing and replace the ventilator. I felt that it was safe and that there was a good chance it would work. It didn't. It failed.*

*For over a year now, I've had infections and all kinds of signs of rejection by my body, and the site of implantation is still not closed. That's why I am still on this ventilator, why I can't go into the swimming pool anymore, and why I haven't moved beyond my initial level of recovery, where I plateaued. And yet I'm telling you this because it is important to know that living a fearless life means that you might go through an experience that doesn't actually work out for you. The way to stay positive, to avoid being bitter or feeling like a failure, is to look at the fact it might help somebody else. For example, this failure of the diaphragm pacing has led to modifications in how doctors perform the procedure, and the set of patients who followed me have all gotten off the ventilator.*

*In 1996 I was one of the first to experiment with something called "treadmill walking therapy," where I was held up by a harness and put on a treadmill, just like in a gym. This kind of therapy works because the spine has energy and memory, and so the central pattern generator in the lumbar area remembers how to walk. It doesn't take much brain power to walk. After 60 days of treadmill therapy, a lot of paraplegic patients have been able to walk again. So far in the United States alone, more than 500 people have made it out of their wheelchairs that way.*

*I, however, had an accident when I was put on a treadmill one day because the doctors wanted to shoot a video of how it works. They cranked up the treadmill to three and a half miles an hour. I got up on it, and I took some beautiful steps. They got the shot. It was perfect, and the actor in me was happy. But then I broke my leg. My femur, the big bone in my thigh, snapped right in half. I still have a 12-inch metal plate with 15 screws in there holding it together. What happened? It turned out that I had osteoporosis and my bone density wasn't strong enough to take the pace of the treadmill. So for me, there is no more treadmill at the moment. But for others, there is a new protocol, a new standard. Now they know that before they put anybody on a treadmill, they must do a bone density scan to make sure the patient doesn't have osteoporosis. Something good came out of that.*

*You might wonder why I went in so early on some of these experiments. I'd been pushing neuroscientists to be fearless, to not get hung up in the laboratory doing*



GETTY IMAGES

Reeve addressing the Democratic National Convention, 1996

experiments forever. So, I felt that if I was pushing scientists to be fearless on the biological level, I had to do the most I could on the rehab level.

There are also going to be times in life when living fearlessly is very simple. One of the first things that happened after surviving my surgery was that I lost my finesse. My social skills went down the drain. I realized that social skills are, to a large extent, mini-lies. Now when someone asks me a question, I have learned to tell the truth because, really, what the hell do I have to lose?

There are lots of ways of being fearless. I highly recommend it. To a large extent, the key to fearlessness is the “no matter what.” Keep that in mind. It’s truly amazing what we can do by allowing the spirit and mind to flourish. Our capabilities go way beyond our understanding. Trust in that and go forward. Get past the clutter, the noise inside you that says, “I can’t, I can’t, I’m not good enough, I don’t feel like it, I’m sick, I don’t want to.” That is just like static on a radio. Just clear the channel, find good reception, and you’ll be amazed by what you can do.

**This essay was adapted from Reeve’s closing speech at a Living a Fearless Life conference in New York City in the spring of 2004, hosted by The Omega Institute, [www.omega.org](http://www.omega.org)**

**The lesson I had to learn when I had my injury was pretty drastic...my life before that as an actor had been one of self-sufficiency, perseverance, and discipline.**

### **CONSORTIUM FOR SPINAL CORD MEDICINE**

Care for people with spinal cord injuries has become more evidence-based. Since 1995, a group of 25 health professional and consumer organizations (including the Reeve Foundation) has made this its mission. The Consortium for Spinal Cord Medicine, funded and administered by Paralyzed Veterans of America, is centered around clinical practice guidelines: these are recommendations to healthcare providers based on current medical literature and research findings that expert methodologists have graded for scientific strength and validity.

Using this research along with professional and consumer input, the Consortium Steering Committee updates these guidelines and develops new ones, promoting a research agenda that encourages scientific rigor and outcome evaluation.

The Consortium’s clinical practice guidelines for healthcare professionals and

companion consumer guides help people living with paralysis put this information to use in their daily lives. These easy-to-understand publications provide guidance and address questions on clinical subjects ranging from pressure injuries to bowel care to expected outcomes one year out from injury.

Printed and downloadable versions of the clinical practice guidelines and consumer guides are available. Some consumer guides are available in Spanish.

#### **Clinical Practice Guidelines for Healthcare Professionals**

- Acute Management of Autonomic Dysreflexia
- Bladder Management for Adults with Spinal Cord Injury
- Depression Following Spinal Cord Injury
- Early Acute Management in Adults with Spinal Cord Injury
- Management of Mental Health Disorders, Substance Use Disorders and Suicide in Adults with Spinal Cord Injury
- Neurogenic Bowel Management in Adults with Spinal Cord Injury
- Outcomes Following Traumatic Spinal Cord Injury
- Preservation of Upper Limb Function Following Spinal Cord Injury
- Pressure Ulcer Prevention and Treatment Following Spinal Cord Injury
- Prevention of Venous Thromboembolism in Spinal Cord Injury
- Respiratory Management Following Spinal Cord Injury
- Sexuality and Reproductive Health in Adults with Spinal Cord Injury

#### **Consumer Guidelines**

- Autonomic Dysreflexia: What You Should Know
- Bladder Management Following Spinal Cord Injury: What You Should Know
- Depression: What You Should Know
- Expected Outcomes: What You Should Know
- Neurogenic Bowel: What You Should Know
- Preservation of Upper Limb Function Following Spinal Cord Injury: What You Should Know
- Pressure Ulcers: What You Should Know
- Respiratory Management Following Spinal Cord Injury: What You Should Know

#### **Spanish Consumer Guides**

- Intestino Neurológico: Lo Que Usted Debe Saber (Neurogenic Bowel)
- Reflejo Disfuncional Autonomo: Lo Que Usted Debe Saber (Autonomic Dysreflexia)
- Ulceras por Decubito: Lo Que Usted Debe Saber (Pressure Ulcers)

**Guidelines are downloadable at [www.pva.org](http://www.pva.org).**

## CLINICAL TRIALS

Drugs and treatments are developed—or as the research community says it, “translated” —from laboratory experiments. Clinical research is usually conducted via a series of trials that begin with a few people and become progressively larger as safety, efficacy, and dosage are better understood.

Because full-scale clinical trials are expensive and time consuming, usually only the most promising of treatments emerging from research labs are selected in the translation process. A National Institute of Neurological Disorders and Stroke panel noted that future trials on treating paralysis should be based on minimum risk with significant benefit in a relevant animal model that has been independently replicated by other labs. Questions remain as to what minimal level of clinical improvement would warrant various levels of risk and expectation.

Once laboratory and animal studies show promise, a Phase I clinical trial is initiated, used to test the safety of a therapy for a particular disease or condition.

A Phase II clinical trial usually involves more subjects at several different centers and is used to test safety and efficacy on a broader scale, such as to test different dosing for medications or to perfect techniques for surgery.

A Phase III clinical trial involves many centers and sometimes hundreds of subjects. The trial usually involves two patient groups comparing different treatments, or, if there is only one treatment to test, patients who do not receive the test therapy get a placebo (dummy drug) instead.

Many Phase III trials are double-blinded (neither the subjects nor the doctors treating them know which treatment a subject receives) and randomized (placing subjects into one of the treatment groups in a way that can't be predicted by the patients or investigators). Success in Phase III leads to approval by the FDA for clinical use. A Phase IV might be carried out after approval to detect possible rare undesirable side effects that previous phases did not detect.

**Informed consent:** The government has strict safeguards to protect people who participate in clinical trials. Every clinical trial in the United States must be approved and monitored by an Institutional Review Board (IRB), an independent committee of physicians, statisticians, community advocates, and others who assess risk and ensure that the trial is ethical and that the rights of study participants are protected. The IRB makes sure participants know as much as possible.

Informed consent is a process that stresses the need for participants to understand the key facts about a clinical trial before deciding whether or not to join. These facts include why the research is being done, who the researchers are, what the

researchers want to accomplish, what will be done during the trial and for how long, what risks and what benefits can be expected, and what the possible side effects are. Informed consent continues as long as you are in the study. Before joining a trial, participants must meet the study's eligibility guidelines, such as age, type of disease, medical history, and current medical condition. People may leave a trial at any time. For information about all clinical trials taking place in the United States, see <http://clinicaltrials.gov> (search by condition or diagnosis). Be very cautious before joining a trial outside the jurisdiction of the FDA or seeking an unproven or experimental treatment. Legitimate clinical trials never charge patients to participate. See also [www.closerlookatstemcells.org](http://www.closerlookatstemcells.org)

## NACTN: CLINICAL TRIALS NETWORK

Today some spinal cord research has entered a translational phase, moving from laboratory science to clinical application, and clinical trials are either underway or being planned for promising therapies. This kind of translation requires specialized infrastructure to manage the process; there also must be coordination of preclinical data, clinical assessment, treatment and outcome measures, and, at some point, commercialization and reimbursement.

To help select and move promising therapies from the lab to the clinic, the Christopher & Dana Reeve Foundation formed the North American Clinical Trials Network, a group of eleven clinical research centers plus clinical coordinating, data management and pharmacology centers.



Dr. Robert Grossman

Created in 2004 with funding from the Department of Defense, NACTN is a consortium of university hospital neurosurgical and neurorehabilitation teams. NACTN's lead investigator, neurosurgeon Robert G. Grossman (Houston Methodist Hospital), explains that given the complexity of SCI and the high cost of mounting trials, “there can be no progress without partnerships, without collaborations, without alliance-building. Spinal cord injury is too difficult and too expensive to go-it-alone and there is no room for failure due to ill-conceived planning or lack of cutting-edge spinal cord expertise.”

NACTN is a unique resource in the rapidly evolving field of SCI clinical trials. Its principal investigators have expertise in the surgical management of SCI,



the design and conduct of clinical trials, and laboratory and clinical research to encourage repair and recovery after spinal cord injury. The network has formed international partnerships to speed therapy development and delivery; has consulted with universities and industry about clinical trials; and made important knowledge contributions to the field through scientific presentations and publications.

Now in partnership with the AO North America Charitable Fund, the network is engaged in a Phase II/III clinical trial, *Riluzole in Spinal Cord Injury Study (RISCIS)* ([ClinicalTrials.gov](https://clinicaltrials.gov/ct2/show/study/NCT01597518) Identifier: NCT01597518). This large international trial is evaluating the drug riluzole, a neuroprotective that is given soon after injury. In addition, the NACTN centers are conducting a RISCIS substudy on the pharmacology of riluzole in order to determine the best dosage for patients. RISCIS builds on the findings of NACTN's earlier Phase I safety trial in humans.

NACTN's SCI Registry is a database of the natural history of patients with SCI that tracks a patient's acute care and follow-up from admission to a NACTN center to twelve months after injury. Information collected is wide-ranging: demographics, the initial clinical assessment of the injury, radiological imaging, course of treatment including stabilization, medication, surgery and complications, and evolving neurological status. While other spinal cord registries exist, NACTN's is the only one focused on acute data.

The Registry provides a statistical baseline upon which to compare potential therapies and can better inform outcome prediction by helping investigators to more carefully stratify SCI cases. It has been used by scientists and clinicians from academic research labs and industry as well as by the NACTN investigators themselves.

### **NEURORECOVERY NETWORK**

The NeuroRecovery Network (NRN) was founded in 2004 as a cooperative group of innovative rehabilitation centers that develop and deploy therapies to promote functional recovery and improve the health and quality of life for people living with paralysis.

The basis of NRN therapy is activity-based training and started with a heavy focus on Locomotor Training (LT). The idea behind activity-based training, especially patterned activity such as in LT, is that repetitive stimulation of muscles and nerves can encourage plasticity in the nervous system (or the ability of neurons to develop new connections or strengthen/weaken existing ones). In LT, the body of the paralyzed patient is suspended in a harness over a treadmill, while specially trained therapists move his or her legs to simulate walking.



Eric LeGrand, injured playing football for Rutgers in 2010, doing Locomotor Training

NRN centers report that participants experience beneficial changes as a result of the therapy. A significant number who were unable to walk when they entered the program are now able to walk. For others, there are significant improvements in trunk control, endurance, speed of walking and balance, which translate into better ability to perform activities of daily living and reduced dependence on caregivers; there are measurable improvements in cardiovascular, pulmonary, and bladder function and increased bone density. In general, NRN participants show improved overall physical well-being and quality of life.

"Our results support the concept that human spinal cord circuitry can respond to task-specific sensory cues, which can result in recovery in walking," said Susan J. Harkema, Ph.D., Director of the NRN, University of Louisville professor and associate director of the Kentucky Spinal Cord Injury Research Center. "The existence of the NRN and standardization of locomotor training protocols are crucial to determining the outcomes of these and future studies. By standardizing protocols across all NRN centers, we have an improved ability to understand the capacity for recovery in a chronic spinal cord injury population." In 2016, the NRN expanded to include two pediatric sites and its first international community fitness and wellness affiliate.



## NRN CENTERS

### **NRN Centers:**

- Craig Hospital, Englewood, CO
- Frazier Rehab Institute, Louisville, KY
- Kessler Institute for Rehabilitation, West Orange, NJ
- Magee Rehabilitation Hospital, Philadelphia, PA
- Ohio State University Medical Center, Columbus, OH

### **NRN Pediatric Centers:**

- Children's Hospital of Pittsburgh of UPMC, Pittsburgh, PA
- Frazier Rehab Institute, Louisville, KY
- St. Mary's Hospital for Children, Bayside, NY

### **NRN Community Fitness and Wellness Facilities:**

There are also several NRN Community Fitness and Wellness facilities that work with individuals with walking difficulties related to any cause (not just SCI); these fitness facilities host activity-based exercise programs designed specifically for individuals with physical disabilities. The community centers are operated more like fitness facilities.

- Courage Kenny Rehabilitation Institute, Minneapolis, MN
- Frazier Rehab Institute Community Fitness and Wellness Facility, Louisville, KY
- Journey Forward, Canton, MA
- Neurokinex, Gatwick, U.K.\*
- NextSteps Chicago, Willow Springs, IL
- NextStep, Orlando, FL\*
- NextStep, Kansas City, KS\*
- NextStep, Lawndale, CA

\* denotes affiliate status

For more information or to apply to participate in NRN studies or programs:

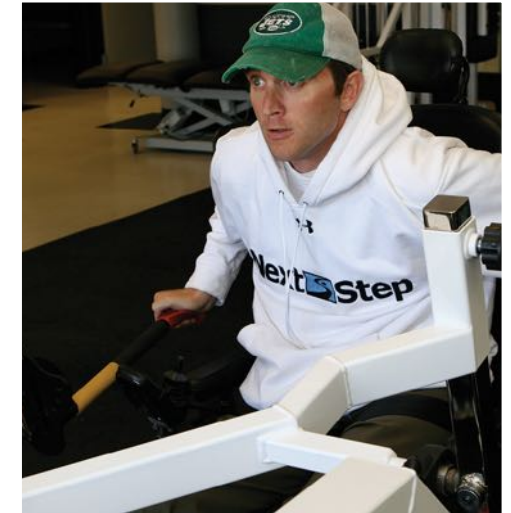
[www.ChristopherReeve.org/NRN](http://www.ChristopherReeve.org/NRN)

## COMMUNITY-BASED RECOVERY

Janne Kouri has an ironman work ethic and a relentless routine. Kouri's not just training, though. He's recovering. Before: total paralysis. Now: walking with a walker. Kouri puts himself through the paces at a facility he and his family created, NextStep Fitness near Los Angeles. The gym is a community-based facility in the Reeve Foundation's NeuroRecovery Network (NRN), the activity-based program that maximizes health and function after paralysis.

Kouri, born in Sweden and raised in New York, broke his neck in 2006 diving into the Pacific and hitting a sandbar. He and his then-fiancée Susan Moffat checked out his rehab options—all over California,

and beyond. They weren't hearing the word recovery. Said Kouri, "I wanted a proactive, progressive place, not one where you just learn how to live your life in a wheelchair." They heard about Frazier Rehab in Louisville, the lead center in the NRN, ground zero for locomotor training. The head of Frazier's rehab research, Susan Harkema, Ph.D., urged Kouri to come there. "She was the only one who gave us hope," he said. "She said 'we'll push him, get him up on the treadmill.'"



Janne Kouri

"After about four months of five days a week training, I was able to wiggle my big toe," he said. "But the more immediate results were better muscle tone, cardiovascular health and improved blood pressure." There's also a mental part: "Simply put, it felt great to stand up and 'walk' again."

When it was time to move back to California, Kouri could move his arms again and maneuver a wheelchair but he wanted to continue the aggressive therapy. He and Susan soon discovered that there were no locomotor training sites on the West Coast. If they wanted it, they'd have to build it. With encouragement from Harkema and the NRN, Kouri opened NextStep as a nonprofit, the first NRN facility that's not in an academic or medical setting. "We want to bring the idea of lifetime wellness into many communities," said Kouri. "People should not have to move their families to get needed exercise."



Rob Summers

CHRISTOPHER VOELKER

## **UNPRECEDENTED NEURORECOVERY**

*The epidural stimulation program at the University of Louisville's Kentucky Spinal Cord Injury Research Center has emerged as one of the most groundbreaking treatment efforts of the last decade.*

*The research began with a singular goal long rejected by a field of skeptics: to restore motor function to people living with partial or complete paralysis.*

*In 2009, Rob Summers became the first person to have an epidural stimulator implanted in his lower back. The stimulator's electrodes would deploy continuous electrical currents to his spinal cord, hopefully activating nerve circuits and providing signals to the body that would normally come from the brain. Within three days of the surgery, Summers, who had sustained a C6-C7 injury during a hit-and-run accident in 2006, was able to stand independently. After another seven months of locomotor training, he was able to voluntarily move his toes, ankles, knees and hips.*

*The mobility achievements thrilled Summers and the research team, but the treatment also yielded unexpected functional gains in bladder control, sexual function and temperature regulation.*

*"When you get secondary function back, it changes everything," Summers says. "You can adapt."*

*As a result, Summers' life expanded. Without having to catheterize every four hours, going out to dinner on the spur of the moment or even flying across the country became less complicated. Before the implant, the former college baseball star couldn't spend more than 20 minutes outside without experiencing tunnel vision; these days, he regularly wheels six-mile loops around Louisville and has been able to return to the ball field to coach local youth teams.*

*"I was able to be present there on the field with the kids, at every practice, at every game, on every road trip," he says. "I was able to just be there and do something that I love."*

*A total of 27 people have been implanted in the epidural stimulation program at Louisville so far. Though there are many hurdles to clear before treatment reaches the public, including developing more advanced stimulator technology and receiving FDA approval, the research has already helped reinvigorate the field and advance the idea that there is much that can be done to treat spinal cord injuries.*



*Susan Harkema, Ph.D., Rob Summers and Reggie Edgerton, Ph.D. Summers was able to stand on his own, benefitting from the research of Harkema and Edgerton.*

## STEM CELLS

In 1998, scientists isolated pluripotent stem cells from early human embryos and grew them in culture. In the years since this discovery, evidence has emerged that these stem cells can become almost any of the 350 known specialized cells of the body; this leads to the notion that stem cells can repair or replace cells or tissues that are damaged or destroyed by disease and injuries.

There is tremendous expectation for stem cell therapy; it's too soon to say just how or when stem cells will be recognized as standard treatment for disease or trauma, but research and some clinical trials are beginning to show promise. What follows is a brief primer on stem cell terminology.

**Stem cell:** A cell from the embryo, fetus, or adult that, under certain conditions, has the ability to reproduce itself for long periods or, in the case of adult stem cells, throughout the life of the organism. A stem cell can give rise to specialized cells that make up the tissues and organs of the body.

**Pluripotent stem cell:** A cell from the embryonic germ layers, from which all cells of the body arise that can develop and self-replicate.

**Induced pluripotent stem cells (iPSCs):** Until recently the only known sources of human pluripotent stem cells were human embryos or certain kinds of fetal tissue; in 2006, scientists in Japan discovered a way to genetically reprogram skin cells to become very similar to embryonic stem cells. Since these cells are specific to the donor, this increases compatibility if such cells were to be used for therapies, thus forming the basis for personalized medicine. However, as with embryonic stem cells, researchers do not fully understand how iPSCs are locked in to their cell lineages. Research is moving quickly: iPSCs are being tested experimentally in numerous disease models, including SCI; moreover, iPSCs are also being used widely as tools to model disease states in a culture dish, providing a unique way to screen therapeutic agents.

**Embryonic stem cell:** Derived from embryos that develop from eggs that have been fertilized in vitro in a fertilization clinic and then donated for research purposes with informed consent of the donors. The current challenges: to direct differentiation of embryonic stem cells into specialized cell populations; and to devise ways to control their proliferation once placed in people. Uncontrolled, these cells can form teratomas, a benign form of cancer.

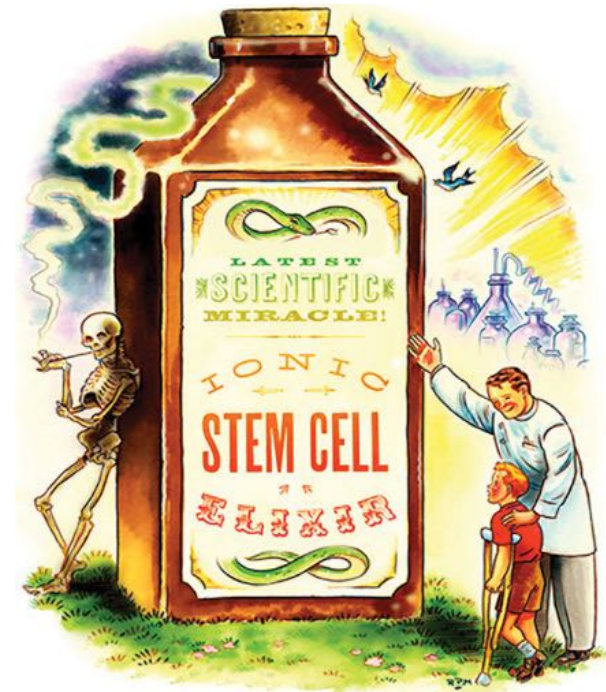
**Differentiation:** The process by which an unspecialized cell (such as a stem cell) specializes into one of the many cells that make up the body. During differentiation, certain genes become activated and others are inactivated in an intricately regulated fashion.

**Adult stem cell:** An undifferentiated (unspecialized) cell that occurs in a differentiated (specialized) tissue, renews itself, and becomes specialized to maintain and repair the tissue in which it is found. Adult stem cells are capable of making identical copies of themselves for the lifetime of the organism. These cells have been identified in brain, bone marrow, peripheral blood, blood vessels, skeletal muscle, skin, teeth, heart, gut, liver, ovarian epithelium, fat and testis.

**Progenitor or precursor cell:** This type of cell can occur in fetal or adult tissues and is partially specialized. When a progenitor/precursor cell divides, it can form similar cells or it can form two specialized cells, neither of which is capable of replicating itself.

**Somatic cell nuclear transfer (also known as therapeutic cloning):** This process involves removing the nucleus of an unfertilized egg cell, replacing it with the material from the nucleus of a "somatic cell" (e.g., skin, heart, or nerve cell), and stimulating this cell to begin dividing. Stem cells can be extracted five to six days later.

**Sources and further reading:** NIH: <https://stemcells.nih.gov>; International Society for Stem Cell Research: [www.isscr.org](http://www.isscr.org); ISSCR Patient Handbook on Stem Cell Therapies: [www.closerlookatstemcells.org](http://www.closerlookatstemcells.org); FDA Stem Cell Warning: [www.fda.gov/consumers/consumer-updates/fda-warns-about-stem-cell-therapies](http://www.fda.gov/consumers/consumer-updates/fda-warns-about-stem-cell-therapies)



ROSS MACDONALD



## **STEM CELL CAUTION**

While stem cell therapy may eventually yield gains for individuals living with spinal cord injuries, it's important to remain cautious until comprehensive research demonstrates the safety and effectiveness of potential treatments. The FDA continues to warn patients about seeking unproven and potentially harmful treatment from rogue stem-cell clinics that operate within the U.S. and around the world. The only stem cell treatments currently approved by the FDA are for certain cancers and disorders of the blood and immune system. In 2019, Japan became the first government to approve a stem-cell treatment for spinal cord injuries. But, in an article in *Nature*, stem cell researchers in the U.S. voiced concerns that there was insufficient evidence the treatment worked. A recent phase I safety study of mesenchymal stem cell treatment for spinal cord injury conducted by the Mayo Clinic reported promising results, but further study and more large-scale clinical trials are needed. Before participating in any stem cell treatment, make sure it is FDA approved or part of an FDA approved clinical trial.

### **Some essential questions to ask a stem cell clinic or trial:**

- Will this affect whether I can get into another clinical trial?
- What benefits can I expect?
- How will this be measured, and how long will it take?
- What other medications or special care might I need?
- How is this stem cell procedure done?
- What is the source of the stem cells?
- How are the stem cells identified, isolated, and grown?
- Are the cells differentiated into specialized cells before therapy?
- How do I know if the cells are delivered to the right part of my body?
- If the cells are not my own, how will my immune system be prevented from reacting to the transplanted cells?
- What do the cells actually do, and is there scientific evidence that this procedure could work for my disease or condition? Where is this published?

## **WALKING QUADRIPLÉGICS AND PARAPLEGICS**

The effect a spinal cord injury has on mobility varies widely, from creating weakness in a limited region of the body to causing paralysis and loss of sensation in all four limbs.

People with incomplete injuries—those where messages can still travel across the site of the injury to the brain—have the best chance of regaining some level of walking. Among quadriplegics, this can include individuals with C1-C8 injuries classified AIS\* C-D, and for paraplegics, those with T1-S1 injuries classified AIS C-D. For L2 injuries and below, individuals with both motor complete and incomplete injuries (classified AIS A-D) have the potential of being able to walk using bracing and assistive devices.

As with any spinal cord injury, a range of abilities is found among 'walking' quadriplegics and paraplegics; there is no one-size-fits-all definition or outcome.

One person might choose a mix of wheelchair and walking for moving around inside the home, but always use a wheelchair in public; another may count walking as the primary means of navigating both home and community, with limited wheelchair use overall.

Howard Menaker became paralyzed from the chest down in 2014 after an infection that developed during lower back surgery caused swelling which compressed his spine. A couple months after the injury, when he could still barely sit up, he began an intensive rehabilitation program at the International Center for Spinal Cord Injury (ICSCI) at the Kennedy Krieger Institute.

"My mobility has progressed from being entirely dependent on a wheelchair to learning how to stand, to walking with a walker, to using lofstrand crutches and now, sometimes, just a quad cane," Menaker says.

At home, Menaker rarely uses his wheelchair, preferring crutches or the quad cane he grows more comfortable with each day. He weighs factors like how far he'll have to walk and what his energy level is when deciding how to balance walking and wheelchair use in public spaces.

When attending the theater with his husband, Menaker sometimes uses his wheelchair to travel from the parking garage, but switches to crutches when he reaches the lobby. For trips with many stops, he might choose the wheelchair to avoid fatigue, but he visits his barber—two blocks away and two



flights up —on crutches.

*“I’m really fortunate and I know that,” Menaker says. “And I know the more I walk, the better I can walk.”*

*Menaker has maintained his progress through regular visits to the ICSCI’s activity-based therapy program where doctors monitor his cardiovascular fitness and bone density and oversee gait training that helps him practice correct walking patterns.*

*Dr. Cristina Sadowsky, Clinical Director of the ICSCI, says activity is important for everyone with a spinal cord injury, including those who move between walking and using a wheelchair. Gait training helps avoid abnormal walking patterns that can cause orthopedic issues and nerve pain. Exercise can mitigate overuse although changes to the body that accompany aging, including degenerative joints, may eventually limit walking ability.*

*People who both walk and use wheelchairs must be attuned to the dangers of falling. Slippery floors, elevated thresholds and uneven cobblestones on a patio can become hazards that lead to serious injuries like broken bones and concussions. Learning how to avoid falls and, when that’s not possible, how to slide into a fall more safely is important for all ‘walking’ quadriplegics and paraplegics.*

*Regaining mobility after a spinal cord injury to the extent that functional walking is possible can sometimes cause unexpectedly complicated emotions.*

*Donna Lowich, now a Senior Information Specialist at the Reeve Foundation, sustained a C4, C5, C6 injury in 1985 when her son Jeffrey was just four years old. Though she worked hard to be able to use a walker, people were not always kind when she left her wheelchair.*

*At the grocery store, where she would use the cart in place of the walker, her slower steps prompted strangers to mutter under their breath about her pace. Once, a neighbor wondered why, if she could use an assisted device, she couldn’t just walk on her own. The comments stung.*

*“It’s a difficult situation to explain,” Lowich said of trying to convey the specific circumstances of an injury.*

*In the early years, it was a struggle to move between walking and the wheelchair; sometimes, neither one felt right. Lowich grew frustrated using a walker in public*

*when she couldn’t keep up with others, and strangers’ reactions made her feel embarrassed or even in danger of falling as they rushed to move around her. But at the same time, she resisted using the wheelchair.*

*“I kept saying that I’d gotten this far, going from not being able to walk at all to this,” she says. “I felt like when I used the wheelchair, it was kind of like saying I’d reached my potential. And I didn’t want to say that.”*

*Eventually, Lowich realized that, whether using the walker to shop for her family or a wheelchair to get to the ball field to watch Jeffrey play, the choices she made about mobility didn’t define her; they simply helped her access the life she wanted.*

*“You have to find the balance,” she says.*

*\*ASIA Impairment Scale (AIS)*

## ASK NURSE LINDA



*Linda Schultz, PhD, CRRN, aka Nurse Linda, is a leader, teacher, and provider of rehabilitation nursing for over 30 years. In fact, Nurse Linda worked closely with Christopher Reeve on his recovery and has been advocating for the Reeve Foundation ever since.*

*In our community, Nurse Linda is the moderator of our Ask a Nurse discussion. She focuses on contributing functional advice, providing the “how-to” on integrating various healthcare improvements into daily life, and answering your specific questions.*

*And if you want more Nurse Linda, you can find her on the Reeve Connect community answering questions in real time. Don’t worry, we archive her answers so you can refer back and sift through her advice. Visit Nurse Linda at [ChristopherReeve.org/Nurse](https://ChristopherReeve.org/Nurse)*



## SPINAL MUSCULAR ATROPHY

Spinal muscular atrophy (SMA) refers to a group of inherited neuromuscular diseases that affect the nerve cells (motor neurons) and the control of voluntary muscles. SMA, the leading genetic cause of death in infants and toddlers, causes lower motor neurons in the base of the brain and the spinal cord to disintegrate, preventing them from delivering the necessary signals for normal muscle function.

Involuntary muscles, such as those that control bladder and bowel function, are not affected in SMA. Hearing and vision are not affected, and intelligence is normal or above average.

The three major childhood-onset forms of SMA are now usually called Type 1, Type 2, and Type 3. All three types are also known as autosomal recessive SMA—both parents must pass on the defective gene in order for their children to inherit the disease.

All forms of SMA affect the skeletal muscles of the trunk and limbs. In general, those muscles closer to the center of the body are more affected than those farther away. SMA Type 1, the most severe form, mostly affects the neurons controlling the mouth and throat muscles and therefore involves more problems with chewing and swallowing. Respiratory muscles are involved to varying degrees in all forms of the disease. In SMA Type 1, the onset of the disease is noted within the first six months of the child's life. Children with SMA Type 1 are unable to sit without support, and death usually occurs before age two.

SMA Type 2 is an intermediate form of the disease. Onset is between seven and eighteen months. Children with SMA Type 2 usually learn to sit without support, but they don't learn to stand or walk without aid. The child's survival depends in large part on the degree of respiratory and swallowing difficulties.

SMA Type 3 is a milder form of this condition. Onset occurs after the age of eighteen months and most often between the ages of five and fifteen. Weakness of the muscles of chewing and swallowing is rare, and respiratory effects are generally not as severe as in the first two forms. These children may live into adulthood. Respiratory complications, if they occur, pose the most serious threat to life.

At present, there is no known treatment that will stop or reverse SMA. Physical therapy and orthopedic devices can help preserve walking function. Braces or surgery may also help to counteract scoliosis, or curvature of the spine.

Researchers around the world have collaborated to find the causes of SMA, which in most cases result from a deficiency of a protein called SMN (survival of motor neuron). This deficiency occurs when a mutation is present in both copies of the SMN1 gene—one on each chromosome 5. Scientists hope to characterize the genes, study gene function and disease course, and find ways to prevent, treat, and, ultimately, cure these diseases.

### **SOURCES**

Spinal Muscular Atrophy Foundation, Muscular Dystrophy Association, National Institute of Neurological Disorders and Stroke

### **SPINAL MUSCULAR ATROPHY RESOURCES**

**Spinal Muscular Atrophy Foundation** hopes to accelerate the development of a treatment or cure for SMA. Toll-free 1-877-FUND-SMA; [www.smafoundation.org](http://www.smafoundation.org)

**Cure SMA (CSMA)** raises funds to promote research into the causes and treatment of the spinal muscular atrophies; supports families affected by SMA. Toll-free 1-800-886-1762; [www.curesma.org](http://www.curesma.org)

**Muscular Dystrophy Association (MDA)** provides services and supports research for a group of hereditary muscle-destroying disorders, including spinal muscular atrophies. Toll-free 1-800-572-1717; [www.mda.org/disease/spinal-muscular-atrophy](http://www.mda.org/disease/spinal-muscular-atrophy)

### **SPINAL TUMORS**

Brain and spinal cord tumors feature abnormal tissue growth inside the skull or the bony spinal column. Tumors are classified as benign (noncancerous) if the cells that make up the growth are similar to normal cells, grow slowly, and are confined to one location. Tumors are malignant (cancerous) when the cells are different from normal cells, grow quickly, and can spread easily to other locations.

Because the central nervous system (CNS) is housed within rigid, bony quarters (the skull and spinal column), any abnormal growth can place pressure on sensitive nerve tissues and impair function. While malignant cells elsewhere in the body can easily seed tumors inside the brain and spinal cord, malignant CNS tumors rarely spread out to other body parts.

Most spinal cord cancers are metastatic, meaning that they arise from a



*Tumor mass compressing T6*

wide variety of primary cancers. These include lung, breast, prostate, head and neck, gynecologic, gastrointestinal, thyroid, melanoma, and renal cell carcinoma.

When new tumors begin within the brain or spinal cord, they are called primary tumors. Primary CNS tumors rarely grow from neurons—nerve cells that perform the nervous system's important functions—because once neurons are mature they no longer divide and multiply. Instead, most tumors are caused by out-of-control growth among cells that surround and support neurons. Primary CNS tumors—such as gliomas and meningiomas—are named by the types of cells comprising them, their location, or both.

The cause of most primary brain and spinal cord tumors remains a mystery. Scientists

don't know exactly why and how cells in the nervous system or elsewhere in the body lose their normal identity and grow uncontrollably. Some of the possible causes under investigation include viruses, defective genes, and chemicals. Brain and spinal cord tumors are not contagious or, at this time, preventable.

More than 359,000 persons in the United States are estimated to be living with a diagnosis of primary brain or central nervous system tumor. More than 195,000 Americans are diagnosed with a brain tumor each year. Brain tumors are the most common form of solid tumor in children. Spinal cord tumors are less common than brain tumors. About 10,000 Americans develop primary or metastatic spinal cord tumors each year. Although spinal cord tumors affect people of all ages, they are most common in young and middle-aged adults.

Brain and spinal cord tumors cause many diverse symptoms, which generally develop slowly and worsen over time. Some of the more common symptoms of a brain tumor include headaches; seizures (a disruption of the normal flow of brain cell electricity that can lead to convulsions, loss of consciousness, or loss of bladder control); nausea and vomiting; and vision or hearing problems. Increased intracranial pressure can also decrease blood flow in the eye and trigger swelling of the optic nerve, which in turn causes blurred vision, double



vision, or partial visual loss. Other symptoms of a CNS tumor may include the following: behavioral and cognitive symptoms, motor or balance problems, pain, sensory changes such as numbness, and decreased skin sensitivity to temperature.

**Diagnosis:** Special imaging techniques, especially computed tomography (CT) and magnetic resonance imaging (MRI), have greatly improved the diagnosis of CNS tumors. In many cases, these scans can detect the presence of a tumor even if it is less than half an inch across.

**Treatment:** The three most commonly used treatments are surgery, radiation, and chemotherapy. When a tumor compresses the spinal cord or its surrounding structures, corticosteroids may be given to reduce the swelling and preserve nerve function until the tumor can be removed.

Surgery to remove as much tumor as possible is usually the first step in treating an accessible tumor—as long as there is little risk of neurological damage. Fortunately, neurosurgical advances now make it possible for doctors to reach tumors that were previously considered inaccessible.

Doctors treat most malignant, inaccessible, or inoperable CNS tumors with radiation and/or chemotherapy. Radiation therapy bombards tumor cells with lethal beams of energy. Chemotherapy uses tumor-killing drugs that are given orally or injected into the bloodstream. Because not all tumors are vulnerable to the same anticancer drugs, doctors often use a combination of drugs for chemotherapy.

The overall outcome of radiation therapy is not always good. Radiation can damage spinal cord myelin, which can lead to paralysis. Researchers are looking for better ways to target radiation or enhance its effectiveness, perhaps by making tumor tissue more vulnerable. Researchers are studying brachytherapy (small radioactive pellets implanted directly into the tumor) as the optimum way to deliver radiotherapy to the tumor while sparing surrounding normal tissues.

Some cells within tumors are quite resistant to radiation. Using a gene therapy approach, scientists hope to kill these cells by inserting a “suicide” gene that could make the tumor cells sensitive to certain drugs or program the cancerous cells to self-destruct.

Blocking the formation of blood vessels (angiogenesis) is a very promising tool for the treatment of various cancers. Since brain tumors are the most angiogenic of all cancers, blocking their blood supply might prove to be

especially effective.

The gamma knife is a newer tool that provides a precisely focused beam of radiation energy that delivers a single dose of radiation on target. The gamma knife does not require a surgical incision; doctors have found it can help them reach and treat some small tumors that are not accessible through surgery.

Although most primary tumors of the spinal cord are not life-threatening, they can cause significant disability. Goals of rehabilitation include functional improvement in mobility, self-care, and pain management.

### **SOURCES**

National Institute of Neurological Disorders and Stroke, American Brain Tumor Association, National Cancer Institute

### **SPINAL TUMOR RESOURCES**

**American Brain Tumor Association (ABTA)** supports medical research and offers information and support for people with tumors and their families. 773-577-8750, toll-free 1-800-886-2282; [www.abta.org](http://www.abta.org)

**Making Headway Foundation** offers services and funds research for children with brain or spinal cord tumors. 914-238-8384; [www.makingheadway.org](http://www.makingheadway.org)

**Musella Foundation for Brain Tumor Research & Information, Inc.** is dedicated to improving the quality of life and survival times for brain tumor survivors. The Foundation has information on clinical trials and treatment outcomes. Toll-free 1-888-295-4740; [www.virtualtrials.com](http://www.virtualtrials.com)

**National Brain Tumor Society** funds research to find treatments and improve clinical care for brain and spinal cord tumors. It offers information and access to quality of life and psychosocial support. 617-924-9997; [www.brainumor.org](http://www.brainumor.org)

**National Cancer Institute**, part of the National Institutes of Health and the Department of Health and Human Services with an annual research budget of over \$6 billion, is the leading U.S. agency to fight cancer of all kinds. Includes resources and information on brain and spinal cord cancers; [www.cancer.gov](http://www.cancer.gov)

### **STROKE**

**A stroke occurs when the blood** supply to the brain is suddenly blocked or when a blood vessel in the brain bursts. Deprived of oxygen, nerve cells in the



affected area of the brain can't function and die within minutes. A person with loss of blood flow to the heart is said to be having a heart attack; similarly, a person with loss of blood flow to the brain or sudden bleeding in the brain can be said to be having a "brain attack."

Although stroke is a disease of the brain, it can affect the entire body, causing cognitive and memory deficits, speech problems, emotional difficulties, daily living problems, and pain. Paralysis is a common outcome of stroke, often on one side of the body (hemiplegia). The paralysis or weakness may affect only the face, an arm or a leg, or it may affect one entire side of the body and face.

A person who suffers a stroke in the left hemisphere of the brain will show right-sided paralysis, or paresis. Likewise, a person with a stroke in the right hemisphere will show deficits on the left side of the body.

There are two main types of stroke. Ischemic strokes occur as a result of an obstruction (clot) within a blood vessel supplying blood to the brain; ischemic strokes account for about 87 percent of all cases. Hemorrhagic strokes result from a weakened blood vessel that ruptures and bleeds into the surrounding brain.

Stroke is the nation's fifth leading cause of death and is a leading cause of serious, long-term disability in the United States. Each year, about 795,000 people in the United States have strokes; of these incidents, 137,000 of the people die.

**Risk factors:** The most important risks for stroke are hypertension, heart disease, diabetes, and cigarette smoking. Others include heavy alcohol consumption, high blood cholesterol levels, illicit drug use, and genetic or congenital conditions, particularly vascular abnormalities. An increase in the red blood cell count is another risk factor for stroke—excess red blood cells thicken the blood and make clots more likely. Eighty percent of strokes are preventable.

**Symptoms:** The symptoms of a stroke include sudden numbness or weakness, especially on one side of the body; confusion, trouble speaking or understanding speech; vision impairment in one or both eyes; sudden difficulties walking; dizziness or loss of balance or coordination; and severe headache with no known cause.

**Treatment:** Ischemic stroke is treated by removing the obstruction and restoring blood flow to the brain. In hemorrhagic stroke, doctors attempt to prevent the rupture and bleeding of aneurysms and arteriovenous malformations.

When blood flow to the brain is interrupted, some brain cells die immediately, while others remain at risk. The damaged cells can often be saved by early intervention with a clot-dissolving drug called tissue plasminogen activator (t-PA) if administered within three hours of the onset of the stroke. Unfortunately, only 3 to 5 percent of those who suffer a stroke reach the hospital in time to receive treatment.

The appropriate response to a brain attack is emergency action—every minute lost, from the onset of symptoms to the time of emergency room contact, cuts into the limited window of opportunity for intervention. Meanwhile, other neuroprotective drugs are being developed to prevent the wave of damage after the initial attack.

**Early recovery:** The brain often compensates for the damage caused by stroke. Some of the brain cells that do not die may resume functioning. Sometimes, one region of the brain takes over for a region damaged by the stroke. Stroke survivors sometimes experience remarkable and unanticipated recoveries that can't be explained.

General recovery guidelines show that 10 percent of stroke survivors recover almost completely; 25 percent recover with minor impairments; 40 percent experience moderate to severe impairments requiring special care; 10 percent require care in a nursing home or other long-term care facility; 15 percent die shortly after the stroke.

**Rehabilitation:** This doesn't reverse the effects of a stroke but rehab builds strength, capability, and confidence so a person can continue daily activities despite the effects of stroke. Such activities may include the following: self-care skills such as feeding, grooming, bathing, and dressing; mobility skills such as transferring, walking, or moving a wheelchair; communication skills; cognitive skills such as memory or problem-solving; and social skills for interacting with other people.

Rehabilitation starts in the hospital and as soon as possible. For those who are stable, rehab may begin within two days after the stroke has occurred and continue as necessary after release from the hospital. Rehabilitation options may include the rehab unit of a hospital, a subacute care unit, a specialty rehab hospital, home therapy, outpatient care, or long-term care in a nursing facility.

Stroke may cause problems with thinking, awareness, attention, learning, judgment, and memory. A stroke survivor may be unaware of his or her surroundings. Language problems are common, usually the result of damage



to the left lobes of the brain. Also, stroke survivors may experience pain, uncomfortable numbness, or strange sensations, due to many factors including damage to the sensory regions of the brain, stiff joints, or a disabled limb.

Many people who have had strokes are affected by spasticity, which causes stiff, tight muscles. Muscle tightness prevents people from doing everyday things such as holding a spoon or tying a shoe. A combination

of medication and physical therapy can loosen the muscles. Some stroke survivors may be candidates for intrathecal baclofen, which places a pump into the abdominal wall to deliver small doses of liquid baclofen into the fluid surrounding the spinal cord. This relaxes the muscles without the mind-numbing side effects often associated with the drug.

A stroke can also lead to emotional problems. Stroke patients may have difficulty controlling their emotions or may express inappropriate emotions in certain situations. One common disability that occurs with many stroke patients is depression. A depressed person may refuse or neglect to take medications, may not be motivated to perform exercises that will improve mobility, or may be irritable. Depression can create a vicious cycle—it deprives the stroke survivor of social contacts, which could in turn help dispel depression. Family can help by stimulating interest in other people or by encouraging leisure activities. Chronic depression can be treated with

counseling, group therapy, or antidepressant medications.

Stroke survivors often find that once-simple tasks around the house become extremely difficult or impossible. Many adaptive devices and techniques are available to help people retain their independence and function safely and easily. The home usually can be modified so the stroke survivor can manage personal needs. See Chapter 7 for more on home modification and adaptive equipment.

There are numerous research projects related to preventing and treating stroke. When a stroke occurs, some brain cells die immediately; others remain at risk for hours and even days due to an ongoing sequence of destruction. Some damaged cells can be saved by early intervention with drugs. The search for so-called neuroprotective drugs, ongoing for many years, has been difficult and frustrating, as one drug after another that showed great promise in animal studies and early human trials was found ineffective in large-scale clinical studies.

Meanwhile, the only approved clot-busting treatment, t-PA, is underutilized. New delivery methods and refinements of t-PA are being developed, including intra-arterial t-PA, which is infused into a main artery in the neck or even smaller arteries in the brain for faster, safer delivery.

*Here are some of the research leads for treating stroke:*

- An enzyme (DSPA) found in saliva from vampire bats may help dissolve blood clots in the brains of stroke survivors. This enzyme may be much more potent than existing anticoagulant drugs and may cause fewer bleeding problems because it only targets the clot itself.
- Erythropoietin, a hormone produced by the kidney, appears to protect some neurons from executing genetically programmed “cell suicide” missions.
- A protein called fibronectin may protect against serious brain damage from stroke.
- Trials have taken place to see if taking amphetamines for several weeks after a stroke will help kick-start the process of self-repair in the brain. Results have been inconclusive but more research is needed.
- For many years, doctors have relied on warfarin, a drug with potentially dangerous side effects (it is also used as rat poison), to reduce the risk of stroke in people at risk for clotting in the heart.
- Cell transplantation has shown some early-trial success in humans who have had a stroke. To be sure, there is great excitement for stem cells as a stroke treatment.
- A study called Pilot Investigation of Stem Cells in Stroke (PISCES) from a

British company called ReNeuron is holding clinical trials (including in the U.S.) to test the safety of a manufactured neural stem cell line in people who have stabilized following an ischemic stroke. See [www.reneuron.com](http://www.reneuron.com).

- Researchers have reported that transplanted adult stem cells (from bone marrow) restored function in laboratory animals with stroke. Human trials have begun.
- Human umbilical cord blood cells have been effective in animal models; trials are underway to test these cells in children with strokes. For information on clinical trials, see [www.clinicaltrials.gov](http://www.clinicaltrials.gov).
- Research advances have led to new therapies and new hope for people who are at risk or who have had a stroke. For example, the Heart Outcomes Prevention Evaluation (HOPE) study found a 33 percent reduction in stroke incidence in diabetics who were given the hypertension drug ramipril. Treatment with statins (cholesterol-lowering drugs) decreases the risk of stroke as well as heart attacks in people with known coronary heart disease.

Clinical trials have tested the safety and effectiveness of a protein called E-selectin, administered by way of a nasal spray, to prevent the formation of blood clots that could cause stroke.

In the area of stroke rehabilitation, an approach called constraint-induced movement-based therapy (CIT) has improved recovery in people who have lost some function in a single limb. The therapy entails immobilizing a patient's good limb to force use of the weakened limb. CIT is thought to promote a remodeling of nerve pathways, or plasticity.

### **SOURCES**

American Stroke Association, National Institute of Neurological Disorders and Stroke

### **STROKE RESOURCES**

**American Stroke Association (ASA)**, affiliated with the American Heart Association, covers the full spectrum, including medical care, rehabilitation, recovery, caregiving, prevention, and research. ASA features the Stroke Family Support Network, which provides information and support to stroke families at any stage of recovery. Toll-free 1-800-242-8721; [www.stroke.org](http://www.stroke.org)

## **TRANSVERSE MYELITIS**

Transverse myelitis (TM) is a neurological disorder caused by inflammation of the spinal cord. Attacks of inflammation can damage or destroy myelin, the fatty insulating substance that covers nerve cell fibers. This causes scars that interrupt communication between the nerves in the spinal cord and the rest of the body.

Symptoms of TM include a loss of spinal cord function over several hours to several weeks. What usually begins as a sudden onset of lower back pain, muscle weakness, or abnormal sensations in the toes and feet can rapidly progress to more severe symptoms, including paralysis. Demyelination (loss of nerve fiber conductivity) usually occurs at the thoracic level, causing problems with leg movement and bowel and bladder control.

Some people recover from TM with minor or no lasting problems, while others have permanent impairments that affect their ability to perform ordinary tasks of daily living.

Transverse myelitis occurs in adults and children, in men and women, and in all races. No familial predisposition is apparent. The peak number of new cases per year appears to occur in people between ten and 19 years and 30 and 39 years of age. About 1,400 new cases of transverse myelitis are diagnosed annually in the United States, and approximately 33,000 Americans have some type of disability resulting from TM.

The exact causes of transverse myelitis are not known. The inflammation that damages the spinal cord may result from viral infections, abnormal immune reactions, or insufficient blood flow through the blood vessels located in the spinal cord. Transverse myelitis may also occur as a complication of syphilis, measles, Lyme disease, and some vaccinations, including those for chickenpox and rabies. Transverse myelitis often develops following viral infections due to varicella zoster (the virus that causes chickenpox and shingles), herpes simplex, Epstein-Barr, influenza, human immunodeficiency virus (HIV), hepatitis A, or rubella. Bacterial skin infections, middle-ear infections, and bacterial pneumonia have also been linked with TM.

Some experts believe that infection causes a derangement of the immune system, which leads to an indirect autoimmune attack on the spinal cord. The immune system, which normally protects the body from foreign organisms, mistakenly attacks the body's own tissue, which causes inflammation and, in some cases, damage to the spinal cord myelin.

**Treatment:** As with many disorders of the spinal cord, no effective cure exists for people with transverse myelitis. The best medicine has to offer is symptom management.

Therapy generally begins when the patient first experiences symptoms. Physicians may prescribe steroids during the first few weeks of illness to decrease inflammation. The goal is to keep the body functioning, hoping for complete or partial spontaneous recovery of the nervous system. Some who don't respond to steroids may undergo plasma exchange therapy (plasmapheresis). This involves replacing plasma, thus removing antibodies that may be involved in inflammation.

People with acute symptoms, such as paralysis, are most often treated in a hospital or in a rehabilitation facility under the care of a specialized medical team. Later, if patients begin to recover limb control, physical therapy to help improve muscle strength, coordination, and range of motion begins.

Transverse myelitis usually includes the following symptoms: (1) weakness of the legs and arms, (2) pain, (3) sensory alteration, and (4) bowel and bladder dysfunction. Most patients will experience weakness of varying degrees in their legs; some also experience it in their arms.

Pain is the primary symptom of transverse myelitis in about half of all patients. The pain may be localized in the lower back or may consist of sharp sensations that shoot down the legs or arms or around the torso. Most people with transverse myelitis report heightened sensitivity to heat, cold, or touch; for some a light touch with a finger may cause significant pain (called allodynia).

**The prognosis:** Recovery from transverse myelitis usually begins within two to 12 weeks of the onset of symptoms and may continue for up to two years. However, if there is no improvement within the first three to six months, significant recovery is unlikely. About one-third of people affected with TM experience good or full recovery. Another one-third show fair recovery and are left with deficits such as spastic gait, sensory dysfunction, and urinary urgency or incontinence. The remaining one-third show no recovery, using wheelchairs, perhaps with marked dependence on others for basic functions of daily living.

**Research:** The National Institute of Neurological Disorders and Stroke (NINDS) supports research to clarify the role of the immune system in TM and other autoimmune diseases or disorders. Other work focuses on strategies to repair demyelinated spinal cords, including approaches using cell transplantation. The ultimate goals of these studies are to encourage

regeneration and to restore function to patients dealing with paralysis.

### **SOURCES**

National Institute of Neurological Disorders and Stroke (NINDS), Transverse Myelitis Association

### **TRANSVERSE MYELITIS RESOURCES**

**Cody Unser First Step Foundation** raises research funds to fight paralysis and to build awareness of transverse myelitis and living actively. 832-421-2150; [www.codysfirststep.org](http://www.codysfirststep.org)

**Johns Hopkins Hospital Department of Neurology** has established a specialized center in Baltimore to care for people with transverse myelitis. The center has gathered physicians and healthcare experts in a variety of disciplines, including neurology, urology, rheumatology, orthopedic surgery, neuroradiology, rehabilitation medicine, and physical and occupational therapy. Johns Hopkins Transverse Myelitis Center, 410-502-7099, toll-free 1-800-765-5447; [https://www.hopkinsmedicine.org/neurology\\_neurosurgery/centers\\_clinics/transverse\\_myelitis/](https://www.hopkinsmedicine.org/neurology_neurosurgery/centers_clinics/transverse_myelitis/)

**Siegel Rare Neuroimmune Association (SRNA)** features news and information for the TM community; facilitates support and networking. 855-380-3330; <https://wearesrna.org>



# 2

## HEALTH MANAGEMENT & WELLNESS

A secondary condition refers to a range of complications which result from a primary disabling condition (stroke, MS, spinal cord injury, cerebral palsy, etc.) These may include medical, social, emotional, mental, family, or community problems. Some can be life threatening if not managed correctly.

### SECONDARY CONDITIONS

#### Autonomic Dysreflexia

Autonomic dysreflexia (AD) is a potentially life-threatening medical emergency that affects people with spinal cord injuries at the T6 level or higher. Although rare, some people with T7 and T8 injuries can develop AD. For most people, AD can be easily treated, as well as prevented. The key is knowing your baseline blood pressure, triggers and symptoms.

Autonomic dysreflexia requires quick and correct action. AD can lead to stroke. Because many health professionals are not familiar with this condition, it is important for people who are at risk for AD, including the people close to them, to know all about it. It is important for at-risk people to know their baseline blood pressure values and to be able to communicate to healthcare providers how to identify potential causes as well as manage an AD emergency.

Some of the signs of AD include high blood pressure, pounding headache, flushed face, sweating above the level of injury, goose flesh below the level of injury, nasal stuffiness, nausea and a slow pulse (slower than 60 beats per minute). Symptoms vary by individual; learn yours.

**What to do:** If AD is suspected, the first thing to do is sit up or raise the head to 90 degrees. If you can lower your legs, do so. Next, loosen or remove anything tight and check blood pressure every five minutes. An individual with SCI above T6 often has a normal systolic blood pressure in the 90-110 mm Hg range. A blood pressure reading of 20 mm to 40 mm Hg above baseline in adults may be a sign of autonomic dysreflexia, or 15mm above baseline in



children, and 15mm to 20mm above baseline in adolescents. Most importantly, locate and remove the offending stimulus, if possible. Begin by looking for your most common causes: bladder, bowel, tight clothing, or skin issues. Keep in mind as you remove the cause that your AD may get worse before it gets better.

Autonomic dysreflexia is caused by an irritant below the level of injury, usually related to bladder (irritation of the bladder wall, urinary tract infection, blocked catheter or overfilled collection bag) or bowel (distended or irritated bowel, constipation or impaction, hemorrhoids or anal infections). Other causes include skin infection or irritation, cuts, bruises, abrasions or pressure injuries (decubitus ulcers), ingrown toenails, burns (including sunburn and burns from hot water) and tight or restrictive clothing.

AD can also be triggered by sexual activity, menstrual cramps, labor and delivery, ovarian cysts, abdominal conditions (gastric ulcers, colitis, peritonitis) or bone fractures.

What happens during an episode of AD? Autonomic dysreflexia indicates over-activity of the autonomic nervous system—the part of the system that controls things you don't have to think about, such as heart rate, breathing and digestion. A noxious stimulus (would be painful if one could sense it) below the injury level sends nerve impulses to the spinal cord; they travel upward until blocked at the level of injury. Since these impulses cannot reach the brain, the body doesn't respond as it would normally. A reflex is activated that increases activity of the sympathetic portion of the autonomic nervous system. This results in a narrowing of the blood vessels, which causes a rise in blood pressure. Nerve receptors in the heart and blood vessels detect this rise in blood pressure and send a message to the brain. The brain then sends a message to the heart, causing the heartbeat to slow down and the blood vessels above the level of injury to dilate. However, since the brain is not able to send messages below the level of injury, blood pressure cannot be regulated. The body is confused and can't sort out the situation.

Generally speaking, medications are used only if the offending stimulus cannot be identified and removed, or when an episode of AD persists even after removing the suspected cause. A potentially useful agent is nitroglycerine paste (applied topically above level of injury). Nifedipine and nitrates are commonly used, in their immediate-release form. Other medications such as Hydralazine, mecamylamine, diazoxide, and phenoxybenzamine might also be used. If an erectile dysfunction drug (e.g. Cialis, Viagra) has been used within

24 hours, other medications should be considered as blood pressure could drop dangerously low.

For the most part, autonomic dysreflexia can be prevented. Keep catheters clean and adhere to your catheterization and bowel schedules.

### **SOURCES**

Paralyzed Veterans of America, Miami Project to Cure Paralysis/University of Miami School of Medicine

### **AUTONOMIC DYSREFLEXIA RESOURCES**

**Reeve Foundation's Paralysis Resource Center** offers a free wallet card (adult or pediatric version, in English or Spanish) describing AD and its emergency management. Make sure your providers are informed. Call toll-free 1-800-539-7309 or search at [www.ChristopherReeve.org/cards](http://www.ChristopherReeve.org/cards)

**Paralyzed Veterans of America**, in support of The Consortium for Spinal Cord Medicine, offers authoritative clinical practice guidelines for autonomic dysreflexia. A consumer guide to AD is also available. Toll-free 1-800-424-8200; [www.pva.org](http://www.pva.org)

## **BLADDER MANAGEMENT**

Paralysis at any level usually affects bladder control. The nerves controlling these organs attach to the very base of the spinal cord (levels S2–S4) and are therefore cut off from brain input. Although it may not be possible to regain the control one had before paralysis, a wide range of techniques and tools are available to manage what is termed a neurogenic bladder.

Here's how an unaffected bladder works: Urine, the excess water and salts that are extracted from the bloodstream by the kidneys, is piped down thin tubes called ureters, which normally allow urine to flow only in one direction. The ureters connect to the bladder, which is basically a storage bag that does not like pressure. When the bag is full, pressure rises and nerves send a message via the spinal cord to the brain. When one is ready to empty the bladder, the brain sends a message back down the spinal cord to the bladder, telling the detrusor muscle (the bladder wall) to squeeze and the sphincter muscle (a valve around the top of the urethra) to relax and open. Urine then passes down the urethra to exit the body.

It is a rather elegant process of muscle coordination just to go pee.

After paralysis, however, the body's normal system of control goes haywire; messages can no longer pass between the bladder muscles and the brain. Both the detrusor and the sphincter may be overactive due to lack of brain control. An overactive detrusor can contract at small volumes against an overactive sphincter; this leads to high bladder pressures, incontinence, incomplete emptying, and reflux – along with recurrent bladder infections, stones, hydronephrosis (kidney distention), pyelonephritis (kidney inflammation), and renal failure.

### The neurogenic bladder is usually affected in one of two ways:

**1. Spastic (reflex) bladder:** when the bladder fills with urine, an unpredictable reflex automatically triggers it to empty; this usually occurs when the injury is above the T12 level. With a spastic bladder you do not know when, or if, the bladder will empty. Physicians familiar with spinal cord injury often recommend a bladder relaxing medication (anticholinergic) for reflexive bladder; oxybutynin (Ditropan) is common, with a primary side effect of dry mouth. Tolterodine, propiverine, or transdermal oxybutynin may result in less dry mouth. Botulinum toxin A (Botox) may be an alternative to anticholinergics. It has been FDA approved for detrusor overactivity treatment in individuals with SCI and multiple sclerosis. The advantage: Botox is used focally in the bladder, thus avoiding systemic side effects, including dry mouth.

**2. Flaccid (non-reflex) bladder:** the reflexes of the bladder muscles are sluggish or absent; it can become over-distended, or stretched. Stretching affects the muscle tone of the bladder. A flaccid bladder may not empty completely. Treatments may include sphincter relaxing medications (alpha-adrenergic blockers) such as terazosin (Hytrin) or tamsulosin (Flomax). Botox injected into the external urinary sphincter may improve bladder emptying. Also, surgery is an option to open the sphincter. Bladder outlet surgery, or sphincterotomy, reduces pressure on the sphincter and thus allows urine to flow out of the bladder easier. An alternative to sphincterotomy is placement of a metal device called a stent through the external sphincter, thus ensuring an open passage. One drawback to both sphincterotomy and stenting is that sperm from an ejaculation ends up in the bladder (retrograde), rather than coming out the penis. This doesn't rule out having a child but complicates it; sperm can be collected from the bladder but can be damaged by urine.

Dyssynergia occurs when the sphincter muscles do not relax when the bladder contracts. The urine cannot flow through the urethra, which can result in the urine

backing up into the kidneys (called reflux), which can lead to serious complications.

The most common method of bladder emptying is an intermittent catheterization program (ICP), which drains the bladder on a set schedule (every four to six hours is common). A catheter is inserted in the urethra to drain the bladder, then removed. An indwelling catheter (Foley) drains the bladder continuously. If drainage originates from a stoma (a surgically created opening) at the pubic bone area, bypassing the urethra, it's called a suprapubic catheter. Advantage: unrestricted liquid intake. Disadvantage: besides the need for a collection device, indwelling catheters are more prone to urinary tract infection. An external condom catheter, which also drains continuously, is an option for men. Condom catheters also require a collection device, e.g. legbag.

### STERILE VS. CLEAN

*The rules were changed a few years ago. No longer is it necessary to reuse a catheter over and over again, rinsing it out after 30 or 40 uses. Medicare and other payers now reimburse for single use intermittent catheters. It makes perfect sense that disposable catheters might reduce the incidence of bladder infection, especially the closed "no touch" systems with a tip that remains sterile. Still, Medicare is not so compelled as to pay for sterile catheters, at least not until a person gets really sick from a bladder infection – twice – and then gets a doctor's prescription. A regular catheter is enormously cheaper (less than \$200 a month versus \$1500 a month or more for disposable sterile catheters). Another type of premium catheter on the market features a super slippery hydrophilic coating to allow easier insertion. There is evidence these are associated with fewer UTIs and reduced urethral trauma compared to conventional polyvinyl chloride catheters. LoFric is a well-known brand; most major urological companies have a hydrophilic line now. You can get these paid for, too, once you prove your urethral openings are at risk.*

There are several surgical alternatives for bladder dysfunction. A Mitrofanoff procedure constructs a new passageway for urine using the appendix; this allows catheterization to be done through a stoma in the abdomen directly to the bladder, a great advantage for women and for people with limited hand function. Bladder augmentation is a procedure that surgically enlarges the bladder, using tissue from the intestines, to expand bladder capacity and thus

### **CRANBERRIES?**

*As for cranberries and bladder health, well, a lot of folks swear by the juice or dried fruit, a lot of people say forget about them; there are published reports in support of both sides. The National Center for Complimentary and Alternative Medicine leans toward the pro-cranberry side, and suggests that cranberries limit the ability of e-coli bacteria to stick to the wall of the bladder. The center admits that research hasn't been well conducted, or clear. Of course the berry and supplements industries lead the cheers, and a paper a few years back from Scotland noted some evidence that cranberry juice may decrease the number of symptomatic bladder infections over a 12 month period in women. More recently, a group at the Kessler Institute in New Jersey suggested that cranberry supplements have no effect in preventing urinary tract infections. In this study, 21 people with SCI were given either cranberry tablets or placebos. After four weeks, they crossed over to the other group. Urinary pH between the cranberry and placebo groups was compared weekly. There was no statistically significant effect for cranberry supplements in reducing bacterial counts or UTIs. Bottom line: can't hurt you to try.*



reduce leaking and the need for frequent catheterization.

It is common for people with multiple sclerosis and other spinal cord diseases to have problems with bladder control. This can involve a little leaking after a sneeze or laugh, or loss of all control. For many people, appropriate clothing and padding can compensate for lack of control. Some women benefit from strengthening the pelvic diaphragm (Kegel exercises) to improve retention of urine.

**Urinary tract infection:** People who live with paralysis are at a high risk for urinary tract infection (UTI), which until the 1950s was the leading cause of death after paralysis. The source of infection is bacteria, a group or colony of tiny, microscopic, single-celled life forms that live in the body and are capable of causing disease. Bacteria from the skin and urethra are easily brought into

the bladder with ICP, Foley and suprapubic methods of bladder management. Also, many people are not able to completely empty their bladder; bacteria are more likely to grow in urine that stays in the bladder.

Some of the symptoms of UTI are cloudy, smelly urine, fever, chills, nausea, headache, increased spasms and autonomic dysreflexia (AD). One may also feel burning while urinating, and/or discomfort in the lower pelvic area, abdomen or lower back.

Once symptomatic, the first line of treatment is antibiotics, including the fluoroquinolones (e.g. ciprofloxacin), trimethoprim, sulfamethoxazole, amoxicillin, nitrofurantoin and ampicillin. The key to preventing a UTI is to halt the spread of bacteria into the bladder. Meticulous hygiene and proper handling of urinary care supplies can help prevent infection. Sediment in the urine can collect in tubing and connectors. This can make it harder for your urine to drain and can make it easier for bacteria to spread. Clean skin is also an important step in preventing infection.

Drinking the proper amount of fluids can help with bladder health, by washing bacteria and other waste materials from the bladder. According to some research studies, cranberry juice, or cranberry extract in pill form, can be an effective preventative for bladder infections. It works by making it hard for bacteria to stick to the wall of the bladder and colonize. Another way to keep the bacteria from colonizing on the bladder wall is the use of D-mannose, a type of sugar available at health food stores. It appears to stick to the bacteria so the bacteria can't stick to anything else.

A complete medical check-up is recommended at least once a year. This should include a urologic exam, including a renal scan or ultrasound to know that the kidneys are working properly. The exam may also include a KUB (kidneys, ureters, bladder), an X-ray of the abdomen that can detect kidney or bladder stones.

Bladder cancer is another concern. Research shows a moderate increase in the risk of bladder cancer among those who have been using indwelling catheters for a long period of time. Smoking also increases the risk for developing bladder cancer.

### **SOURCES**

National MS Society, Spinal Cord Injury Information Network, University of Washington School of Medicine



## BLADDER MANAGEMENT RESOURCES

**Christopher & Dana Reeve Foundation** offers a free Bladder Management booklet in print or downloadable at:

<http://s3.amazonaws.com/reeve-assets-production/2016BladderMgmtToolkit.pdf>

**Paralyzed Veterans of America**, in support of The Consortium for Spinal Cord Medicine, offers authoritative clinical practice guidelines for bladder management. A consumer guide is also available. Toll-free 1-800-424-8200;

[www.pva.org](http://www.pva.org)

**Spinal Cord Injury Rehabilitation Evidence (SCIRE)** project is a Canadian research collaboration of scientists, clinicians and consumers that reviews, evaluates, and translates research knowledge to establish best practices following SCI. [www.scireproject.com](http://www.scireproject.com)

## BOWEL MANAGEMENT

The digestive tract in its entirety is a hollow tube beginning at the mouth and ending at the anus. The bowel, the final portion of the tract, is where the waste products of digested food are stored until they are emptied from the body in the form of stool, or feces.

After food is swallowed, it moves through the esophagus to the stomach, which is basically a storage bag, and then on to the intestines or bowels. The absorption of nutrients occurs in the small intestines, the duodenum, the jejunum and the ileum. Next is the colon, which encircles the abdomen, starting on the right with the ascending colon, passing across the top with the transverse colon, and down the “s”-shaped sigmoid colon to the rectum, which opens at the anus.

Feces move through the bowel by coordinated muscular contractions of the colon walls called peristalsis. This motion is managed by a network of nerve cells at several different levels. The myenteric plexus nerves direct local intestinal movement, seemingly without input from the brain or spinal cord. More than 100 years ago it was discovered that the intestines, even when removed from the body, have an inherent tendency to produce peristalsis. If the intestine wall is stretched, the myenteric plexus triggers the muscles above the stretch to constrict and those below to relax, propelling material down the tube.

The next level of organization comes from autonomic nerves from the brain and spinal cord to the colon, which receives messages through the vagus



nerve. The highest level of control comes from the brain. Conscious perception of a full rectum permits discrimination between solid material and gas, and the decision to eliminate fecal matter when appropriate. Messages relayed via the spinal cord produce voluntary relaxation of the pelvic floor and anal sphincter muscles, allowing the defecation process to occur.

Paralysis disrupts the system. There are two main types of neurogenic bowel, depending on level of injury: an injury above the conus medullaris (at L1) results in upper motor neuron (UMN) bowel syndrome; a lower motor neuron (LMN) bowel syndrome occurs in injuries below L1.

In a UMN or hyperreflexic bowel, voluntary control of the external anal sphincter is disrupted; the sphincter remains tight, which promotes constipation and retention of stool, which cannot be ignored; it is associated with episodes of autonomic dysreflexia. UMN connections between the spinal cord and the colon remain intact, thus reflex coordination and stool propulsion remain intact. Stool evacuation in people with UMN bowel occurs by means

of reflex activity caused by a stimulus introduced into the rectum, such as a suppository or digital stimulation—best triggered at socially appropriate times and places.

LMN or flaccid bowel is marked by loss of stool movement (peristalsis) and slow stool propulsion. The result is constipation and a higher risk of incontinence due to lack of a functional anal sphincter. To minimize formation of hemorrhoids, use stool softeners, minimal straining during bowel efforts, and minimal physical trauma during stimulation.

Bowel accidents happen. The best way to prevent them is to follow a schedule; to teach the bowel when to have a movement. Most people perform their bowel program at a time of day that fits with their lifestyle. The program usually begins with insertion of either a suppository or a mini-enema, followed by a waiting period of approximately 15–20 minutes to allow the stimulant to work. After the waiting period, digital stimulation is performed every 10–15 minutes until the rectum is empty. Those with a flaccid bowel frequently start their programs with digital stimulation or manual removal. Bowel programs typically require 30–60 minutes to complete. Preferably, a bowel program can be done on the commode. Two hours of sitting tolerance is usually sufficient. But those at high risk for skin breakdown need to weigh the value of bowel care in a seated position, versus a side-lying position in bed.

Constipation is a problem for many people with neuromuscular-related paralysis. Anything that changes the speed with which foods move through the large intestine interferes with the absorption of water and causes problems. There are several types of laxatives that help with constipation. Laxatives such as Metamucil supply the fiber necessary to add bulk, which holds water and makes it easier to move stool through the bowels. Stool softeners, such as Colace, also keep the water content of the stool higher, which keeps it softer and thus easier to move. Stimulants such as bisacodyl increase the muscle contractions (peristalsis) of the bowel, which moves the stool along. Frequent use of stimulants can actually aggravate constipation – the bowels become dependent on them for even normal peristalsis.

Faster than a speeding ... There are two main types of suppositories, both based on the active ingredient bisacodyl: those with a vegetable base (e.g. Dulcolax) and those with a polyethylene glycol base (e.g. Magic Bullet). Bullets are said to be about twice as fast as the alternative.

Antegrade continence enema is an option for some people with difficult bowel

problems. This technique involves surgery to create a stoma, or opening, in the abdomen; this allows introduction of liquid above the rectum, thus causing an effective flushing of fecal material from the bowel. This method may significantly decrease bowel care time and allow for the discontinuation of some bowel medications.

*Here are some bowel facts for better digestive management:*

- It is generally not necessary to have a bowel movement every day. Every other day is okay.
- Bowels move more readily after a meal.
- Fluid intake of two quarts daily aids in maintaining a soft stool; warm liquid will also aid bowel movement.
- A healthy diet including fiber in the form of bran cereals, vegetables and fruits helps keep the digestive process working.
- Activity and exercise promote good bowel health.

Some medications commonly used by people with paralysis can affect the bowel. For example, anticholinergic medications (for bladder care) may slow bowel motility, resulting in constipation or even bowel obstruction. Some antidepressant drugs, such as amitriptyline; narcotic pain medications; and some drugs used for the treatment of spasticity, such as dantrolene sodium, contribute to constipation.

Many people report significant improvements in quality of life after colostomy. This surgical option creates a permanent opening between the colon and the surface of the abdomen to which a stool collection bag is attached. Colostomies sometimes become necessary because of fecal soiling or pressure injuries, continual stool incontinence, or excessively long bowel programs. Colostomy enables many people to manage their bowels independently, plus, colostomy takes less time than bowel programs. Studies have shown that people who get colostomies are pleased and would not reverse the procedure; while many may not have embraced the idea of a colostomy at the outset, the procedure can make a huge difference in quality of life, cutting bowel time from as much as eight hours a day to no more than 15 minutes.

### **SOURCES**

Spinal Cord Injury Information Center/University of Alabama at Birmingham,

University of Washington School of Medicine, ALS Association of America, National Multiple Sclerosis Society

## **BOWEL MANAGEMENT RESOURCES**

**Paralyzed Veterans of America**, in support of The Consortium for Spinal Cord Medicine, offers (no charge) authoritative clinical practice guidelines for bowel management. A consumer guide is also available. Toll-free 1-800-424-8200; [www.pva.org](http://www.pva.org)

**Spinal Cord Injury Rehabilitation Evidence (SCIRE)** project is a Canadian research collaboration of scientists, clinicians and consumers that reviews, evaluates, and translates research knowledge to establish best practices following SCI. [www.scireproject.com](http://www.scireproject.com)

## **DEEP VEIN THROMBOSIS**

People living with spinal cord injury (SCI) are at particular risk for deep vein thrombosis (DVT) during their acute hospital course. Deep vein thrombosis is a blood clot that forms in a vein deep in the body, most often in the lower leg or thigh. This can result in a life-threatening danger if the clot breaks loose from the leg vein and finds its way to the lung, causing a pulmonary embolism.

Doctors use anticoagulants, commonly called blood thinners, to prevent blood clots. In spinal cord injury, anticoagulants are generally given within the first 72 hours after injury to all patients. The thinners are usually given for about eight weeks. The most common type of blood thinner used in SCI is a low molecular weight heparin such as enoxaparin or dalteparin. These medications slow the time it takes for blood to clot and also prevent growth of a clot. Blood thinners do not remove existing clots; that sometimes involves surgery.

Some SCI centers use a type of blood filter called an inferior vena cava (IVC) filter in people at high risk for thromboembolism - including those with high cervical injuries or long bone fractures. The appropriateness of IVC filter use as a preventative has not been fully worked out. A recent study showed that placement of an IVC filter may actually increase risk of DVT.

The risk for DVT is highest in the acute phase of SCI but some risk for blood clot formation remains in the SCI population. Routine use of graduated compression stockings is common in people with paralysis.

## **SOURCE:**

National Heart, Lung and Blood Institute

## **DVT RESOURCES**

**National Blood Clot Alliance** is a patient advocacy group that promotes awareness of risk, prevention and treatment of blood clots. [www.stoptheclot.org](http://www.stoptheclot.org)

**Vascular Cures** produces educational materials and promotes public awareness about various vascular diseases. See [vascularcures.org](http://vascularcures.org), and click on Deep Vein Thrombosis.

**Paralyzed Veterans of America**, in support of The Consortium for Spinal Cord Medicine, offers (no charge) an authoritative clinical practice guideline for deep vein thrombosis. Toll-free 1-800-424-8200; [www.pva.org](http://www.pva.org).

## **FATIGUE**

Fatigue is a very common symptom of many conditions related to paralysis. About 80 percent of people with multiple sclerosis report that fatigue significantly interferes with their ability to function. It gets worse as the day progresses; it's aggravated by heat and humidity and may be the most prominent complaint in many MSers who otherwise have few other symptoms.

Fatigue is also a prominent symptom of post-polio syndrome. People who had polio long ago, even those who made complete recoveries from their original polio, sometimes begin years later to feel a lack of energy —tiring much faster than in the past, feeling that once simple things now take a huge effort. These symptoms may be caused by the gradual wearing out of already weakened and damaged nerve cells. Some believe chronic fatigue syndrome, which affects about 1 million people in the United States, may be related to undiagnosed post-polio syndrome. More than 60 percent of people with SCI who experience changes in function identified fatigue as a major problem.

Underlying medical problems such as anemia, thyroid deficiency, diabetes, depression, respiratory problems or heart disease may be factors in a person's fatigue. Also, medications such as muscle relaxants, pain drugs and sedatives can contribute to fatigue. Low fitness levels may result in too little energy reserves to meet the physical demands of daily life. People should consult a physician if fatigue becomes a problem.

Disrupted sleep is reported in up to 35 percent of people with MS; daytime

fatigue may be caused by sleep apnea, periodic leg movements, neurogenic bladder problems, spasticity, pain, anxiety or depression. Better sleep starts with better symptom management. See your doctor about options for treating pain, depression, sleep apnea, etc. There isn't a single remedy for fatigue. Listen to your body; use your energy wisely.

### **SOURCES**

National Multiple Sclerosis Society, Rancho Los Amigos Hospital, Paralyzed Veterans of America, U.S. Department of Health and Human Services' Office on Women's Health

### **Other Complications**

**Heart disease:** People with spinal cord dysfunction have an increased risk of developing heart disease at an earlier age than those in the rest of the population. Cardiovascular diseases are reportedly the leading cause of death for persons who have had a spinal cord injury for more than 30 years. People with SCI are prone to certain metabolic risk factors. They are generally more insulin resistant, which affects the body's ability to transform blood sugar into energy, and can lead to heart disease, diabetes and other conditions. Contributing to the abnormalities are loss of muscle mass (atrophy), increase in body fat, and a harder time maintaining cardiovascular fitness. Some prevention strategies include: screening for blood sugar problems, healthy diet, no smoking, moderation with alcohol, and regular physical exercise.

**Orthostatic hypotension** occurs when blood pressure drops because of a change in posture, such as standing or sitting up from a supine position. People with spinal cord injuries, especially at T-6 or above, are at higher risk of developing low blood pressure because of damage to the autonomic nervous system; dehydration, pregnancy and alcohol use can also cause this condition.

The most common symptoms include lightheadedness, confusion, weakness, blurry vision, headache, nausea and heart palpitations. Orthostatic hypotension most commonly occurs following initial injury, during illness or after an extended period of bedrest. To prevent it, stay hydrated, eat small meals throughout the day to keep blood pressure even and avoid changing position too abruptly, especially when transferring to wheelchairs or standing frames. Doctors may recommend compression stockings, abdominal binders and, if needed, medication to stabilize blood pressure levels.

**Heterotopic ossification** (HO) is the abnormal growth of bone in soft

### **DEALING WITH FATIGUE**

#### **A few ideas for reducing fatigue:**

- *Better nutrition. Caffeine, alcohol, smoking and a diet high in refined carbohydrates, sugar and hydrogenated fats rob your energy. Lack of protein can also lead to fatigue.*
- *Rest. Take it easy on yourself. Give yourself down time as needed. Reach for the best-feeling thoughts, enjoy a laugh whenever you can, and structure relaxation time at least twice a day using yoga, meditation or prayer.*
- *Stay cool. People with MS are less fatigued when they avoid heat and/or use cooling devices (vests, ice packs, etc.).*
- *Find new ways, including the tools of occupational therapy, to simplify work tasks and implement energy saving strategies.*
- *Use adaptive equipment to preserve the energy you do have. There is a wonderful array of gadgets and timesavers on the market (see page 269 for more). For a person with post-polio, this could mean using a wheelchair instead of a walker. Wheelchair users might add a power assist or move up to a full-power unit.*
- *Cut stress. Some people benefit from stress management, relaxation training, membership in a support group or psychotherapy. Although the link between fatigue and depression is not fully understood, psychotherapy has been shown to lessen fatigue in people with MS who are depressed.*
- *Build stamina through exercise. Physical activity was once thought worsen fatigue, but aerobic exercise may benefit those with mild disabilities.*
- *Vitamins, herbs, etc. Some people say their fatigue is improved after taking supplements such as adenosine monophosphate, coenzyme Q-10, germanium, glutathione, iron, magnesium sulfate, melatonin, NADH, selenium, L-tryptophan, vitamins B12, C and A, and zinc. Others include astragalus, borage seed oil, bromelain, comfrey, echinacea, garlic, Ginkgo biloba, ginseng, primrose oil, quercetin, St. John's wort and Shiitake mushroom extract.*
- *For MS, doctors often prescribe amantadine and pemoline to relieve fatigue. Since one of the side effects of both drugs is insomnia, they work best if taken in the morning and at noon.*



tissue. The cause remains unknown, but the condition can develop after musculoskeletal trauma, spinal cord injury or central nervous system injury. Along with painful joints, additional symptoms may include fever, swelling and limited mobility in the affected area.

HO develops below the level of injury, most frequently in the hips but also in knees, elbows or shoulders, and can occur in the early days of the injury or months or years later. For individuals with spinal cord injuries, HO can cause additional health complications, including skin breakdown, increased spasticity and risk of deep vein thrombosis and autonomic dysreflexia. Treatment will likely include physical therapy and medication to slow the abnormal growth. Radiation and surgery may be considered for severe cases.

**Hypo/hyperthermia:** Paralysis can cause the temperature of the body to fluctuate according to the temperature of the environment. Being in a hot room may increase temperature (hyperthermia); a cold room may decrease temperature (hypothermia). Temperature management is essential for some people.

## CHRONIC PAIN

Pain is a signal triggered in the nervous system to alert us to possible injury. Acute pain, the result of sudden trauma, has a purpose. This kind of pain can usually be diagnosed and treated so the discomfort is managed and confined to a given period of time. Chronic pain, though, is much more confounding. It is the kind of alarm that doesn't go away and is resistant to most medical treatments. There may be an ongoing cause of pain—arthritis, cancer, infection – but some people have chronic pain for weeks, months and years in the absence of any obvious pathology or evidence of body damage. A type of chronic pain called neurogenic or neuropathic pain often accompanies paralysis—it is a cruel irony for people who lack sensation to experience the agony of pain.

Pain is a complicated process that involves an intricate interplay between a number of important chemicals found naturally in the brain and spinal cord. These chemicals, called neurotransmitters, transmit nerve impulses from one cell to another.

There is a critical lack of the essential inhibitory neurotransmitter GABA (gamma-aminobutyric acid) in the injured spinal cord. This may “disinhibit” spinal neurons that are responsible for pain sensations, causing them to fire

more than normal. This disinhibition is believed to be the root of spasticity, too. Recent data also suggest that there may be a shortage of the neurotransmitter norepinephrine, as well as an overabundance of the neurotransmitter glutamate. During experiments, mice with blocked glutamate receptors show a reduction in their responses to pain. Other important receptors in pain transmission are opiate-like receptors. Morphine and other opioid drugs work by locking on to these receptors, switching on pain-inhibiting pathways or circuits, and thereby blocking pain.

Following injury, the nervous system undergoes a tremendous reorganization. The dramatic changes that occur with injury and persistent pain underscore that chronic pain should be considered a disease of the nervous system, not just prolonged acute pain or a symptom of an injury. New drugs must be developed; current medications for most chronic pain conditions are relatively ineffective and are used mostly in a trial by error manner; there are few alternatives.

The problem with chronic nerve pain is not just the distraction of hurting. Pain can lead to inactivity, which may lead to anger and frustration, to isolation, depression, sleeplessness, sadness, then to more pain. It's a spin cycle of misery with no easy exit, and modern medicine doesn't offer a wide range of help. Pain control becomes a matter of pain management; the goal is to improve function and allow people to participate in day-to-day activities.

**Types of pain:** Musculoskeletal or mechanical pain occurs at or above the level of spinal cord lesion and may stem from overuse of remaining functional muscles after spinal cord injury or those used for unaccustomed activity. Wheelchair propulsion and transfers are responsible for most mechanical pain.

Central pain or deafferentation pain is experienced below the level of SCI and is generally characterized by burning, aching and/or tingling. Central pain doesn't always show up right away; it may take weeks or months to appear and is often associated with recovery of some spinal cord function. This type of pain is less common in complete injuries. Other irritations, such as pressure injuries or fractures, may increase the burning of central pain.

Psychological pain: Increased age, depression, stress and anxiety are associated with greater post-spinal cord injury pain. This doesn't mean the sensation of pain is in your head—it's real, but pain appears to have an emotional component too.

Complex Regional Pain Syndrome (CRPS) is a chronic pain condition linked

to peripheral or central nervous system damage that can follow injury, surgery or stroke; in 10 percent of cases, there is no known trigger. CRPS causes neuropathic pain. CRPS type 1 (formerly known as reflex sympathetic dystrophy syndrome) occurs after soft-tissue or bone injury while CRPS type II (formerly known as causalgia) follows a known nerve injury.

Persistent pain — described as burning, aching or a “pins and needles” sensation — is the key symptom of CRPS. In addition, skin may be painfully sensitive and become discolored, shiny, thin or cracked; abnormal sweating and changes to growth patterns, including hair loss and excessive nail growth, may occur in or around the affected area; and motor impairment, such as joint stiffness, weakness, tremors and spasms, might also be present.

The prognosis of CRPS varies widely. In some cases, early detection and response helps limit and stabilize the disorder; in others, despite treatment, individuals may experience long term pain and disability. Rehabilitation and physical therapy targeting the desensitization and strengthening of affected areas may be combined with medication, including tricyclic antidepressants, antiseizure drugs and corticosteroids. Treatment might also include spinal cord stimulation and psychotherapy for those who develop depression and anxiety which can heighten the perception of pain and impede rehabilitation progress.

### Treatment Options for Neuropathic Pain:

**Heat and massage therapy:** sometimes these are effective for musculoskeletal pain related to spinal cord injury.

**Acupuncture:** this practice dates back 2,500 years to China and involves the application of needles to precise points on the body. While some research suggests this technique boosts levels of the body’s natural painkillers (endorphins) in cerebrospinal fluid following treatment, acupuncture is not fully accepted in the medical community. Still, it is noninvasive and inexpensive compared to many other pain treatments. In some limited studies, this method helps relieve SCI pain.

**Exercise:** SCI patients who underwent a regular exercise program showed significant improvement in pain scores; this also accounted for improved depression scores. Even light to moderate walking or swimming can contribute to an overall sense of well-being by improving blood and oxygen flow to tense, weak muscles. Less stress equals less pain.

**Hypnosis:** has been shown to have a beneficial effect on SCI pain. Visual imagery therapy, which uses guided images to modify behavior helps some

people alleviate pain by changing perceptions of discomfort.

**Biofeedback:** trains people to become aware of and to gain control over certain bodily functions, including muscle tension, heart rate and skin temperature. One can also learn to effect a change in his or her responses to pain, for example, by using relaxation techniques. With feedback and reinforcement one can consciously self-modify out-of-balance brain rhythms, which can improve body processes and brain physiology. There are many claims made for treating chronic pain with biofeedback, especially using brain wave information (EEG).

**Transcranial electrical stimulation (TCES):** treatment applies electrodes to an individual’s scalp, allowing electrical current to be applied and presumably stimulate the underlying cerebrum. Studies indicate this newer treatment may be useful in reducing SCI-related chronic pain.

**Transcutaneous electrical nerve stimulation (TENS):** is used for pain and has been shown to help with chronic musculoskeletal pain. In general, TENS has not been as effective for pain below injury level.

**Transcranial magnetic stimulation (TMS):** applies electromagnetic pulses to the brain; it has helped with post-stroke pain and in limited studies has reduced post-SCI pain over long-term use.

**Spinal cord stimulation:** electrodes are surgically inserted within the epidural space of the spinal cord. The patient triggers a pulse of electricity to the spinal cord using a small box-like receiver. This is most commonly used for lower back pain but some people with MS or paralysis can benefit.

**Deep brain stimulation:** is considered an extreme treatment and involves surgical stimulation of the brain, usually the thalamus. It is used for a limited number of conditions, including central pain syndrome, cancer pain, phantom limb pain and other types of neuropathic pain.

**Magnets:** are usually dismissed as pseudoscience, but proponents offer the theory that magnetic fields may effect changes in cells or body chemistry, thus producing pain relief.

**Drugs:** options for chronic pain include a ladder of drugs, starting with over the counter nonsteroidal anti-inflammatories such as aspirin, all the way to tightly controlled opiates such as morphine. Aspirin and ibuprofen may help with muscle and joint pain but are of minimal use for neuropathic pain. This includes COX-2 inhibitors (“superaspirins”) such as celecoxib (Celebrex).

**Current medications for most chronic pain conditions are relatively ineffective and the options for treatment are limited. More research is needed.**

At the top of the ladder are opioids, drugs derived from the poppy plant that are among the oldest drugs known to humankind. They include codeine and the king of opiates, morphine, named for Morpheus, the god of dreams.

While morphine is still the go-to

therapy at the top of the treatment ladder, it is not usually a good long-term solution. It depresses breathing, causes constipation, fogs the brain and people develop tolerance and addiction for it. Moreover, it isn't effective against many types of neuropathic pain. Scientists hope to develop a morphine-like drug that will have the pain-deadening qualities of morphine but without the drug's debilitating side effects.

There is a middle ground of medications that work for some types of chronic pain. Anticonvulsants were developed to treat seizure disorders, but are also sometimes prescribed for pain. Carbamazepine (Tegretol) is used to treat a number of painful conditions, including trigeminal neuralgia. Gabapentin (sold as Neurontin) is commonly prescribed "off label" (unapproved by the FDA) for neuropathic pain. (Pfizer, the company that owns Neurontin, pled guilty in 2004 to felonies and agreed to millions of dollars in fines for aggressive marketing of the drug for unapproved uses.)

Meanwhile, Pfizer received FDA approval in 2012 of a newer anticonvulsant to target pain, this time specific to SCI. Approval of pregabalin, marketed as Lyrica, was based on two randomized, double-blind, placebo-controlled Phase 3 trials, which enrolled 357 patients. Lyrica reduced neuropathic pain associated with SCI from baseline compared to placebo; patients receiving Lyrica showed a 30 percent to 50 percent reduction in pain compared to those getting placebo. Lyrica won't work for everyone. It also comes with a wide range of possible side-effects, including anxiety, restlessness, trouble sleeping, panic attacks, anger, irritability, agitation, aggression, and a risk for suicidal behavior.

For some, tri-cyclic antidepressant drugs can be helpful for the treatment of pain. Amitriptyline (sold as Elavil and other brands) is effective in the treatment of post-SCI pain – at least there is some evidence it works in depressed individuals.

In addition, the class of anti-anxiety drugs called benzodiazepines (Xanax, Valium) act as muscle relaxants and are sometimes used to deal with pain. Another muscle relaxant, baclofen, applied by an implanted pump (intrathecally), improves chronic post-SCI pain, but may only work when it is related to muscle spasms.

**Botulinum toxin injections** (Botox) which is used to treat focal spasticity, can also have an effect on pain.

**Nerve blocks:** employ the use of drugs, chemical agents or surgical techniques to interrupt the transmission of pain messages between specific areas of the body and the brain. Types of surgical nerve blocks include neurectomy; spinal dorsal, cranial, and trigeminal rhizotomy; and sympathetic blockade.

**Physical therapy and rehabilitation:** are often utilized to increase function, control pain and speed a person toward recovery.

**Surgeries:** for pain include rhizotomy, in which a nerve close to the spinal cord is cut, and cordotomy, where bundles of nerves within the spinal cord are severed. Cordotomy is generally used only for the pain of terminal cancer that does not respond to other therapies. The dorsal root entry zone operation, or DREZ, destroys spinal neurons corresponding to the patient's pain. This surgery can be done with electrodes that selectively damage neurons in a targeted area of the brain.

**Marijuana:** is illegal by federal law, but its proponents place pot alongside other pain remedies. In fact, for many years, it was sold in cigarette form by the U.S. government for just that purpose. Numerous states have partially decriminalized marijuana for medical reasons but that does not exempt users from federal prohibition laws, nor does it allow doctors to prescribe marijuana. There is medical evidence, however, to support further study; marijuana appears to bind to receptors found in many brain regions that process pain information.

Research in neuroscience will lead to a better understanding of the basic mechanisms of pain, and to more and better treatments in the years to come. Blocking or interrupting pain signals, especially when there is no apparent injury or trauma to tissue, is a key goal in the development of new medications.

### **SOURCES**

National Institute of Neurological Disorders and Stroke (NINDS), National

Multiple Sclerosis Society, Dana Foundation

## **PAIN RESOURCES**

**American Chronic Pain Association (ACPA)** offers peer support and education for individuals with chronic pain. Toll-free 1-800-533-3231; <https://theacpa.org>

**Spinal Cord Injury Rehabilitation Evidence (SCIRE)** project is a Canadian research collaboration of scientists, clinicians and consumers that reviews, evaluates, and translates research knowledge and establishes best rehabilitation practices following SCI. There is a lengthy section on pain. [www.scireproject.com](http://www.scireproject.com)

## **RESPIRATORY HEALTH**

As we breathe, air is brought into the lungs and into close contact with tiny blood vessels that absorb oxygen and transport it to all parts of the body. At the same time, the blood releases carbon dioxide, which is carried out of the lungs with exhaled air.

Lungs themselves are not affected by paralysis, but the muscles of the chest, abdomen and diaphragm can be. As the various breathing muscles contract, they allow the lungs to expand, which changes the pressure inside the chest so that air rushes into the lungs. This is the process of inhaling—which requires muscle strength. As those muscles relax, the air flows back out of the lungs.

If paralysis occurs in level C3 or higher, the phrenic nerve is no longer stimulated and therefore the diaphragm does not function. This means mechanical assistance – usually a ventilator – will be required to facilitate breathing. When the injury is between C3 to C5 the diaphragm is functional but respiratory insufficiency still occurs: The intercostals and other chest wall muscles do not provide the integrated expansion of the upper chest wall as the diaphragm descends during inspiration.

People with paralysis at the mid-thoracic level and higher may have trouble taking a deep breath and exhaling forcefully. Because they may not have use of abdominal or intercostal muscles, these people also lose the ability to force a strong cough. This can lead to lung congestion and respiratory infections.

**Clearing Secretions:** Mucous secretions are like glue, causing the sides of airways to stick together and not inflate properly. This is called atelectasis,

### **PREVENTING RESPIRATORY ISSUES**

- *Maintain proper posture and mobility. Sit up every day and turn regularly in bed to prevent the buildup of congestion.*
- *Cough regularly. Have someone perform manual assist coughs, or perform self-assist coughs; use a machine to help.*
- *Wear an abdominal binder to assist intercostal and abdominal muscles.*
- *Follow a healthy diet and manage your weight – problems are more likely to occur if you are too heavy or too light.*
- *Drink plenty of water. Water helps keep congestion from becoming thick and difficult to cough up.*
- *Do not smoke or be around smokers: Smoking not only causes cancer, but also decreases oxygen in the blood, increases congestion in the chest and windpipe, reduces the ability to clear secretions from lungs, destroys lung tissue, and increases the risk for respiratory infections.*
- *Exercise. Every person living with paralysis can benefit from some type of exercise. For those with a high level of paralysis, it may be helpful to do breathing exercises.*
- *Get vaccinations for both influenza and pneumonia.*

or a collapse of part of the lung. Many people with paralysis are at risk for this. Some people have a harder time knocking down colds or respiratory infections; they have what feels like a constant chest cold. Pneumonia is a serious risk if secretions become the breeding ground for various bacteria. Symptoms of pneumonia include shortness of breath, pale skin, fever and an increase in congestion.

Ventilator users with tracheostomies have secretions suctioned from their lungs on a regular basis; this may be anywhere from every half hour to only once a day.

**Mucolytics:** Nebulized sodium bicarbonate is frequently used to make tenacious secretions easier to eliminate. Nebulized acetylcysteine is also effective for loosening secretions, although it may trigger reflex bronchospasm.

It is important to be aggressive with pulmonary infections: Pneumonia is one



of the leading causes of death for all persons living with spinal cord injury, regardless of the level of injury or the amount of time since the injury.

**Cough:** An important technique for clearing secretions is the assisted cough: An assistant firmly pushes against the outside of the stomach and upward, substituting for the abdominal muscle action that usually makes for a strong cough. This is a much gentler push than the Heimlich maneuver; it's also important to coordinate pushes with natural breathing rhythms. Another technique is percussion: this is basically a light drumming on the ribcage to help loosen up congestion in the lungs.

Postural drainage uses gravity to drain secretions from the bottoms of the lungs up higher into the chest where one can either cough them up and out or get them up high enough to swallow them. This usually works when the head is lower than the feet for 15–20 minutes.

Glossopharyngeal breathing can be used to help obtain a deeper breath, by “gulping” a rapid series of mouthfuls of air and forcing the air into the lungs, and then exhaling the accumulated air. It can be used to help with coughing.

There are several machines on the market that may help people on ventilators cough. The Vest (Hill-Rom; <https://respiratorycare.hill-rom.com/en/patients/products/the-vest-system-105>), consists of an inflatable vest connected by air hoses to an air pulse generator, which can rapidly inflate and deflate the vest, thus applying gentle pressure to the chest wall to loosen and thin mucus and move it to the central airways to be cleared by coughing or suctioning.

The CoughAssist (Philips Respironics; [www.usa.philips.com](http://www.usa.philips.com), search CoughAssist) is designed to boost cough function by mechanically simulating the cough maneuver. This device blows in an inspiratory pressure breath followed rapidly by an expiratory flow. This generates enough peak air flow to clear secretions. Both the Vest and the CoughAssist have been approved by Medicare for reimbursement if determined to be a medical necessity.

Researchers at the Cleveland FES Center devised an electrical stimulation protocol to initiate a forceful cough in patients with quadriplegia, on demand. The system is under evaluation and not yet clinically available. See <http://fescenter.org>

**Ventilators:** There are two basic types of mechanical ventilators. Negative pressure ventilators, such as the iron lung, create a vacuum around the outside of the chest, causing the chest to expand and suck air into the lungs. Positive pressure ventilators, which have been available since the 1940s, work on the opposite principle, by blowing air directly into the lungs. Ventilators

are invasive – an air passage is made in the throat area, fitted with a device most people call a “trach.”

### OFF THE VENT

*Lazlo Nagy became a C4 quadriplegic on a vent after he crashed his motorcycle years ago. Eventually, he wound up in a nursing home with around-the-clock care, and remained quite unsettled. “I used to cry myself to sleep every night because of the anxiety. I was constantly worried, would my battery go dead, would the machine go all night?” After Nagy heard about Christopher Reeve’s experience in a diaphragm pacing clinical trial, he too got a diaphragm pacing implant. “The change in my life has been truly remarkable,” says Nagy. “The nursing facility was billing Medicaid \$16,000 a month. After getting the [pacing] surgery, it went to \$3000—a savings of \$13,000 a month. Eventually I returned to work, I got married, I feel confident I can go out in the world by myself, without an attendant. It’s given me a lot more freedom. I feel safe. I don’t worry that I’m going to suddenly die.”*

**Noninvasive breathing:** Some people, including those with high-level quadriplegia, have had success using a noninvasive breathing system. Positive pressure air is supplied to a mouthpiece from the same type of ventilator used with a trach. The user takes puffs of air as needed. A primary advantage reported for noninvasive ventilation is that because there is no open trach, there may be less chance of bacterial entry and therefore fewer respiratory infections. Also, some patients on non-invasive systems attest to a better, more independent quality of life because they don’t have a trach in their neck and they don’t have to suction the trachea as frequently. Clearly, noninvasive ventilation is not for everyone. Candidates must have good swallowing function; they also need a full support network of pulmonary specialists. There are not many clinicians with expertise in the method, thus its availability is limited.

Another breathing technique involves implantation of an electronic device in the chest to stimulate the phrenic nerve and send a regular signal to the diaphragm, causing it to contract and fill the lungs with air. Phrenic nerve pacers have been available for many years. Two companies offer diaphragm stimulation systems. The Avery pacemaker has been in use since before the FDA approved medical devices, going back to the mid-1960s. The Avery has

been implanted in over 2,000 patients, with about 600 in use now, some continuously for almost 40 years. The procedure involves surgery through the body or neck to locate the phrenic nerve on both sides of the body. The nerves are exposed and sutured to electrodes. A small radio receiver is also implanted in the chest cavity; this is activated by an external antenna taped to the body. For details see [www.averybiomedical.com](http://www.averybiomedical.com)

The Synapse system, pioneered in Cleveland, was used in an early clinical trial by Christopher Reeve in 2003. The Cleveland system, FDA approved for implant in people with spinal cord injury in 2008, is more simply installed, using an outpatient laparoscopic technique. Two electrodes are placed on each side of diaphragm muscle, with wires attached through the skin to a battery powered stimulator. Synapse also has FDA approval to implant the devices in people with ALS. For more see [www.synapsebiomedical.com](http://www.synapsebiomedical.com)

For those with a progressive neuromuscular disability, such as ALS, morning headaches are often the first sign that breathing needs help. Since breathing is shallower during sleep, any drop in volume can lead to trouble – including retention of carbon dioxide, which causes headache.

Others may wake up repeatedly during the night as the shallow breathing causes a sudden jolt. Broken sleep causes daytime sleepiness, lethargy, anxiety, irritability, confusion and physical problems such as poor appetite, nausea, increased heart rate and fatigue. BiPAP (Bi-level Positive Airway Pressure), a type of noninvasive ventilation, is often called for. BiPAP is not a life-support machine—it cannot completely take over breathing. Using a removable mask over the nose, the system delivers a pressurized breath of air into the lungs, then drops the pressure to allow an exhale. The most common use is for people with sleep apnea, characterized by snoring and lack of oxygen during sleep. Sleep apnea is linked to high blood pressure, stroke and cardiovascular disease, memory problems, weight gain, impotency and headaches.

For reasons that are not completely clear, sleep apnea is significantly more common to people with spinal cord injuries, especially those with quadriplegia, among whom an estimated 25-40 percent have the condition. Obesity, common in the SCI population, is a risk factor for sleep apnea. Many people with SCI can't change sleep positions and may remain on their backs, which often leads to breathing obstruction. Respiratory muscle weakness is very likely involved. It may also be that certain medications (baclofen, for example, is known to slow down breathing) affect sleep patterns. People with higher cervical injuries who rely upon neck and upper chest muscles to help with

breathing may be susceptible to sleep apnea because these muscles are inactive during deep sleep.

For people with neuromuscular disease, BiPAP can improve the quality of life while delaying the need for invasive ventilation, or diaphragm pacing, by months or years. Some people use BiPAP as an intermediary step before going on a ventilator.

**Tracheostomy care:** There are many potential complications related to tracheostomy tubes, including the inability to speak or swallow normally. Certain tracheostomy tubes are designed to direct air upward during exhalation and thus permit speech during regular, periodic intervals. Another tracheostomy-associated complication is infection. The tube is a foreign body in the neck, and thus has the potential of introducing organisms that would ordinarily be stopped by natural defense mechanisms in the nose and mouth. Cleaning and dressing of the tracheostomy site daily is an important preventive measure.

**Weaning** (removing ventilator support): In general, those with complete neurologic injuries at C2 and above have no diaphragmatic function and require a ventilator. Those with complete injuries at C3 or C4 may have diaphragmatic function and usually have the potential for weaning. People with complete injuries at C5 and below have intact diaphragmatic function

and may at first require a ventilator; they are usually able to wean. Weaning is important because it reduces the risk of some health issues related to tracheostomy, and also because weaned individuals generally require much less paid assisted care.

**Exercise:** respiratory muscles are both metabolically and structurally plastic and they respond to exercise training. Respiratory muscle training can improve respiratory muscle performance but may also dramatically reduce respiratory infections. There are a number of commercially available hand-held devices for inspiratory muscle training.



BROOKE ELLISON BY DIANA DEROSA

## SOURCES

Craig Hospital, University of Miami School of Medicine, University of Washington School of Medicine/Department of Rehabilitation Medicine, ALS Association of America

## RESPIRATORY HEALTH RESOURCES

**International Ventilator Users Network (IVUN)**, a resource for people who use ventilators, pulmonologists, pediatricians, respiratory therapists, and ventilator manufacturers and vendors to discuss home ventilation. Features a newsletter, articles from healthcare professionals and venturesome vent users.

[www.ventusers.org](http://www.ventusers.org)

**Paralyzed Veterans of America, in support of The Consortium for Spinal Cord Medicine**, offers authoritative clinical practice guidelines for respiratory management. A consumer guide is also available. Toll-free 1-800-424-8200; [www.pva.org](http://www.pva.org)

**Spinal Cord Injury Rehabilitation Evidence (SCIRE)** project is a Canadian research collaboration of scientists, clinicians and consumers that reviews, evaluates, and translates research knowledge and establishes best rehabilitation practices following SCI. There is a section on respiration.

[www.scireproject.com](http://www.scireproject.com)

## **SKIN CARE**

People with paralysis are at high risk of developing skin problems. Limited mobility coupled with impaired sensation can lead to pressure injuries or ulcers, which can be a devastating complication. In 2016, the National Pressure Injury Advisory Panel (<https://npiap.com>) changed the recommended terminology from “pressure ulcer” to “pressure injury.”

The skin, the largest organ system in the body, is tough and pliable. It protects the underlying cells against air, water, foreign substances and bacteria. It is sensitive to injury and has remarkable self-repair capabilities. But skin just can't take prolonged pressure. A pressure injury involves damage to the skin and underlying tissue. Pressure injuries, also called pressure sores, pressure ulcers, bed sores, decubiti or decubitus ulcers, range in severity from mild (minor skin reddening) to severe (deep craters that can infect all the way to muscle and bone). Unrelieved pressure on the skin squeezes tiny blood vessels, which supply the skin with nutrients and oxygen. When skin is starved of blood for

## STAGES OF A PRESSURE INJURY

**Stage One:** *Skin is not broken but is red; color does not fade 30 minutes after pressure is removed. What to do: stay off the sore, keep it clean and dry. Explore causes: check out mattress, seat cushion, transfer procedures and turning techniques.*

**Stage Two:** *The top layer of skin, the epidermis, is broken. The sore is shallow but open; drainage may be present. What to do: Follow steps in Stage One but cleanse wound with water or saline solution and dry carefully. Apply either a transparent dressing (e.g. Tegaderm) or a hydrocolloid dressing (e.g. DuoDERM). If there are signs of trouble see your healthcare provider.*

**Signs of Trouble:** *The sore is getting bigger; the sore starts to smell bad or the drainage becomes greenish in color. Fever is a bad sign.*

**Stage Three:** *Skin has broken down further, into the second layer of skin, through the dermis into the subcutaneous fat tissue. You must see a care provider at this point; this is getting serious and may need special cleaning or debriding agents. Don't wait.*

**Stage Four:** *The skin has broken down all the way to the bone. A lot of dead tissue is present and there is also a lot of drainage. This can be life threatening. You may be looking at surgery.*

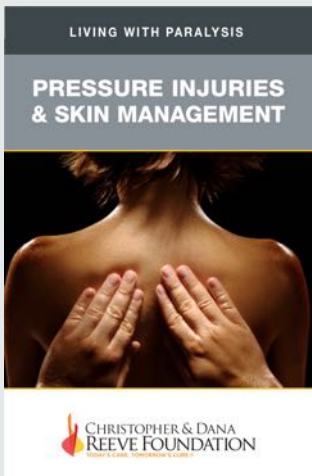
**Healing:** *This occurs when the sore gets smaller, when pinkish skin forms along the edges of the sore. Bleeding might occur but take this as a good sign: circulation is back and that helps healing. Be patient. Skin repair isn't always speedy.*

*When is it safe to put pressure on the affected area again? Only when the sore is completely healed—when the top layer of skin is unbroken and normal looking. The first time pressure is applied, start with 15-minute intervals. Build up gradually over periods of a few days to allow skin pressure tolerance to build. If redness occurs, keep pressure off the area.*

too long, tissue dies and a pressure injury forms.

Sliding around in a bed or chair can cause blood vessels to stretch or bend, leading to pressure injuries. An abrasion can occur when a person's skin is pulled across a surface instead of lifted. A bump or fall may cause damage to

## PRESSURE INJURY BOOKLET



*The Reeve Foundation's Pressure Injuries and Skin Management booklet provides crucial information to help you prevent, spot, and treat a pressure injury. Learn about skin hygiene, what a pressure injury looks like with different skin tones, and when to seek medical care.*

*The Reeve Foundation's educational booklets provide an in-depth look into paralysis-related topics of interest. Find the latest information and resources about secondary conditions such as spasticity, bladder, bowel, and pain; transitioning guides for all stages of a*

*new injury; and lifestyle topics such as parenting, sexual and mental health, among others.*

*The educational booklets are available as a pdf download through the [Reeve Foundation's website](#), or please contact the [Information Specialist Team](#) to order a free print copy.*

the skin that may not show up right away. Other causes of pressure injuries are braces or hard objects that put pressure on the skin. Also, people with limited sensation are prone to skin injuries from burns.

Skin damage from pressure usually begins on the body where the bones are close to the skin surface, such as the hip. These bony prominences apply pressure on the skin from within. If there is a hard surface on the outside, too, the skin is pinched off from circulation. Because the rate of circulation is reduced by paralysis to begin with, less oxygen is available to the skin, lowering the skin's resistance. The body tries to compensate by sending more blood to the area. This may result in swelling, adding still more pressure to the blood vessels.

A pressure injury begins as a red area on the skin. This reddened area may feel hard and/or hot. For those with darker skin, the area may appear shiny. At this stage, the progression is reversible. The skin will return to its normal color if the pressure is removed.

If the pressure is not removed, a blister or scab may form—this means that the tissue underneath is dying. Remove all pressure over the area immediately.

In the next stage, a hole (ulcer) forms in the dead tissue. Frequently, this dead tissue is small on the skin surface, but damaged tissue may extend deep to the bone.

A pressure injury can mean several weeks or even months of hospitalization or bed rest in order for the sore to heal. Complex pressure injuries may require surgery or skin grafting. All of this can cost thousands of dollars and mean valuable time away from work, school or family.

Skin wound treatment by any means is complicated by hard-to-treat infections, spasticity, additional pressure and even the psychological makeup of the person (pressure injuries have been linked to low self-esteem and impulsive behavior). It is an oversimplification to say pressure injuries are always preventable but that's almost true; with vigilant care and good overall hygiene, skin integrity can be maintained.

A wide variety of pressure-relieving support surfaces, including special beds, mattresses, mattress overlays or seat cushions are available to support your body in bed or in a chair. Work with your therapists to know what is available. See page 282 for more on the various types of seating options. Here's an example of a product to help people who can't turn at night and who may not have an attendant to do it for them: Freedom Bed is an automatic lateral rotation system that quietly turns through a 60-degree range of rotation; [www.pro-bed.com](http://www.pro-bed.com)

Remember that the first line of defense is to be responsible for your own skin care. Look at it: Check your skin daily, using a mirror for hard-to-see areas. Skin stays healthy with good diet, good hygiene and regular pressure relief. Keep the skin clean and dry. Skin that is moist from sweat or bodily discharges is more likely to break down. Drink plenty of fluids; a healing wound or sore can lose more than a quart of water each day. Drinking 8 to 12 cups of water a day might not be too much. Note: Beer and wine do not count; alcohol actually causes you to lose water or become dehydrated. Watch your weight, too. Being too thin causes you to lose the padding between your bones and your skin and makes it possible for even small amounts of pressure to break down the skin. Getting too heavy is risky, too. More weight may mean more padding, but it also means more pressure on skin folds. Don't smoke. Research has shown that heavy smokers are more prone to pressure injuries.



## SOURCES

Paralyzed Veterans of America, Craig Hospital, National Library of Medicine, University of Washington School of Medicine/Rehabilitation

## SKIN CARE MANAGEMENT RESOURCES

**Craig Hospital** has developed educational materials, including skin care resources, to help people with spinal cord injuries maintain their health.

[www.craighospital.org/resources](http://www.craighospital.org/resources)

**Paralyzed Veterans of America**, in support of The Consortium for Spinal Cord Medicine, offers an authoritative clinical practice guideline for skin care.

PVA, toll-free 1-800-424-8200, [www.pva.org](http://www.pva.org)

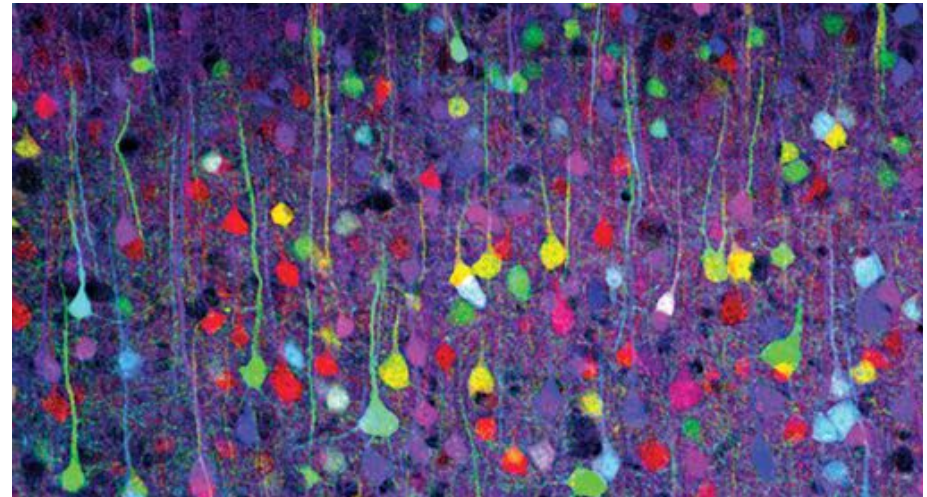
## **SPASTICITY**

Spasticity is a side effect of paralysis that varies from mild muscle stiffness to severe, uncontrollable leg movements. Generally, doctors now call conditions of extreme muscle tension spastic hypertonia (SH). It may occur in association with spinal cord injury, multiple sclerosis, cerebral palsy, or brain trauma. Symptoms may include increased muscle tone, rapid muscle contractions, exaggerated deep tendon reflexes, muscle spasms, scissoring (involuntary crossing of the legs) and fixed joints.

When an individual is first injured, muscles are weak and flexible because of what's called spinal shock: The body's reflexes are absent below the level of injury; this condition usually lasts for a few weeks or several months. Once the spinal shock is over, reflex activity returns.

Spasticity is usually caused by damage to the portion of the brain or spinal cord that controls voluntary movement. Since the normal flow of nerve messages to below the level of injury is interrupted, those messages may not reach the reflex control center of the brain. The spinal cord then attempts to moderate the body's response. Because the spinal cord is not as efficient as the brain, the signals that are sent back to the site of the sensation are often over-exaggerated in an overactive muscle response or spastic hypertonia: an uncontrollable "jerking" movement, stiffening or straightening of muscles, shock-like contractions of a muscle or group of muscles, and abnormal tone in the muscles.

Most individuals with SCI have some spasms. Persons with cervical injuries and



*Neurons are labeled with different colors in the cerebral cortex of a "Brainbow" mouse, imaged on a laser-scanning confocal microscope at the Lichtman Lab, Harvard University.*

those with incomplete injuries are more likely than those with paraplegia and/or complete injuries to experience SH. The most common muscles that spasm are those that bend the elbow (flexor) or extend the leg (extensor). These reflexes usually occur as a result of an automatic response to painful sensations.

While spasticity can interfere with rehabilitation or daily living activities, it is not always a bad thing. Some people use their spasms for function, to empty their bladders, to transfer or to dress. Others use SH to keep their muscles toned and to improve circulation. It may also help maintain bone strength. In a large Swedish study of people with SCI, 68 percent had spasticity but less than half of those said that their spasticity was a significant problem that reduced activities of daily living or caused pain.

**Changing spasticity:** A change in a person's spasticity is something to pay attention to. For example, increased tone could be the result of a cyst or cavity forming in the spinal cord (post-traumatic syringomyelia). Untreated, cysts can lead to further loss of function. Problems outside your nervous system, such as bladder infections or skin sores, can increase spasticity.

Treatment usually includes medications such as baclofen, diazepam or zanaflex. Some people with severe spasms utilize refillable baclofen pumps, which are small, surgically implanted reservoirs that apply the drug directly to the area of spinal cord dysfunction. This allows for a higher concentration of drug without the usual mind-dulling side effects of a high oral dosage.

Physical therapy, including muscle stretching, range of motion exercises, and other physical therapy regimens, can help prevent joint contractures (shrinkage or shortening of a muscle) and reduce the severity of symptoms. Proper posture and positioning are important for people in wheelchairs and those at bed rest to reduce spasms. Orthotics, such as ankle-foot braces, are sometimes used to limit spasticity. Application of cold (cryotherapy) to an affected area can also calm muscle activity.

For many years doctors have used phenol nerve blocks to deaden nerves that cause spasticity. Lately, a better but more expensive nerve block, botulinum toxin (Botox), has become a popular treatment for spasms. An application of Botox lasts about three to six months; the body builds antibodies to the drug, reducing its effectiveness over time.

Sometimes, surgery is recommended for tendon release or to sever the nerve-muscle pathway in children with cerebral palsy. Selective dorsal rhizotomy may be considered if spasms interfere with sitting, bathing or general caretaking.

Spasticity comes with the territory for many people who are paralyzed. Treatment strategy should be based on one's function: Is the spasticity keeping you from certain activities? Are there safety risks, such as losing control while driving your power chair or car? Are spasticity drugs worse than the symptoms, affecting concentration or energy? Check with your physician to discuss your options.

### **SOURCES**

National Institute of Neurological Disorders and Stroke, National Multiple Sclerosis Society, United Cerebral Palsy Association, National Spinal Cord Injury Statistical Center, Craig Hospital

### **SPASTICITY RESOURCES**

**Medtronic** manufactures implantable pumps for delivery (intrathecally) of drugs such as baclofen to control spasticity. [www.medtronic.com](http://www.medtronic.com)

**National Multiple Sclerosis Society** offers information and resources on spasticity. Toll-free 1-800-344-4867 or search “spasticity” at [www.nationalmssociety.org](http://www.nationalmssociety.org)

## **SYRINGOMYELIA | TETHERED CORD**

Syringomyelia and tethered spinal cord can occur from months to many decades after spinal cord injury. In post-traumatic syringomyelia (syr-ingo-my-EE-lia) a cyst or fluid-filled cavity forms within the cord. This cavity can expand over time, extending two or more spinal segments from the level of SCI. The clinical symptoms for syringomyelia and tethered spinal cord are the same and can include progressive deterioration of the spinal cord, progressive loss of sensation or strength, accompanied by sweating, spasticity, pain and autonomic dysreflexia (AD) -- new levels of disability long after a person has had a successful rehabilitation.

Tethered spinal cord is a condition where scar tissue forms and holds the spinal cord itself to the dura, the soft tissue membrane that surrounds it. This scarring prevents the normal flow of spinal fluid around the spinal cord and impedes the normal motion of the spinal cord within the membrane. Tethering causes cyst formation; it can occur without evidence of syringomyelia, but post-traumatic cystic formation does not occur without some degree of cord tethering.

Magnetic resonance imaging (MRI) detects cysts in the spinal cord, unless rods, plates or bullet fragments are present.

Tethered cord and syringomyelia are treated surgically. Untethering involves a delicate surgery to release the scar tissue around the spinal cord to restore spinal fluid flow and the motion of the spinal cord. In addition, a small graft may be placed at the tethering site to fortify the dural space and decrease the risk of re-scarring. If a cyst is present, a shunt may be placed inside the cavity to drain fluid from the cyst. Surgery usually leads to improved strength and reduced pain; it does not always bring back lost sensory function.

Syringomyelia also occurs in people who have a congenital abnormality of the brain called a Chiari malformation. During development of the fetus, the lower part of the cerebellum protrudes from the base of the head into the cervical portion of the spinal canal. Symptoms usually include vomiting, muscle weakness in the head and face, difficulty swallowing, and varying degrees of mental impairment. Paralysis of the arms and legs may also occur. Adults and adolescents with Chiari malformation who previously showed no symptoms may show signs of progressive impairment, such as involuntary, rapid, downward eye movements. Other symptoms may include dizziness, headache, double vision, deafness, an impaired ability to coordinate movement, and

episodes of acute pain in and around the eyes.

Syringomyelia can also be associated with spina bifida, spinal cord tumors, arachnoiditis, and idiopathic (cause unknown) syringomyelia. MRI has significantly increased the number of diagnoses in the beginning stages of syringomyelia. Signs of the disorder tend to develop slowly, although sudden onset may occur with coughing or straining.

Surgery results in stabilization or modest improvement in symptoms for most people although delay in treatment may result in irreversible spinal cord injury. Recurrence of syringomyelia after surgery may make additional operations necessary; these operations may not be completely successful over the long term. Up to one half of those treated for syringomyelia have symptoms return within five years.

### **SOURCES**

National Institute of Neurological Disorders and Stroke, American Syringomyelia & Chiari Alliance Project

### **SYRINGOMYELIA RESOURCES**

**American Syringomyelia & Chiari Alliance Project** offers news on syringomyelia, tethered cord and Chiari malformation, sponsors research. Toll-free 1-800-272-7282; [www.asap.org](http://www.asap.org)

**Bobby Jones Chiari & Syringomyelia Foundation** is an educational and advocacy organization. 718-966-2593; <https://bobbyjonescsf.org>

### **AGING: NOT FOR THE WEAK**

The life expectancy of people living with spinal cord injuries has increased thanks to decades of progress in treatment and care. At the same time, a growing number of people are acquiring disabilities later in life. As a result, more seniors are living with disabilities, including paralysis, than ever before.

Everyone ages differently, and the health issues faced by this population will vary based on individual factors like severity of injury, family health history, lifestyle, and the age at which the disability was acquired.

For people who become paralyzed later in life, the cause is most often strokes or falls related to deteriorating health associated with aging. They age into disability, experiencing multiple chronic diseases common to the general

senior population alongside the challenges of learning to manage a new disability in old age. But aging is accelerated for people living with spinal cord injuries acquired at birth or at an early age. These individuals, aging with disability, will experience symptoms of aging earlier than the general population and face a greater number of secondary conditions, including muscle and bone deterioration, endocrine-related issues such as diabetes, chronic pain, pressure injuries, and kidney and bladder stones.

Carefully monitoring physical changes and receiving regular preventative care from doctors, physiatrists or rehabilitation specialists familiar with disabilities can help those aging with spinal cord injuries maintain good health. Adaptations can also be made to prevent or slow the development of new conditions: avoiding repetitive movements and weight gain, and engaging in strengthening exercises can improve muscle and bone health; staying hydrated and receiving regular kidney and bladder checkups can help decrease the risk of urinary tract infections, stones in kidneys and bladder and damage from long-term catheter use; and deep breathing exercises, regular respiratory assessments and increased physical activity can help slow diminishing lung capacity.

People living with spinal cord injuries face a higher risk of developing cardiovascular disease which, along with septicemia and respiratory complications, is a leading cause of death within the community. Regular checkups to assess heart health are especially critical as nerve damage caused by injury can prevent symptoms from being felt and identified; screening blood pressure, cholesterol, diet, weight, tobacco and alcohol use, and medications that might increase cardiovascular risk, can help catch early warning signs before disease progresses.

Staying physically active and socially engaged are key factors in aging successfully. Exercise is important throughout the lives of those with disabilities, including in later years. Participating in seated aerobics, wheelchair propulsion, swimming and wheelchair sports are all effective ways to stay physically and mentally fit.

Building a strong social network decreases the risk of isolation and depression that are serious problems for many seniors. Seek out local community centers, wellness programs, adult education classes or faith-based activities. Volunteering is another way to feel useful and support others. And don't be afraid to adapt to the realities of aging in order to maintain independence; embrace the adaptive equipment that may be needed to remain mobile; find

more accessible housing that suits new lifestyles; and ask family, friends or medical providers for help when it's needed.

### **SOURCES**

Model Systems Knowledge Translation Center, Craig Hospital, Disability and Health Journal Vol 9 Issue 4 October 2016, Northwest Regional SCI System Department of Rehabilitation Medicine at the University of Washington, Archives of Physical Medicine and Rehabilitation Vol 98 Issue 6 June 1, 2017, University of Washington's Aging with a Physical Disability Rehabilitation Research and Training Center's State of the Science (SOS) meeting, April 2011 Washington D.C.

### **AGING RESOURCES**

**Eldercare Locator** connects seniors and people with disabilities to various social services including transportation, housing, insurance and benefits, and elder rights information. The Eldercare Locator can help you find your local Aging & Disability Resource Center. Call 800-677-1116 <https://eldercare.acl.gov>

**National Center on Elder Abuse** disseminates information on elder abuse to the public and professionals and provides technical assistance to states and community-based organizations. <https://ncea.acl.gov>

**National Institute on Aging** provides health information for seniors. [www.nia.nih.gov/health](http://www.nia.nih.gov/health)

**National Long Term Care Ombudsman Resource Center** can help you locate your state and local ombudsmen. Ombudsmen advocate for the rights of people living in long-term care facilities and nursing homes. <https://ltombudsman.org>

## **MENTAL HEALTH**

### **Mental Health**

People living with spinal cord injuries face higher risks of developing anxiety, depression and other mental health disorders than the general population. It is important for individuals and their families to be alert to any changes in mental health, not only immediately after injury, but in the years that follow. Seeking early and effective treatment for disorders is critical, including for those conditions that may have been present prior to injury. If untreated, mental

disorders can not only derail successful physical rehabilitation and recovery but become debilitating and potentially life-threatening.

**Depression** is a common and serious mood disorder experienced by millions of people each year. Estimated rates of depression among those living with spinal cord injuries is higher than that of the general population, ranging from 11% to 37%. More than simply 'feeling down,' depressive episodes last at least two weeks and are marked by a loss of pleasure and interest in daily life, and problems with sleeping, eating, energy levels, concentration and self-worth. Thinking about death and suicide are also symptoms of depression. Anyone experiencing such thoughts should reach out to a family member, friend or medical professional immediately. Boys Town, in cooperation with the Reeve Foundation, has a dedicated number for individuals living with paralysis who are in emotional crisis which is open 24 hours per day--call 866-697-8394. Another resource open 24 hours a day is the National Suicide Prevention Lifeline, call 1-800-273- 8255 to be connected to a crisis center or trained counselor.

Depression can coincide with the onset of serious medical illnesses, such as diabetes, cancer, heart disease, and Parkinson's disease, or major life changes, trauma or stress. Treatment is essential and the earlier it begins, the better; untreated, episodes might last a year or more, worsen existing pain from injury and increase the risk of suicide. Depression is treated with psychotherapy—known as 'talk therapy' – medication or a combination of both. Antidepressant medications, which are not addictive, target brain chemicals which help regulate mood and stress. It may be necessary to try several antidepressants before determining which best improves symptoms and has manageable side effects. Therapy options with evidence-based approaches specific to the treatment of depression include cognitive-behavioral therapy, interpersonal therapy, and problem-solving therapy. Regular exercise and participation in community and family support programs might also help manage symptoms.

**Post-traumatic stress disorder (PTSD)** is a chronic condition that can develop in people who experience shocking events such as car accidents, diving accidents, falls or violent incidents. Symptoms may appear immediately or years after the trauma, and include re-experiencing symptoms, avoidance symptoms, arousal and reactivity symptoms, and cognition and mood symptoms. A person with PTSD may experience a wide array of physical and emotional changes such as frequent nightmares and vivid flashbacks of the incident; denial, marked by an unwillingness to think about, discuss or



participate in activities related to the trauma; memory problems, especially as related to the triggering event; a negative sense of self-worth and lack of hope; trouble sleeping and concentrating; a sense of detachment from family, friends and activities that once brought happiness; feeling easily startled, scared or constantly alert to danger; and engaging in destructive personal behavior like excessive drinking or reckless driving.

Symptoms must last longer than a month and be severe enough to interfere with relationships or work to be diagnosed as PTSD. Individuals should be aware that the disorder can coexist, or develop concurrently with other conditions, such as substance abuse, depression and suicidal feelings; each must be addressed and immediately treated. PTSD treatment typically includes medication and counseling such as cognitive behavior therapy (CBT.) CBT may help people face and control fears by exposing them to the trauma they experienced in a gradual, controlled way. It may also help people with PTSD understand and address negative memories. The goal of treatment is to help individuals manage symptoms and re-engage in activities that they enjoyed before developing PTSD.

**Substance use disorder** is a disease that changes a person's brain and behavior, resulting in a lack of control over use of legal or illegal drugs, including alcohol, marijuana and prescription medications. People living with spinal cord injuries experience higher rates of substance abuse than the general population; it has been identified as a risk factor for SCI and is a frequently reported comorbid condition in newly injured individuals.

While substance abuse is a serious health issue for anyone, it can be especially damaging for those with SCI, impeding rehabilitative progress, and leading to poorer health outcomes, decreased life satisfaction, depression, anger and anxiety. Additionally, it can increase risk for seizures, pressure ulcers, urinary tract infections, and reinjury. Symptoms include intense cravings and a regular need for the substance, taking unplanned and larger amounts over a longer period of time, needing increased amounts of the substance to feel the intended effects and not being able to stop, despite wanting to or realizing that it's causing work, health and other life problems.



Substance abuse is treatable, no matter whether it developed before or after the injury. New SCI patients with prior addiction will experience withdrawal during initial hospitalization; for some, the injury prompts a wake-up call and desire to seek treatment. Pain management among those with SCI must be carefully monitored as misuse of prescribed opioids can lead to the disorder. Depending on the substance, treatments will vary, but therapy and support groups are part of most programs. Working with a licensed therapist or licensed drug and alcohol counselors can help resolve and manage problems related to the substance abuse and other co-existing mental health concerns. Each disorder must be treated; individuals experiencing mental health issues such as depression or PTSD, are more likely to develop substance abuse disorders. Severe cases may require hospitalization or in-patient programs. The earlier the condition is identified and treated, the better the outcome will be.

### **SOURCES**

National Institute of Mental Health, National Survey on Drug Use and Health, Model Systems Knowledge Care Center, Mayo Clinic, National Suicide Prevention Lifeline, Mayo Clinic Proceedings, May 2020, Archives of Physical Medicine and Rehabilitation, November 2004

### **MENTAL HEALTH RESOURCES**

**Christopher & Dana Reeve Foundation** booklet “Women’s Mental Health After Paralysis”. A free 40-page booklet covering depression, PTSD, adjusting to spinal cord injury, stress and anxiety. Call 1-800-539-7309 or go to [www.ChristopherReeve.org/Ask](http://www.ChristopherReeve.org/Ask) for a free copy.

**Craig Hospital** has a series of articles on emotional and mental health as well as alcohol and substance abuse for people living with brain injury and spinal cord injury. <https://craighospital.org/resources>

**Model Systems Knowledge Translation Center:** Adjusting to Life After SCI [https://msktc.org/lib/docs/Factsheets/SCI\\_Adjusting\\_To\\_Life\\_After.pdf](https://msktc.org/lib/docs/Factsheets/SCI_Adjusting_To_Life_After.pdf)

**National Institute of Mental Health: Post Traumatic Stress Disorder** <https://www.nimh.nih.gov/health/topics/post-traumatic-stress-disorder-ptsd/index.shtml>

**Paralyzed Veterans of America** has a booklet titled “Depression: What You Should Know—A Guide for People with Spinal Cord Injury.” [www.pva.org](http://www.pva.org)

## Depression

Depression is common among people who live with paralysis, but it's not normal – becoming discouraged, grief-stricken or sad is normal, but depression represents a condition that is a health problem unto itself. Most forms of depression, however, can be treated.

While about 10 percent of the U.S. non-disabled population is said to be moderately or severely depressed, research shows that about 20 to 30 percent of people with long-term disabilities have a depressive condition.

Depression affects a person in many ways. It involves major changes in mood, outlook, ambition, problem solving, activity level and bodily processes (sleep, energy and appetite). It affects health and wellness: People with a disability who are depressed may not look after themselves; they may not drink enough water, take care of their skin, or manage their diet. It affects one's social world. Friends and families are tuned out. Depressed people can't find pleasure, success or meaning. They may develop substance abuse problems. Thoughts of suicide often occur when things look most hopeless. In spinal cord injury, for example, risk is highest in the first five years after the injury. Other risk factors include dependence on alcohol or drugs, lack of a spouse or close support network, access to lethal means, or a previous suicide attempt. People who've tried to kill themselves before are likely to try again. The most important factors in preventing suicide are spotting depression early, getting the right treatments for it, and instilling problem solving skills.

Many factors contribute to depression. These may include the effects of disability – pain, fatigue, changes in body image, shame, and loss of independence. Other life events, such as divorce, loss of a loved one, loss of a job or financial problems can also lead to or magnify depression.

There are effective ways for helping people cope with the stresses of paralysis. Depression is highly treatable using psychotherapy, pharmacotherapy (antidepressants), or a combination of both. Tricyclic drugs (e.g., imipramine) are often effective for depression but may have intolerable side effects. SSRIs (Selective Serotonin Reuptake Inhibitors, e.g., Prozac) have fewer side effects and are usually as effective as tricyclics. SSRIs may exacerbate spasticity in some persons.

Venlafaxine (e.g., Effexor) is chemically similar to tricyclics and has fewer side effects. In theory, it may also alleviate some forms of neurogenic pain, a

## TAKING CARE

*Mental Health America offers these tips to reduce depression:*

- Stay connected
- Stay positive
- Get physically active
- Help others
- Get enough sleep
- Create joy and satisfaction
- Eat well
- Take care of your spirit
- Get help if needed

huge contributor to depression. In fact, aggressive treatment of pain problems is crucial to the prevention of depression.

Among those with MS, some experience mood swings and/or uncontrollable laughing or crying (called emotional lability). These result from damaged areas in emotional pathways in the brain. It is important for family members and caregivers to know this and realize that people with MS may not always be able to control their emotions. Mood stabilizing medications such as amitriptyline (e.g., Elavil) and valproic acid (e.g., Depakote) are used to treat these emotional

changes. It is also important to recognize that depression is very common in MS – even more so than in other equally disabling chronic illnesses.

Life is worth living, despite what health professionals are sometimes prone to judge: According to a Colorado survey, 86 percent of SCI high-level quadriplegics rated their quality of life as average or better than average, while only 17 percent of their ER doctors, nurses, and technicians thought they would have an average or better quality of life if they acquired quadriplegia.

If you are depressed, get help, including professional counseling or participation in a support group. An active lifestyle can also help to break through depression.

## SOURCES

Rancho Los Amigos National Rehabilitation Center, Paralyzed Veterans of America, National Multiple Sclerosis Society

## DEPRESSION RESOURCES

**Anxiety and Depression Association of America (ADAA)** promotes education, training, and research for anxiety, depression, and stress-related

disorders Links people who need treatment with healthcare professionals.

[www.adaa.org](http://www.adaa.org)

**Mental Health America** is dedicated to addressing all aspects of mental health and mental illness, including depression. Contact MHA toll-free at 1-800-969-6642; visit [www.mhanational.org](http://www.mhanational.org)

**Not Dead Yet** opposes legalized assisted suicide and euthanasia. NDY notes that the duration of disability almost always correlates with acceptance in persons with spinal cord injury paralysis. [www.notdeadyet.org](http://www.notdeadyet.org)

**Paralyzed Veterans of America**, in support of The Consortium for Spinal Cord Medicine, offers a clinical practice guideline for depression as a secondary condition of paralysis. PVA, toll-free 1-800-424-8200, [www.pva.org](http://www.pva.org).

#### **Suicide Prevention Hotlines (all free):**

**Boys Town Hotline** in conjunction with the Reeve Foundation: 866-697-8394

**National Suicide Prevention Lifeline:** 800-273-TALK (8255), veterans should press '1'

**The Trevor Project:** 866-488-7386 (for LGBTQ youth between ages of 13-24)

**TransLife Line:** 877-565-8860 (for people who are transgender)

#### **Coping & Adjustment**

Individuals who are new to paralysis, whether from a sudden accident or the progression of a disease, will most likely experience grief. Families, too, enter this strange, new “why-me” world with its hallmarks of mourning, helplessness, second-guessing and regret. While everyone deals with loss and change in their own way, there are aspects of the adjustment process that many people share.

At first, many react to paralysis as if nothing really happened, refusing to accept that changes in their body and in their ability to move are not going to get better or heal in ways they always have. Some may see the injury as an annoyance similar to getting the flu that will pass with time. Psychologists call this denial. Elisabeth Kübler-Ross, who has famously outlined the stages of grieving, notes that denial has a beneficial function as a “buffer” after unexpected shocking news.

Some people find refuge in the denial stage for a long time, using it as an excuse to do nothing, or to do too much to overcome limitations and act “normal.” Most, however, will begin to gain knowledge about their condition and have some perspective on what has happened. As denial fades, hope emerges. Thus begins the process of adjustment.

When denial can no longer be maintained, it is often replaced with other dark feelings—anger, rage, envy and resentment. These can be seen as defense mechanisms that allow a person time to mobilize other defenses. Guilt may be part of the mix, too, especially in people whose poor judgment or self-destructive behavior may have contributed to their disability. Self-loathing may also appear when one’s notion of “normal” is turned upside down.

Many people within the universe of disability – including those who experience paralysis first hand as well as family members—can become extremely frustrated. They may see themselves as victims whose lives are ruined because they can never live the happy life they always knew they would; they see no way out. These people may react with hostility to others. This, of course, adds stress to caregivers and loved ones. There’s nothing wrong with anger—unless you hold on to it and let it smolder. The best advice, easier said than done, is to let anger run its course, and let it go. How? Some find relief in religion, others by quieting the mind using meditation.

Fear is another common feeling: Where is all this chaos leading? Will it get worse? Will my spouse stay with me? Will I ever love or work or be taken seriously again? For many, the greatest fear is losing control over their lives. These thoughts are common for newly paralyzed individuals; many persons continue to hold on to them, even the irrational ones, long after their injury.

Extreme sadness is natural after paralysis – there has, of course, been great loss. Sadness passes. It’s important not to confuse the blues we all experience when something bad happens with depression. Depression is a medical condition that can lead to inactivity, difficulty concentrating, a significant change in appetite or sleep time, and feelings of dejection, hopelessness or worthlessness. A depressed person may have thoughts about suicide. Suicide is greater for people with SCI compared to the nondisabled population. It is the leading cause of death for people with SCI younger than 55.

To be sure, paralysis ignites many emotions and feelings, most of them negative. A person’s reactions to all this baggage may result in behavior that is bad for health and happiness. For example, a person who feels worthless may not take proper care of his or her bladder or skin or nutrition. Also, people with a history of alcohol and/or substance abuse may return to old patterns of self-destruction. Others may start drinking or taking drugs to quiet their anxieties. Unhealthy behavior leads to unhealthy results. Neglect of personal care (which has been called “existential suicide”) risks a wide range of health problems

such as respiratory complications, urinary tract infection, and pressure injuries.

In time, one processes the toxic feelings. Another phase of adjustment begins. Generally, at some point following paralysis, people may begin to admit that they have a serious condition, though they may hold on to the belief that the situation is not a long-term problem.

As the process continues, it is important for people to contact others who share similar experiences. There are peer support groups for every sort of condition related to paralysis in most communities, including the Reeve Foundation Peer & Family Support Program. The Internet is a great tool for connecting with paralysis survivors who have been down the same path and can testify that there is still a future ahead full of life and rewarding experience.

Given time, a person will eventually come to terms with their loss and reach the final stage of the grieving process: acceptance. Most people come to accept a realistic view of their condition, find meaning in life, and begin to make plans for the life ahead of them.

Adjustment may ultimately depend on motivation. Early on, people may be motivated to work hard at therapy to gain strength and function, still believing, perhaps, that paralysis can be beaten by sheer will power. Many people with SCI continue to hope that they will walk again. While treatments for paralysis are coming, the best approach is to move forward and live a full life now. Hope for restoring function is fine and not unrealistic, but if it means waiting on the sidelines until medical research delivers the cure, it's an aspect of denial.

People who adjust well to life after paralysis are motivated by personal goals—getting through college, getting a good job, raising a family. People who set these kinds of goals report greater life satisfaction, and they feel less shameful about their condition. How do you get motivated? It may help to think about what you always wanted out of your life before. Most people have the same personality, the same sense of style and humor as they did before being paralyzed; there is no reason not to strive for the same things.

Of course getting things done after losing function to paralysis is a challenge. It may mean learning lots of new ways to solve problems. It may be necessary to ask others for help, even when doing everything on your own becomes a stubborn way to assert your independence. Asking for help is okay – it's one of the ways to get what you need and get things done.

Adjustment to paralysis is a process; changing one's thoughts, feelings, and behavior doesn't happen overnight. It takes time to know what is true,

### **ANGER MANAGEMENT**

*You can't eliminate anger, and it wouldn't be a good idea even if you could. Life will always deliver your share of frustration, pain, loss, and the unpredictable actions of others. You can't change that; but you can change the way you let such events affect you, especially if anger is an issue.*

*Simple relaxation techniques, such as deep breathing and pleasing imagery, can help calm down angry feelings. Try this:*

- *Breathe deeply, from your diaphragm; breathing from your chest won't relax you. Picture your breath coming up from your stomach.*
- *Slowly repeat a calm word or phrase such as "relax," or "take it easy." Repeat it to yourself while breathing deeply.*
- *Use imagery; visualize a relaxing experience, from your memory or your imagination. Practice these techniques daily and remind yourself that the world is "not out to get you."*

*Source: American Psychological Association; [www.apa.org](http://www.apa.org)*

what is realistic, what is rational. It takes time to rebuild one's identity, to find a new balance in relationships, to discover that what is important is what is happening now. Negative emotions are self-limiting, but they can be transformed. Keep your options open as best you can. Don't ignore the support and problem-solving experiences of others in similar circumstances. Figure out what's next and how to get there.

### **SOURCES**

University of Alabama at Birmingham Research and Training Center on Secondary Conditions of Spinal Cord Injury/UAB Spain Rehabilitation Center, National Multiple Sclerosis Society, Quebec Paraplegic Association, Paralyzed Veterans of America, American Stroke Association

### **COPING AND ADJUSTMENT RESOURCES**

**Reeve Foundation Peer & Family Support Program (PFSP)** provides emotional support, guidance and the sharing of real-world experiences from mentor/peers who are living well after paralysis. Call toll-free 1-800-539-7309 or see [www.ChristopherReeve.org/peer](http://www.ChristopherReeve.org/peer)



## LIVE THE LIFE YOU HAVE

“It is possible to find peace in the wake of suffering.” That is one of clinical psychologist Daniel Gottlieb’s main messages. Another one is that “there is no relationship between disability and happiness.” A third, one he often uses in various iterations, is this: “Don’t spend so much of your energy pursuing the life you want or avoiding the life you fear. Have the faith to live the life you have—and live it fully, with great love and gratitude.”



Dr. Dan Gottlieb, Ph.D.

Gottlieb’s personal narrative—the inspiration and wisdom of the archetypal wounded healer who’s spent half his life as a quadriplegic – shapes those messages. Dr. Dan, as he goes by, is well known in the Philadelphia area, where he makes his home and where he hosts a weekly program on public radio, “Voices in the Family.” He began his psychology practice in 1969; he and his wife had two daughters. In 1979 he survived a nasty automobile accident which left him paralyzed from the chest down. He describes years of despair, compounded by more and more pain and loss. He says he was filled with self-loathing, insecurity, shame and depression; he came to hate his body, which he described as a “terrorist.”

◆

**Live the life you have  
instead of waiting for the  
life you want or longing  
for the life you had.**

“Most of what I was engaged in,” says Gottlieb, “was self-pity and feeling victimized.” His parents and sister died; his marriage broke up and his ex-wife later died of cancer. His grandson was born with a learning disability. His own health has taken many unpredictable spirals over the years.

Along the way, Gottlieb discovered a powerful resilience. Tapping into his reserves of compassion, he has armed himself to ride out the storms. “Don’t fight with the life you have,” he says. “Yes, there’s a great deal of suffering out there. And there are ways to diminish suffering. But we all have a certain narrative in our head how to fix this, how it will happen. It’s either when we walk again, or when our bladder starts working, or when we lose the pounds, or when our spouse changes, or when the insurance company comes through – we get a picture in our head of the circumstances we need to make ourselves happy. Live the life you have instead of waiting for the life you want or longing for the life you had.”

Gottlieb often encounters people with disabilities who have hope for a certain outcome. “They live their lives waiting for tomorrow telling themselves ‘that’s when I will be happy.’ To me, hope is all about believing that tomorrow can bring joy regardless of today’s circumstances.”



## PEER & FAMILY SUPPORT PROGRAM

A new injury or diagnosis can be overwhelming and scary—for the entire family. One of the most comforting ways to deal with the confusion and to begin to see a full and active life ahead is to connect with someone who has already been where you have been, had the same questions and is now thriving in life. The Reeve Foundation's Peer & Family Support Program (PFSP) makes sure someone will be there to help. In communities across the United States, the PFSP provides emotional support, as well as information on local and national resources, to people living with paralysis, including service members, and to their family members and caregivers. Peer mentors empower people impacted by paralysis to live as independently as possible, engage with their communities, and navigate life transitions. The PFSP provides one-on-one support to anyone, whether they are new to paralysis or have been living with it for years, who would like to talk to a mentor—someone who shares and understands individual circumstances and who can offer personal experiential advice, connections and support and maybe provide the spark to get a person moving forward again.

There are some things that are so important and personal that they can't be understood except by another person who has gone through them.

That's what the PFSP is about; there are issues related to medical care and

### HERE'S AN EXAMPLE OF HOW THE PFSP WORKS:

“ I was matched with my mentor Craig while I was doing my rehabilitation following my spinal cord injury. I was very concerned with how to still be an active father and husband. Craig met his wife after he was injured and subsequently had three little boys; he was able to offer great insights and advice on being a husband and a dad while living with a spinal cord injury. As we continued to meet, Craig was very helpful in suggesting what kind of goals I should set for my rehab. I did exceptionally well, and I give a lot of the credit for my success to the support and guidance I received from Craig at the time.

Once I was discharged and went home, I sought out Craig for advice on how to adjust to my new life in the wheelchair away from the rehabilitation center. Craig gave me a lot of encouragement and shared specifics of how he lives his daily life. Craig helped me determine what kind of vehicle my family should buy in terms of what would work best for me at that moment and would also be easily adapted for me to drive in the near future. In addition to the relationship that I had with Craig, his wife really helped my wife to understand what to expect and how to handle certain situations.

Throughout our relationship, the most important thing Craig taught me is that I am still the same man, father and husband that I was before my injury and to not let the injury change that about myself. Thanks to Craig's help and support, I feel like I can take on the world.”

adaptive equipment, or those very personal issues, that an experienced hand is well suited to help you with.

If you are living with paralysis, or you are the parent, spouse, or family member of an individual living with paralysis, you might benefit from talking to someone who has experienced the same day-to-day realities and long-term challenges that you are facing. The Reeve Foundation peer mentors are adept at sharing their personal knowledge in order to empower you and there is never a charge for their services. The PFSP matches both people living with paralysis and family members with trained and certified mentors who are of similar age, gender, level of paralysis, and type of paralyzing condition whenever possible. To learn more about the program or request a mentor, contact the PFSP toll-free at 1-800-539-7309 or by email at

[peer@ChristopherReeve.org](mailto:peer@ChristopherReeve.org).

## ALTERNATIVE MEDICINE

There are many alternative medicine approaches that may have benefits for those with spinal cord injury or disease. Although these approaches to wellness and healing fall outside of mainstream traditions, they may offer a bridge between eastern and western medicine. Don't think of these alternatives as an either/or substitute for your regular care but rather as a complement.

Laurance Johnston, Ph.D., former head of research for the Paralyzed Veterans of America, has compiled information on alternative therapies for SCI. His book, *Alternative Medicine and Spinal Cord Injury: Beyond the Banks of the Mainstream*, details numerous treatments that you won't hear about in most rehab centers. His take on this is open-minded: "to expand the healing spectrum available to individuals with physical disability, especially SCI and multiple sclerosis, and allow these individuals to make informed decisions about their own healthcare."

Johnston points out that doctors might warn people from using alternatives, but mainstream medicine is hardly safe: more than 100,000 people die from adverse drug reactions in hospitals; two million people enter hospitals and get infections there they didn't have before; medical mistakes kill as many as 100,000 people annually. "These statistics are especially relevant to people with spinal cord dysfunction, who are often prone to overmedication, life-threatening infections, and more hospitalization," Johnston says.

Worried that alt-med therapies are not validated by rigorous clinical studies? Indeed, they are not backed by high-grade evidence. But according to Johnston, only 10-20 percent of what physicians practice has been scientifically proven. "Most conventional, as well as alternative, medicine is based on a history of use and experience," says Johnston. Here are a few highlights of medical alternatives:

**Acupuncture:** there are claims that it improve sensation, bowel and bladder function, may improve muscle spasms, vision, sleep, sexual functioning, and bladder control in people with MS.

**Qigong:** may reduce central cord pain.

**Ayurveda:** India's ancient holistic medicine attempts to keep one healthy and disease free. Certain spices are recommended for clearing toxins after any sort of injury, including turmeric, black pepper, ginger, coriander, fennel, and licorice.

**Herbal Remedies:** Many herbs specifically support and nourish the nervous system. Fresh extract of skullcap (of the mint family) may reduce nerve inflammation; a tincture of milky oats (i.e., immature oat seeds) may rebuild the neuronal myelin sheath; an external liniment of cow parsnip, (a common weed of the parsley family) is a traditional Southwestern Hispanic remedy for treating injured nerves and stimulating regeneration.



**Aromatherapy:** Essential oils are used to prevent respiratory infections, promote mucus clearing, fight depression, and promote sleep. They're cheap and have no side effects.

**Magnets:** There are claims they enhance circulation, promote wound healing, and reduce carpal tunnel syndrome.

**Edgar Cayce:** America's most famous medical intuitive believed the main cause of multiple sclerosis was the lack of gold; his therapy involved administering gold vibrational energy through two electrotherapy devices, the wet cell battery and radial appliance. Cayce's recommendations for SCI also emphasized the use of gold vibrational energy.

See [www.healingtherapies.info](http://www.healingtherapies.info) and National Center for Complementary and Integrative Health, [www.nccih.nih.gov](http://www.nccih.nih.gov)

## FITNESS AND EXERCISE

If not now, when? It's never too late to get a fitness program going. Exercise is good for mind and body, and almost anyone can do it, regardless of functional capabilities. Some people exercise to buff up. Others do it to get stronger, to build endurance and stamina, to help keep joints loose and flexible, to reduce stress, to get more restful sleep, or just because it makes them feel better.



### **MINDFULNESS, MEDITATION, PRAYER**

*Mindfulness is the practice of letting go of the noise in our head. Instead of doing and reacting and trying to fix everything, being mindful is about sitting still, being aware of what is happening in this present moment—not with words and thinking, but by listening fully with a mind free of judgments and opinions and all the rest of the baggage that become a major source of stress. Observe thoughts and emotions but let them pass without judgment.*



*Mindfulness meditation is not hard, there is no right or wrong way to do it, but it may take practice to quiet the mind for an extended period of time. Your mind will wander. That's ok, just pay attention to the thoughts and let them go by.*

*Start by setting aside 10 to 20 minutes a day at first. No special gear needed. No cost. All you'll need is a quiet space. Most people meditate with closed eyes, but you can focus on an object, a candle, for example. Concentrating on the flame might make it easier to clear the noise.*

*The main idea is to focus your attention; this is what helps free your mind from the many distractions that cause stress and worry. Focus attention on such things as a specific object, an image, a mantra. One way to start is to focus on breathing. Concentrate on the inhale and the exhale, slow and relaxed. Always bring the wandering mind back to the breath.*

*As your meditation skills increase, consciously visualize the release of tension, beginning at the head, eyelids, shoulders, fingers, and moving slowly down to the toes. Breathe relaxation into all the muscles and all parts of the body.*

*Prayer is the best known and most widely practiced example of meditation. Some people use religious mantras to focus, relax and quiet the mind.*

*The clinical effects of meditation are becoming more clear. Mindfulness is taught at many medical centers to help people cope with a broad range of physical and psychological symptoms, including reducing anxiety, pain, and depression, enhancing mood and self-esteem, and decreasing stress. Some people use meditation to enhance creativity or improve performance.*

*For information see National Center for Complementary and Integrative Health. [www.nccih.nih.gov/health/meditation/overview.htm](http://www.nccih.nih.gov/health/meditation/overview.htm)*

No doubt about it, exercise is good for you. It prevents secondary conditions such as heart disease, diabetes, pressure injuries, carpal tunnel syndrome, obstructive pulmonary disease, hypertension, urinary tract infections and respiratory disease. Research shows that people with multiple sclerosis who joined an aerobic exercise program had better cardiovascular fitness, better bladder and bowel function, less fatigue and depression, a more positive attitude and increased participation in social activities.

In 2002, seven years after his injury, Christopher Reeve demonstrated to the world that he had recovered modest movement and sensation. Reeve's recovery defied medical expectations but had a dramatic effect on his daily life. He believed his improved function was the result of vigorous physical activity. He began exercising the year he was injured. Five years later, when he first noticed that he could voluntarily move an index finger, Reeve began an intense exercise program under the supervision of the late Dr. John McDonald, then at Washington University in St. Louis, who suggested that these activities may have awakened dormant nerve pathways, thus leading to recovery.

Reeve included daily electrical stimulation to build mass in his arms, quadriceps, hamstrings and other muscle groups. He rode a functional electrical stimulation (FES) bicycle, did spontaneous breathing training and also participated in aquatherapy. In 1998 and 1999, Reeve underwent treadmill (locomotor) training to encourage functional stepping. See below for more on FES bicycle ergometry; see pages 63-65 for more on locomotor training.

Not everyone can or should expect to get function back by exercising. But here's another great reason to get fit: Exercise helps us stay smart, and it keeps the brain healthy. Neuroscience research supports the notion that exercise enhances brain cell proliferation, fights degenerative disease and improves memory. A number of human studies have shown that exercise increases alertness and helps people think more clearly.

Whatever motivates you to exercise is a good reason. Weight loss is a start. There is an epidemic of obesity in the United States. Unfortunately, people with disabilities are even more prone to carrying excess weight due to a combination of altered metabolism and decreased muscle mass, along with a generally lower activity level.

There are compelling reasons to shed the extra pounds. Research shows that people who use wheelchairs are at risk for shoulder pain, joint deterioration and even painful rotator cuff tears, due to the amount of stress they place





on their arms. The more weight to push, the more stress on the shoulder. Plus, extra pounds adds risk to the skin. As people gain weight, the skin traps moisture, greatly increasing the risk of pressure injuries. Inactivity can also result in loss of trunk control, shortening or weakness of muscles, decreased bone density and inefficient breathing.

But people with paralysis may not be hearing the message. According to the President's Council on Physical Fitness and Sports, people with disabilities are less likely to engage in regular moderate physical activity than people without disabilities. It's the same as in the general population. It's often the "work" part of working out that keeps people from getting a fitness program going.

Physical activity, however, need not be strenuous to achieve health benefits. You don't have to be an athlete. Significant health benefits can be obtained with a moderate amount of physical activity, preferably daily. Adequate activity can be obtained in longer sessions of less intense activities (such as 30–40 minutes of wheeling oneself in a wheelchair) or in shorter sessions of

more strenuous activities (such as 20 minutes of wheelchair basketball).

Additional health benefits can be gained through greater degrees of physical activity. People who can maintain a regular routine of physical activity that is of longer duration or of greater intensity are likely to derive greater benefit. Previously sedentary people who begin physical activity programs should start with short intervals of physical activity (5–10 minutes) and gradually build up to the desired level of activity.

For paralyzed people unable to perform voluntary exercise, functional electrical stimulation (FES) has been shown to build muscle mass, improve circulation and metabolism, and favorably alter muscle fiber composition. According to a team at the Miami Project to Cure Paralysis, FES cycling reverses cardiac muscle atrophy in people living with quadriplegia. FES works, but it's not available widely and it's not for everyone. Ask your doctor about it and see the next section for more information.

Set realistic fitness goals but stick with a program. Stop exercising if you feel any pain, discomfort, nausea, dizziness, lightheadedness, chest pain, irregular heartbeat, shortness of breath or clammy hands. Always stay hydrated.

People with paralysis should consult a physician before beginning a new program of physical activity. Overtraining or inappropriate activity can be counterproductive. For example, in people with multiple sclerosis, exercise can lead to a condition called cardiovascular dysautonomia, which lowers heart rate and decreases blood pressure. Also, because exercise tends to warm up the body, sensitivity to heat (especially in people with MS) can induce fatigue, loss of balance and visual changes; use cooling aids as needed (cool vests, ice packs). [www.steelevest.com](http://www.steelevest.com)

### **SOURCES**

National Center on Health, Physical Activity and Disability, President's Council on Physical Fitness and Sports, National MS Society, Craig Hospital, Paralyzed Veterans of America

### **FITNESS AND FES RESOURCES**

**National Center on Health, Physical Activity and Disability (NCHPAD)** features resources on fitness, exercise and recreation. A good place to start when you decide to get fit. Toll-free 1-800-900-8086; [www.nchpad.org](http://www.nchpad.org)

**The Cleveland FES Center** promotes techniques to restore function for persons with paralysis. Home of the FES Information Center. 216-231-3257; <http://fescenter.org>

## FES BIKES

Functional electrical stimulation (FES) is an assistive device that provides low-level electrical current to muscles in a paralyzed body. Electrodes may be applied to the skin as needed or they may be implanted under the skin. FES can power the legs in order to power a stationary bike (or ergometer as they are called). An FES system was FDA approved and commercialized for quadriplegics to initiate a grip using a shoulder shrug (very effective, patients loved having use of their hands, but the company did not survive). FES has been used to facilitate standing, breathing, coughing, and urinating.

FES biking, the most commercially developed form, has been shown since the 1980s to be a very good means of working out a paralyzed body. FES builds muscle mass, is good for the heart and lungs, may help with bone strength and immune function. Some people have used FES systems to help them walk, with braces. FES or any physical activity improves overall health and well being. Might FES activity affect recovery, too?

The late John McDonald, MD, Ph.D., a neurologist who specialized in spinal cord injury rehabilitation, believed it does. “Maximizing spontaneous recovery of function is something that is possible in the majority of those paralyzed, including the most severe,” he claimed.

McDonald clearly liked the concept; he helped start a company, Restorative Therapies, Inc. ([www.restorative-therapies.com](http://www.restorative-therapies.com)). The RT bike, the RT300 (also available with arm FES) competes with the original FES bike, the Ergo ([www.musclepower.com](http://www.musclepower.com)). The primary difference is that the RT is smaller and is ridden without transferring from a wheelchair. Both cost north of \$15,000;



RT300 from Restorative Therapies, Inc.

some insurance carriers will pay for FES. Another option is the MyoCycle (<https://myolyn.com>) which is designed for home use. So far, Medicare has not reimbursed for FES bikes.

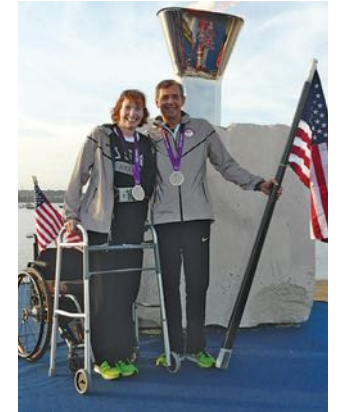
## JEN FRENCH: NEUROTECH

*Neurotechnology is not just about electrical stimulation. It is a whole category of medical devices and therapies that interact with the human nervous system. They can be used in various ways; to provide meaningful function, to treat a specific condition or to supplement therapy. Devices can be applied externally such as to the surface of the skin or implanted with a surgical procedure. For paralysis, options can range in the following:*

- breathing, cough or respiratory systems
- hand, arm and shoulder systems
- bladder or bowel control
- spasticity or pain management
- pressure injury prevention and wound healing
- standing and ambulation systems
- exercise and rehabilitation systems

*Whether you are looking to extend the rehabilitation process or combat the common secondary conditions, neurotechnology may be an option. It is important to first learn about the technologies then consult with a trained medical professional prior to initiating any program.*

*How do I know? I have been using neurotechnology devices since my spinal cord injury in 1998 from a snowboarding accident. I used surface electrical stimulation to help rehabilitate my upper extremities and FES cycling for exercise early in my rehabilitation process. Later, I was implanted with experimental electrodes in my lower extremities from the Cleveland FES Center. The system allows me to fight off common secondary conditions such as muscle atrophy and pressure injuries. I also use it for daily function. In my wheelchair, I use it for trunk control and to aid in propelling my manual wheelchair. It also gives me the freedom to stand out of my wheelchair; to reach high items, make difficult transfers, join a standing ovation and walk down the aisle at my wedding. Take the time to learn more about neurotechnologies and how they may be right for you. <https://neurotechnetwork.org> — Jen French*



Jen French and JP Creignou, silver medalists, sailing, 2012 Paralympics.

## NUTRITION

It goes without saying, or at least it should, that good health depends on good nutrition. Food affects how we look and feel, and how our bodies work. Eating right provides energy, boosts our immune system, keeps us at the proper body weight, and keeps all body systems in harmony. Eating wrong can cause weight gain, diabetes, heart disease, cancer and other “ailments of civilization.”

Eating well is even more essential for persons who are living with paralysis. Because of changes that occur to the body after trauma or disease, it’s more important than ever to understand the role nutrition plays in maintaining health.

After a spinal cord injury, most people lose some weight. The injury puts stress on the body as it uses its energy and nutrients to repair itself. Stress ramps up the metabolic rate; the body burns calories faster. Moreover, many newly injured people are not able to eat a regular diet. As muscles atrophy, the weight loss continues—for about a month. Later, the problem isn’t too few pounds, it’s too many. People living with SCI are more prone to inactivity, and thus don’t burn calories. That’s the pathway to obesity.

Compared to the general population, people with spinal cord injuries are prone to two diet-related problems: heart disease and diabetes. For reasons that are not fully understood, blood chemistry becomes impaired: Insulin tolerance is too high. (The body produces more and more of the hormone insulin to transport energy to the body tissues. This is one of the pathways to diabetes.) Meanwhile, “bad” cholesterol and triglycerides are too high, and “good” cholesterol is too low.

There are no clear guidelines for people living with SCI to manage their metabolic profile. The advice is what doctors say to everyone: moderate your lifestyle; don’t eat so much; get some exercise; don’t smoke; don’t get heavy.

For some it isn’t just the food, it’s the way the food is presented. People with amyotrophic lateral sclerosis and other conditions who have problems swallowing must regulate the consistency and texture of foods. Food should be softer and cut into smaller pieces that can slide down the throat with minimum chewing. If food or drinks are too runny, some of the liquid can run into the airway to the lungs and cause coughing. If food is too dry, such as toast, it tends to irritate the throat and causes coughing. This problem can often be solved by adding butter, jam, etc. Foods that may be easier to manage include custards, sherbet, puddings, plain yogurt, canned fruit, applesauce, crustless toast with butter, dark chicken, salmon, thick soups, scrambled eggs, and mashed potatoes. Avoid extra-spicy or acidic foods, soft bread, cookies, crackers, dry cereal,

graham crackers, peanut butter, lettuce, celery, rice, and fruits and vegetables with skin or seeds (peas, corn, apples, berries).

Bowel management is directly related to diet. Since the messages from the brain that control the muscular movements of the bowel are out of order, it’s difficult for food to move through the intestinal system. A high fiber diet – 25-35 grams of fiber every day – and plenty of fluids is recommended. True, that’s a lot of fiber. Where does it come from? Vegetables, fruits, nuts, popcorn. Some people take supplements, such as Metamucil. What to avoid: high-fat foods. They don’t easily move through the system.

For some people with paralysis due to disease, diet and nutrition become almost a religious issue, though certainly not without some confusion, and controversy. There are many adherents, for example, of special diets for people with multiple sclerosis. The National Multiple Sclerosis Society recommends the standard food pyramid, with a low-fat, high-carbohydrate program with a variety of grains, fruits and vegetables. The Swank MS diet, originated by an Oregon doctor almost 50 years ago, prescribes a strict no-fat, no-dairy routine. Roy Swank has claimed to reduce the frequency and severity of recurrences in his MS patients by cutting out animal fat – this being the one essential first step for anyone with MS, he says.

Roger MacDougall, an Oscar-nominated Hollywood writer in the 1950s, had a severe case of MS – his legs were paralyzed, he was almost blind, he had no voice. Using a high-protein, low-carbohydrate diet that has become known as the “Paleolithic diet,” he says he got completely better. “I have not been cured. I am simply experiencing a remission – but a remission which I firmly believe to be self-induced.” MacDougall’s premise is that until the advent of agriculture, 10,000 years ago, we were all hunter-gatherers and ate meats and nuts and berries from natural sources; we have not evolved to deal with the processed food products of modern agriculture and thus we can become allergic to certain types of foods – wheat and other glutes, refined sugar and high-fat meat. He suggests that these allergies can lead to autoimmune disease, such as MS, arthritis, etc. MacDougall’s answer: Eat like a caveman. Or at least eat more sporadically. The latest diet trend: Eat what you want for five days, fast for two. There might well be something to that: scientists know that rats, mice, and worms that eat very little live longer than those that eat normal diets. The same may be true for humans – people who carefully regulate their calories and eating patterns may stay healthier and extend their life span. It is always best to consult with your healthcare team before beginning any diet or fast.



## **SOURCES**

Spinal Cord Injury Information Network, Rehabilitation Research and Training Center on Aging and Spinal Cord Injury at Rancho Los Amigos, ALS Association

## **NUTRITION RESOURCES**

**Nutrition.gov** is a resource on diet and food, including ways these relate to disease, activity, etc. [www.nutrition.gov](http://www.nutrition.gov)

**National Institutes of Health: Office of Dietary Supplements** offers reliable information on nutritional supplements. [www.ods.od.nih.gov](http://www.ods.od.nih.gov)

### **DIETARY CONCERNS RELATED TO PARALYSIS**

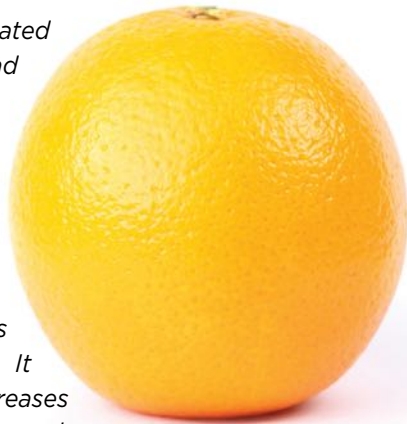
**Pressure injuries:** An active pressure injury requires a diet high in protein, vitamins, and minerals.

**Kidney or bladder stones:** Some individuals with spinal cord dysfunction may be prone to stones. Certain beverages are more likely to create calcium crystals in the urine (beer, coffee, cocoa, cola drinks). Dairy products (milk, cheese, yogurt, ice cream) can also lead to trouble. The best way to avoid kidney or bladder stones is to drink a lot of water.

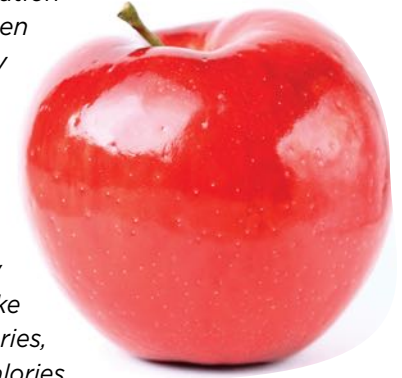
**Urinary tract infection:** Carbonated beverages (soda), orange juice and grapefruit juice may cause the urine to become alkaline, a breeding ground for bacteria that can cause UTI.

**Weight control:** Obesity is on the rise across the United States and people with disabilities are part of the picture. Extra weight decreases mobility, endurance and balance. It can make transfers difficult and increases the risk of pressure injuries. There are dangers to being underweight, too; it increases the risk for infections and pressure injuries, resulting in less energy and more fatigue.

**General guidelines:** Most nutritionists stick pretty close to the standard food pyramid (most calories from complex carbohydrates — breads and



starches — with plenty of dairy and avoidance of refined sugars and fat). This foundation of American eating habits has been challenged in recent years by many popular high-protein diets. Going against prevailing dogma, there is research suggesting that carbohydrates are also a problem in obesity, diabetes and heart disease. Nonetheless, the usual rehab nutrition program typically recommends a carbohydrate intake representing 50-60 percent of total calories, with protein being 20 percent of total calories.



**Protein:** People with mobility limitations generally need more protein in their diets to help prevent tissue or muscle breakdown. At least two 4-ounce servings of a high-protein food should be consumed every day; eat even more than that if there is an active pressure injury.

**Fiber:** To promote normal bowel functioning and to prevent constipation and diarrhea, nutritionists recommend whole grain breads and cereals, fresh fruits and vegetables, raw nuts and seed mixes with dried fruits and peanut butter.

**Fluids:** A lot of water is necessary to prevent dehydration and to keep your kidneys and bladder flushed.

**Minerals and vitamins:** Fruits and vegetables are good sources of vitamin A and the family of B vitamins. There is some evidence that taking extra vitamin C and a zinc supplement helps keep the skin healthy.

**Antioxidant vitamins:** These round up free radicals that can damage the body's cells, and may stimulate the immune system. Many people with chronic neurological disease take supplements, including vitamins A (beta-carotene), C and E. Fruits and vegetables are good sources. Grape seed extract, co-enzyme Q 10 and pycnogenol are other sources.

**Vitamin D:** It's a good idea to take a supplement if you don't get out in the sun much. There is data showing a link between vitamin D and multiple sclerosis: the farther away from the equator a person lives, the higher the risk of MS.



## SEXUAL HEALTH

### FOR MEN

Paralysis affects a man's sexuality both physically and psychologically. Men wonder, "Can I still do it?" Men worry that sexual pleasure is a thing of the past. They worry that they can no longer father children, that mates will find them unattractive, that partners will pack up and leave. It is true that, after disease or injury, men often face changes in their relationships and sexual activity. Emotional changes occur, of course, and these too can affect a person's sexuality.

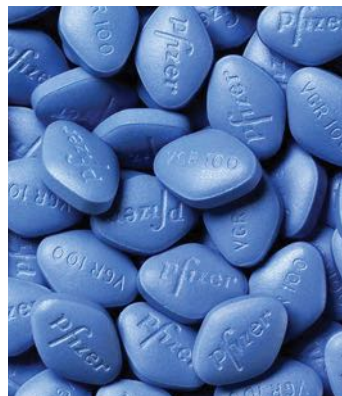
Erections are the number one issue after paralysis. Normally, men have two types of erections. Psychogenic erections result from sexual thoughts or seeing or hearing something stimulating. The brain sends these arousing messages through the nerves of the spinal cord that exit at the T10-L2 levels, then relays them to the penis, resulting in tumescence. The ability to have a psychogenic erection depends on the level and extent of paralysis. Generally, men with an incomplete injury at a low level are more likely to have psychogenic erections than men with high-level, incomplete injuries. Men with complete injuries are less likely to experience psychogenic erections.

A reflex erection occurs when there is direct physical contact to the penis or other erotic areas such as the ears, nipples or neck. A reflex erection is involuntary and can occur without sexual or stimulating thoughts. The nerves that control a man's ability to have a reflex erection are located in the sacral segments (S2-S4) of the spinal cord. Most paralyzed men are able to have a reflex erection with physical stimulation unless the S2-S4 pathway is damaged.

Spasticity is known to interfere with sexual activity in some people with SCI. During genital stimulation, spasticity is more likely to be increased and autonomic dysreflexia may occur, thus requiring temporary cessation of sexual activity. In addition, ejaculation has been reported to decrease spasticity for up to 24 hours.

Indeed, ejaculation is the number two issue. Researchers report that ejaculation occurs in up to 70 percent of men with incomplete lower-level injuries and in as many as 17 percent of men with complete lower-level injuries. Ejaculation occurs in about 30 percent of men with incomplete upper-level injuries and almost never in men with complete upper-level injuries.

While many men who are paralyzed can still "get it up," the erection may not be hard enough or last long enough for sexual activity. This condition is called erectile dysfunction (ED). Numerous treatments and products (pills, pellets, shots and implants) are available for treating ED but paralyzed men may have special concerns or problems with their use. It is important to see your doctor or urologist for accurate information on the various treatments as they relate to specific conditions.



Research and reported experience of men with paralysis show that Viagra, Cialis and Levitra significantly improve the quality of erections and the satisfaction of sex life in most men with ED who have injuries between T6 and L5. Men who have low or high blood pressure or vascular disease should not take these drugs. Some medications cannot be taken with ED drugs—review this with the prescribing physician especially if you are likely to experience autonomic dysreflexia.

Penile injection therapy is an option that involves injecting a drug (papavarine or alprostadil) or a combination of drugs into the side of the penis. This produces an erection that can last for an hour or two and is firm enough for sexual intercourse in about 80 percent of men, regardless of age or the cause of ED. If not used correctly, these drugs can result in a prolonged erection, called priapism, which, untreated, can damage the penile tissue. Other risks from the injection are bruising, scarring or infection. An injection erection is a more difficult option for those with limited hand function.

Another option is called medicated urethral system erection (MUSE), wherein a medicated pellet (alprostadil, the same drug used in penile injection therapy) is placed into the urethra for absorption into the surrounding tissue. Intraurethral medications are not generally considered to be effective in men with SCI and are seldom prescribed.

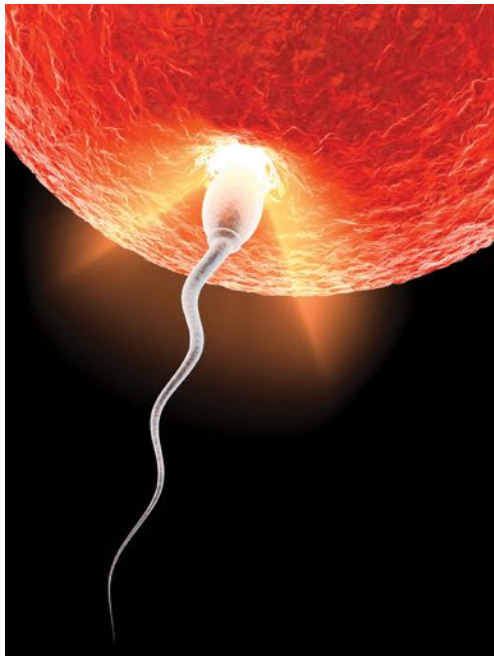
Beyond drug options, vacuum pumps produce an erection. The penis is placed in a cylinder and the air is pumped out, causing blood to be drawn into the erectile tissues. Tumescence is maintained by placing an elastic constriction ring around the base of the penis. It's important to remove the ring after intercourse to avoid the risk of skin abrasion or breakdown. A battery-operated vacuum model is an available option. Premature loss of rigidity and

lack of spontaneity are unwanted side effects.

A penile prosthesis, often the last treatment option for ED because it is permanent and requires surgery, involves inserting an implant directly into the erectile tissues. There are various types of implants available, including semi-rigid or malleable rods and inflatable devices. Generally, the penis may not be as firm as a natural erection. There are risks of mechanical breakdown, and the danger that the implant could cause infection or push out through the skin. Research showed that 67 percent of females interviewed were satisfied with results of implant treatment for their partner's ED.

**Orgasm:** A study of 45 men with SCI and 6 able-bodied controls demonstrated that 79 percent of the men with incomplete lesions and 28 percent of those with complete injuries achieved orgasm in the laboratory setting. Predictors of orgasm were completeness of injury and prior history of orgasm post-injury.

Paralyzed men with ED should have a thorough physical exam by a urologist familiar with their condition before using any medications or assistive devices. Men with spinal cord injuries above the T6 level must be watchful for signs of autonomic dysreflexia (AD). Signs include flushing in the face, headaches, nasal congestion and/or changes in vision. See page 90 for more on AD.



**Fertility** is the third biggest issue: Men with paralysis usually experience a change in their ability to biologically father a child, due to the inability to ejaculate. Some men experience retrograde ejaculation: Semen travels in reverse, back into the bladder. The number of sperm a man produces does not usually drop in the months or years after paralysis. However, the motility (movement) of the sperm is considerably lower than for non-paralyzed men. There are options, though, for improving the ability to father children.

**Penile vibratory stimulation (PVS)** is an inexpensive and fairly reliable way to produce an ejaculation at home. Vibrostimulation is most successful in men with SCI above the T10 level. A variety of vibrators/massagers are available for this purpose. Some are specifically designed with the output power and frequency required to induce ejaculation while minimizing skin problems. See [www.urologyhealthstore.com](http://www.urologyhealthstore.com)

**Rectal probe electroejaculation (RPE)** is an option (albeit in a clinic with several technicians around) if the vibratory method is not successful. RPE, borrowing from animal husbandry, places an electrical probe in the rectum; a controlled electrical stimulation produces an ejaculation. Electroejaculation is generally a safe and effective way to obtain a sperm sample, although using a vibratory stimulus generally produces samples with better sperm motility than from electrostimulation.

The sperm from men with SCI are healthy but usually not strong swimmers, and often not hardy enough to penetrate the egg. Because of their reduced motility, the sperm need a little high-tech help. Men with SCI stand a good chance of becoming biological fathers when they have access to specialized clinics and care. The recent development of intracytoplasmic sperm injection (ICSI), which involves the direct injection of a single mature sperm into an oocyte (egg), can often solve the problem of conception.

If sperm cannot be retrieved using PVS or RPE, minor surgery can be performed to remove sperm from the testicle.

There are lots of success stories but high-tech, assisted fertility is not a slam-dunk. It can be emotionally draining and also quite expensive. Get the facts and treatment options from a fertility specialist experienced in issues of paralysis. Some couples grappling with infertility have successfully utilized donor sperm (from a sperm bank) to impregnate the woman. Couples may also want to explore the very rewarding options available to adopt children.

**Sex after stroke:** Heart disease, stroke or surgery doesn't mean that a satisfying sex life must end. After the first phase of recovery is over, people find that the same forms of lovemaking they enjoyed before are still rewarding. It is a myth that resuming sex often causes a heart attack, stroke or sudden death. Still, fears about performance can greatly reduce sexual interest. After recovery, stroke survivors may feel depressed. This is normal, and in 85 percent of the cases it goes away within three months.

To be sure, a man can continue or initiate a romantic and intimate relationship

with a partner after a paralyzing disease or injury. Good communication with his partner is essential. It is important for both partners to understand the physical changes that have occurred, but it is equally important to talk about each other's feelings. The couple can then explore and experiment with different ways to be romantic and intimate.

For people with limited arm and hand function, it is often necessary to ask caregivers to provide physical assistance prior to sexual activity. Help might be needed with undressing, preparation, and positioning.

Many couples consider oral-genital intercourse. Whatever seems satisfying and pleasurable is acceptable as long as both partners agree.

Here's something in the adaptive equipment realm for men with paralysis: IntimateRider is a swing chair that offers a natural gliding motion to improve what the company calls "sexual mobility." The IntimateRider was designed by a person with C6-C7 quadriplegia to improve his sex life after spinal cord injury. The chair moves with very little pushing effort, allowing the pelvis to thrust during sex. [www.intimaterider.com](http://www.intimaterider.com)

While it's been said that the largest sex organ is the brain, it's not always easy to make major adjustments in one's sexual persona. Professional counseling can help in working through feelings of fear or anxiety over establishing or continuing a healthy relationship after paralysis. A counselor can also work with couples on healthy ways to communicate their needs and feelings.

**Safe sex:** The risk of sexually transmitted disease (STD) is the same both before and after paralysis. STDs include diseases such as gonorrhea, syphilis, herpes and the HIV virus; these can cause other medical problems, such as infertility, urinary tract infections, pelvic inflammatory disease, vaginal discharge, genital warts and AIDS. The safest, most effective way to prevent sexually transmitted diseases is to use a condom with a spermicidal gel.

### **SOURCES**

The American Urological Association, University of Miami School of Medicine, Cleveland Clinic

### **SEXUAL AND REPRODUCTIVE HEALTH RESOURCES**

**Paralyzed Veterans of America**, in support of The Consortium for Spinal Cord Medicine, offers authoritative clinical practice guidelines for sexuality and

reproductive health. PVA, toll-free 1-800-424-8200, [www.pva.org](http://www.pva.org).

**Spinal Cord Injury Rehabilitation Evidence (SCIRE)** project is a Canadian research collaboration (scientists, clinicians and consumers) that reviews, evaluates, and translates research knowledge to establish best rehabilitation practices following SCI. Includes section on sexuality. [www.scireproject.com](http://www.scireproject.com)

### **FOR WOMEN**

Paralysis itself doesn't affect a woman's libido or her need to express herself sexually, nor does it affect her ability to conceive a child. Generally speaking, sexuality in the paralyzed female is less affected than in the male; it is physically easier for the woman to adapt her sexual role, even though it may be more passive than that of a non-disabled woman. The main difference in sexual functioning between women with disabilities and those without can be accounted for by the difficulties women with disabilities have in finding a romantic partner. Their level of sexual desire may be the same, but the level of activity is generally less because fewer women with disabilities have partners.

There are no physiological changes after paralysis that prevent women from engaging in sexual activity. Positioning can be an issue but can usually be accommodated. Autonomic dysreflexia can be anticipated and controlled. Many women experience a loss of vaginal muscle control and many are unable to produce vaginal lubrication. Both problems are likely the result of the interruption in normal nerve signals from the brain to the genital area. There is no remedy for muscle loss. Lubrication, of course, can be augmented.

Typically, lubrication occurs as a psychogenic (mental) and reflex (physical) response to something sexually stimulating or arousing. It has been suggested that lubrication in women is the physiological equivalent of the erection in the male, and is probably innervated in the same way. Women can substitute water-based (never oil-based, such as Vaseline) lubricants such as K-Y Jelly.

Low sex drive is common among women with paralysis; indeed, it is reported among all women. Meanwhile, Viagra was clinically tested by a group of women with spinal cord injuries; almost all reported that the drug stimulated arousal. In some, it enhanced lubrication and sensation during intercourse.

In some conditions of paralysis, such as multiple sclerosis, cognitive problems can undermine sexuality. People with short-term memory or concentration loss may drift off during sexual activities in a way that can be disheartening to the



partner. It requires love and patience, with lots of communication, to bring this out in the open and to seek the needed psychological or medical treatment.

Women who are paralyzed often fear bowel and bladder accidents during times of intimacy. There are a number of ways to reduce the chance of accidents. The first is to limit fluid intake if a sexual encounter is planned. Women who use intermittent catheterization should empty the bladder

before beginning sexual activity. Women who use a suprapubic or Foley catheter find that taping the catheter tube to the thigh or abdomen keeps it out of the way. The Foley can be left in during sexual intercourse because, unknown to many men and even women, the urethra (urinary opening) is separate from the vagina.

The best way to avoid a bowel accident is to establish a consistent bowel program. Women may also want to avoid eating right before engaging in sexual activity. With good communication, an occasional bladder or bowel accident won't destroy a rewarding sex life.

**Orgasm:** Sexual success is often measured, wrongly, by whether or not partners achieve orgasm. A woman with paralysis, like men with similar levels of function, can achieve what is described as a normal orgasm if there is some residual pelvic innervation. Dr. Marca Sipski of the University of Alabama/Birmingham School of Medicine thinks paralyzed women retain an orgasm

reflex that requires no brain input. The ability to achieve orgasm seems unrelated to the degree of neurological impairment in women with lesions down to T5 level; her research indicates the potential is still there, but women may give up trying to have orgasms because they lack the ability to feel touch in the genital area.

A small body of research suggests that women with SCI can achieve orgasm using a clitoral vacuum suction device (Eros device), FDA approved to treat female orgasmic dysfunction. The device increases blood flow, thus creating clitoral engorgement; this in turn may increase vaginal lubrication and heighten orgasm response.

Some paralyzed men and women, with practice and focused thought, are able to experience a "phantom orgasm," through reassignment of sexual response; this involves mentally intensifying an existing sensation from one portion of their body and reassigning the sensation to the genitals.

Women with paraplegia or quadriplegia who are of childbearing age usually regain their menstrual cycle; nearly 50 percent do not miss a single period following injury. Pregnancy is possible and generally not a health risk. While most paralyzed women can have normal vaginal deliveries, certain complications of pregnancy are possible, including increased urinary tract infections, pressure injuries and spasticity. Autonomic dysreflexia (AD) is a serious risk during labor for those with injuries above T6. Also, loss of sensation in the pelvic area can prevent the woman from knowing that labor has begun.

Another potential risk of pregnancy is the development of thromboembolism, in which blood vessels become blocked by clots. With high thoracic or cervical lesions, respiratory function may be impaired with the increased burden of pregnancy or the work of labor, requiring ventilator support.

Women with disabilities often do not receive adequate healthcare services. For example, routine pelvic exams are not done due to lack of awareness of the need, problems getting onto the exam table, or not being able to find a doctor with knowledge about their disability. Providers might wrongly assume that women with disabilities are not having sex, especially if their disability is severe, and therefore may neglect to screen these women for sexually transmitted diseases (STDs) or even perform a full pelvic exam. Unfortunately, some healthcare providers even suggest to women with disabilities that they abstain from sex and not bear children, even if they can conceive children.



**Breast health:** Women with disabilities must be aware that they are among the one in eight women who will get breast cancer. Screening is essential. Women with limited use of their arms and hands may need to perform exams using alternate positions or with the help of an attendant or family member. In the clinic, getting a wheelchair in the door is the easy part; services or programs provided to patients with disabilities must be equal to those provided for persons without disabilities.

**Birth control:** since paralysis does not usually affect fertility in the female, contraception is important. There are also some special considerations. Oral contraceptives are linked to inflammation and clots in blood vessels, and the risk of these is greater with SCI. Intrauterine devices cannot always be felt in the paralyzed woman and may cause undetected complications. Use of diaphragms and spermicides can be difficult for those with impaired hand dexterity.

Sexuality does not disappear after paralysis. Explore sexuality with an open heart and an open mind.

### SOURCES

Center for Research on Women with Disabilities, Spain Rehabilitation Center, Paralyzed Veterans of America

### WOMEN WITH DISABILITIES RESOURCES

**Center for Research on Women with Disabilities (CROWD)** focuses on issues related to health (including reproduction and sexuality), aging, civil rights, abuse and independent living. CROWD hopes to expand the life choices of women with disabilities to fully participate in community life: believe in oneself, honor the body, defy the myths, demand answers. 832-819-0232;

[www.bcm.edu/crowd](http://www.bcm.edu/crowd)

**Craig Hospital** provides some resources specifically for women including ones for breast cancer, pregnancy after SCI, sexual function for women after SCI, and a video on bladder management tools for women with SCI (co-produced with the Reeve Foundation). <https://craighospital.org>

**National Resource Center for Parents with Disabilities, from Through the Looking Glass**, a resource on childbirth and parenting, adaptive equipment for childcare, networking and support. 1-800-644-2666; [www.lookingglass.org](http://www.lookingglass.org)

### **Navigating the OBGYN's Office**

Women with disabilities continue to experience significant barriers and health disparities when seeking obstetric and gynecological care. Frustrating experiences with doctors who lack training treating patients living with paralysis and inaccessible medical offices cause too many women to delay necessary, preventative check-ups. Regular pap smears and mammograms increase the possibility of early cancer detection, but bone health, menopause, and reproductive and family planning are among other health issues as important for women with paralysis to monitor as those in the general population.

Cody Unser, an advocate for people with disabilities, was inspired to fight for better access and support after her own negative experiences seeking care while a graduate student in Washington, D.C. Arriving at the first gynecologist's office, Unser, who is paralyzed from the chest down, found herself at the top of a flight of stairs; when she called reception and explained she was in a wheelchair, they told her they couldn't help. At the second office she tried, Unser was able to enter the building but left in tears after an upsetting appointment: the exam table was inaccessible and the ensuing staff scramble to help her transfer, along with the provider's insensitive attitude, left her feeling defeated.

"It was so degrading," she says. "And I thought, 'I can't be the only woman in a wheelchair having such a hard time.'"

Unser decided to assess health care issues for women with disabilities for her next class assignment, a paper that later became an article for U.S. News & World Report headlined 'Wheelchair Barbie' Goes to the Gynecologist. Since then, she has spoken at dozens of OBGYN residency programs across the country about the urgent changes needed to achieve equitable care.

"There needs to be a mandatory, semester-long course around disability issues at every medical school," Unser says. "No matter what field students go into, whether they want to be an OBGYN or primary care doctor, they're going to have patients with disabilities at some point. More sensitivity is needed."

Here are Unser's tips for navigating inaccessible offices and advocating for better care:

#### **On-site access**

"The main lesson I've learned is to call with questions before you make any

appointment. Unfortunately, we can't assume that accessibility is universal," she says.

Unser recommends asking not only about access to the building, but about the inside of the office itself. Are the hallways wide enough? Is the reception desk low enough to offer privacy for wheelchair users at check-in? Do bathrooms have support bars? Will the appointment schedule allow for extra time that a woman with mobility challenges might need?

The biggest barrier may be accessing the examination table itself. Many offices lack height adjustable tables but are equipped with a lower table used for general procedures. Unser requests that her exam takes place in this procedure room so that she can more easily access the table independently. When this is not an option, she suggests a family member, friend or caregiver accompany a woman with a disability to the appointment to help with the transfer.

### Communication

Unser encourages women to advocate for themselves. Be clear and detailed about medical history; the more women share, the more they can get out of the appointment. Outline what is needed and don't hesitate to ask questions.

Women who experience spasms should explain this to the provider and staff; gradual repositioning of legs and gentle stretching may help during the exam. Ask for a nurse to stand alongside the examination table to prevent a fall should spasms occur.

Providers also need to understand autonomic dysreflexia (AD), which can be triggered by the exam. Unser, who carries Reeve Foundation AD wallet cards to give to staff unfamiliar with the condition, asks that her blood pressure be taken before and after the exam.

Unser also invites her provider to ask questions about her life and interests, a way to remind everyone that she has an identity beyond her disability.

### Sexual health

"Women should not be afraid to ask questions about sex," Unser says. "I have osteoporosis. I can break a bone during sex. I need to be able to talk about these issues with my doctor."

Sexual health is an important aspect of any woman's life, including those living with disabilities. Intimacy can be more complicated: newly injured women must navigate the mechanics of a paralyzed body; bladder and bowel management

must be considered ahead of time, limiting spontaneity; and certain medications may cause vaginal dryness. In her visits to residency programs, Unser urges doctors not to make assumptions about the sex lives of women with disabilities who need—and deserve—the same access to conversations about health, sexuality, and reproductive counseling and family planning as other patients.



*Cody Unser*

### SOURCES

New England Journal of Medicine, Sept. 3, 2015; U.S. News & World Report, Sept. 15, 2015; North Carolina Office on Disability and Health; Disabilities Studies Quarterly, Vol 35, No 3 (2015)

### NAVIGATING THE OBGYN'S OFFICE RESOURCES

**Christopher & Dana Reeve Foundation** provides a free booklet "Sexuality & Reproductive Health After Paralysis" as well as a free booklet on "Parenting with Paralysis." Call 1-800-539-7309 or go to [www.ChristopherReeve.org/Ask](http://www.ChristopherReeve.org/Ask) to receive a free copy from an Information Specialist.

**Shepherd Center** has a series of videos for women living with spinal cord injuries on visiting a physician's office, sex and pregnancy amongst others. [www.myshepherdconnection.org/sci/women](http://www.myshepherdconnection.org/sci/women)

## PROFILES:

### *The Impact of the Reeve Foundation*

The profiles in the following pages showcase how the Reeve Foundation's Paralysis Resource Center (PRC) promotes the health, well-being and quality of life of people living with paralysis by providing free comprehensive information, resources and referral services. These profiles are a testament to the impact of the PRC and detail how individuals are leveraging resources to help them get back to their communities and to a place of greater independence.

The Quality of Life Grants Program has awarded more than \$30 million to non-profit organizations across the country that provide life-changing programs for community engagement, improved access and independent living. Please visit [www.ChristopherReeve.org/QOL](http://www.ChristopherReeve.org/QOL) for more information on how to apply for a grant.

Over 100,000 people with paralysis as well as their family or caregivers have contacted our Information Specialists for customized support. The breadth and

depth of their knowledge and connections spans multiple languages, as well as everything from what to expect in rehab, to equipment loan programs, to finding local resources. Please visit [www.ChristopherReeve.org/Ask](http://www.ChristopherReeve.org/Ask) or call 1-800-539-7309 to speak to an Information Specialist.

The Peer & Family Support Program is a national peer-to-peer mentoring network that provides support, encouragement and information to people living with paralysis and their family members. Trained and certified mentors understand the day-to-day realities and long-term challenges of living with paralysis and can offer guidance based on their personal experiences. Please see [www.ChristopherReeve.org/Peer](http://www.ChristopherReeve.org/Peer) to request a peer mentor.

The NeuroRecovery Network (NRN) is a cooperative network of clinical rehabilitation centers and Community Fitness and Wellness Facilities (CFWs) that make up two branches of care for people living with spinal cord injury and other physical disabilities. Each member center is charged with developing and—more importantly—providing activity-based therapies that promote functional recovery and improve the health and overall quality of life for people living with paralysis. Please see [www.ChristopherReeve.org/NRN](http://www.ChristopherReeve.org/NRN) for more information.

Please take a moment to read about how the Reeve Foundation is making a difference across the country, while working to serve thousands of individuals and families living with paralysis.

**Today's Care. Tomorrow's Cure.**

INFORMATION SPECIALISTS

*Erin Cobb*  
*Charlotte, North Carolina*

For the first eight months after being shot by her ex-husband in a 2011 murder-suicide attempt, Erin Cobb operated in crisis mode. A former U.S. Marine and CrossFit athlete, Cobb’s adjustment to life with a spinal cord injury was arduous.

“Not only was I ill-equipped to understand living with a spinal cord injury, I was dealing with doctors who didn’t know how to treat my condition,” says Cobb. “I had a lot of secondary complications. I felt awful all the time. I had no hope, and I didn’t think things could get better.”

Feeling desperate, Cobb’s boyfriend searched the Internet for help and reached out to the Reeve Foundation’s Director of Information & Resource Services.

“She literally saved my life,” says Cobb. “She gave us lots of resources, talked us through the processes and answered all our questions. To have her knowledge and authority to point us in the right direction was life-changing.”

The director gave Cobb a rehab checklist and Cobb chose the Shepherd Center, a spinal cord and brain injury rehabilitation facility in Atlanta. Through in-patient treatment and out-patient therapy, Cobb got stronger and healthier.

“It’s been all uphill from there,” says Cobb. “I have had to get used to my new normal and push myself out of my comfort zone. In 2013, Wells Fargo made the accommodations I needed to go back to work. I’ve also found a way to lift weights again. My problem-solving skills are amazing now. It is all about planning ahead.”



In September 2016, Cobb became a Reeve Foundation representative for the Congressionally Directed Medical Research Programs (CDMRP), a Congressional-appropriated program designed to foster novel approaches to biomedical research. She traveled to Washington, D.C. to review science grants for finding a cure for paralysis.

“I was able to be in the room with brilliant people on the cutting edge in their field, and see where science is going” says Cobb. “I can’t even imagine how far behind the spinal-cord injured community would be without the Reeve Foundation and their incredible support.”



INFORMATION SPECIALISTS

*Linda and Dave Tobin  
Moorhead, Minnesota*

“I don’t know what we would have done without the Reeve Foundation’s help,” says Linda Tobin.

When Linda’s husband, Dave, fell out of an apple tree in 2008 and broke his C4/5 vertebrae with damage to the C3 area of his spinal cord, the couple became overwhelmed by how to move forward.

“Coming home after three months in the hospital was a big shock,” says Linda. “We live in a rural community and there aren’t many resources locally to help. The hardest part was finding people who could do Dave’s level of care.”

A four-year Army veteran who served with Special Airborne Forces as a Blackhawk crew chief in the early 1980s, Dave qualified for some U.S. Department of Veteran Affairs (VA) services but Linda was struggling with all the details to get him into the system. Luckily a mutual friend introduced her to one of the PRC’s Information Specialist team.

“The help we received to get Dave into the VA system was amazing. There’s no way I would have been able to get through all the red tape without the Information Specialist’s guidance,” says Linda.

Through the VA, Dave now has annual evaluations and a new wheelchair. Along with an accessible van, the couple can enjoy an improved quality of life.

“We do a lot locally, go to the barber, the movies, the grocery store, we even go to watch local bands,” says Linda. “We make the best of it.”

Linda also uses the Reeve Foundation website as her go-to resource for information and support.



“I read a lot of the caregiver stories. It’s nice to know you’re not the only person going through this,” says Linda. “Many of the resources are fantastic like the sepsis and AD [autonomic dysreflexia] wallet cards which we have used at the hospital.”

Recently Linda reached out to a new person in her community living with a spinal cord injury to share her experience and offer her support.

“I don’t think I could have gotten to where I am today by myself,” says Linda. “I want to make sure others know what an invaluable resource the Reeve Foundation Information Specialists can be.”

*Dave Tobin passed away on August 26, 2018 due to complications of a pressure injury.*

## INFORMATION SPECIALISTS

### *Dain Dillingham Seattle, Washington*

A Division 1 athlete and an assistant winemaker at A. Morell Wines, Dain Dillingham never thought about disability insurance or services.

“I lived life in an able-bodied bubble,” says Dillingham. “Then a fall from a roof in 2013 on my 28th birthday changed everything.”

Dillingham shattered his C5 vertebrae and became paralyzed from the chest down. His older brother became his full-time caregiver.

“Everything seemed overwhelming, from what kind of bed to get to the details about the care I needed,” says Dillingham.

About a month after he was released from the hospital, Dillingham connected with an Information Specialist on Facebook. The IS introduced Dillingham to the Reeve Foundation’s Online Paralysis Community.

“It was so helpful to see examples of people like me who are living life and participating in the world,” says Dillingham. “A lot of confidence can come from reading others’ stories when it is hard to see the possibilities for yourself. The online community offers a great outlet to connect.”

Dillingham likes to read posts about easy tips and getting back into the workplace, something he hopes to do. He also reads research updates and information about ways to keep his body healthy.

“For people who live in smaller towns, I can only imagine how frightening and confusing it would be without good local resources. Being able to go online and connect to information and research resources is incredible,” says Dillingham. “For me, living on my own would have been scary years ago but reading about how others have accomplished it made it a lot less scary.”



Today, Dillingham lives independently and hopes to pay his success forward by helping others through blogging about his journey. He also wants to join the Reeve Foundation Peer & Family Support Program as a peer mentor.

“I’m in a much better place now than when I was newly injured and I’d like to help others by offering the same support and advice that I received,” says Dillingham. “When you become disabled, your dreams can change and can sometimes seem out of reach. Reading the stories and blogs about people who are still reaching their dreams is very inspiring.”

## PEER & FAMILY SUPPORT PROGRAM (PFSP)

*Peer Mentor Ashley Barnes, Tyler, Texas*  
*Peer Brooke Dahman, Marshall, Texas*

Ashley Barnes is certainly an optimist by nature.

“I’m a social butterfly and I have always had the desire to help others. I am now blessed with the opportunity to uplift others in their darkest moments,” said Barnes.

When a spinal cord injury from a medical procedure that went bad left her a paraplegic, her positive spirit never wavered.

“Crawling into a hole is the easy route, it’s rising above that is harder,” said Barnes. “I want to help out any way I can, giving back is so rewarding for me. If I can help even one person look past the four walls of their hospital room and see life after, that is my calling.”

So it’s not surprising that Barnes jumped on the opportunity to become a Reeve Foundation peer mentor.

“I never knew what wealth was until I was paralyzed and started to give back,” said Barnes. “I didn’t know to value the people around me as what to cherish. I cannot put a price tag on the number of people I’ve been blessed to meet.”

One of the half-dozen peers Barnes mentors is Brooke Dahman who sustained a spinal cord injury from a 2015 four-wheeler accident on her 18th birthday. The pair met during a spinal cord injury meeting at a rehab facility.

“I’ve had a hard time understanding the purpose behind it all,” said Dahman. “Having a friend who knows my struggles has certainly helped. Ashley is so encouraging and uplifting, but she is also realistic and straight. In turn, I feel like I bring out the youthfulness in her.”

In just a short time, the two have developed quite a bond. Dahman calls Barnes “Mama Ashley.” During a recent visit, Barnes taught Dahman how to catheterize in a wheelchair and let Dahman try driving her car.



“I try to make myself 100 percent available for anything from basic life skills to emotional support,” said Barnes. “I want to give Brooke the courage and skills to become more independent. I want her to see that she can still do anything. I don’t treat her differently. I offer empathy, not pity.”

Barnes’ support is paying off. Dahman is now

back to life as a full-time student, working two jobs and she is engaged to be married this summer. She is finally feeling like her life has come full circle.

“I’ve been there and I know those hard days,” said Barnes. “You have to keep yourself moving and being the person you are. Recovery is by far easier with interaction and support from others.”



## PEER & FAMILY SUPPORT PROGRAM (PFSP)

*Peer Mentor Kathy Griffin, Euless, Texas*  
*Peer Mary Harrison, Queens, New York*

“There are so many changes all at once . . . and so many challenges,” said Mary Harrison, whose son, Sean, injured his T2 and T3 vertebrae in a 2016 car accident. “Trying to navigate the Medicaid system is abominable. We are eight months post-injury and we still don’t have a shower chair. We are also in the process of renovating a new house for accessibility.”

Unfortunately, the Harrisons’ experience isn’t unique. Adjusting to life after a spinal cord injury can be completely overwhelming.

“There are so many considerations that go into caring for someone with a spinal cord injury. We are working toward our new normal, but we aren’t there yet,” said Harrison. “While I was taking care of Sean in the hospital, my older son did some research and found the Reeve Foundation. He encouraged me to reach out and talk to someone.”

Harrison was connected with peer mentor Kathy Griffin through the Reeve Foundation’s Peer & Family Support Program. Griffin’s son, TJ, sustained a spinal cord injury during a football game 30 years ago.

“It is great to talk to someone who has been there, someone who knows what you’ve been through as a mom with a child living with a spinal cord injury,” said Harrison. “Kathy is very supportive.”

For Griffin, the opportunity to reach out and help others is extremely rewarding.

“It’s nice to help others avoid repeating the same challenges we ran into,” said Griffin who mentors about ten other parents on everything from making the house more accessible to tips about creating a good bowel program. “I help people set long- and short-term goals to work toward what they want to accomplish.”



In addition to practical and technical support, Griffin also offers a sympathetic ear.

“I let them know that life is going to be ok, life will go on,” said Griffin. “They need to vent and I listen to their struggles. I think people feel a bit freer talking to me than they might a close friend.”

Harrison agrees and would certainly encourage others to reach out to the Reeve Foundation for support.

“It is so important not to feel alone. That’s why support groups work so well for so many topics and challenges,” said Harrison. “But it is easier to find someone in the general population who has been affected by cancer or heart disease. It is harder to find someone on the street affected by spinal cord injury. It is great to have a place like the Reeve Foundation to go to make those connections.”



## QUALITY OF LIFE GRANTS

### *Wilderness Inquiry Minneapolis, Minnesota*

Wilderness Inquiry was established over 40 years ago with a simple mission: to connect people with the natural world. Founded on the belief that anyone could enjoy wilderness on its own terms, one of the organization's first trips was to Minnesota's Boundary Waters in 1977 and included two people who used wheelchairs and two people who are deaf.

"I'll never forget watching one of the participants crawl across a portage trail dragging her wheelchair to prove to herself that she could do it. It blew me away, and put my issues and worries in perspective. I learned then to keep an open mind and never say never," said Greg Lais, Wilderness Inquiry's founder and executive director.

Over time, the organization has grown and changed from local camping trips to life-changing international excursions.

"Just because you have a disability doesn't mean you can't experience the wilderness the same way everybody else would," said Lais. "Our goal is to show people from all different backgrounds that they can enjoy the outdoors and not have to experience nature from a modified environment all the time. We figure out how to make it accessible even in the least accessible areas."

Lais recalled a recent trip to Tikal in Guatemala with a friend who is living with spinal cord injury.

"The Mayans didn't have the ADA and there are lots of stairs," said Lais. "We created a device we call a rickshaw which is essentially two poles that go through the wheelchair to carry it when needed. It allowed us to navigate all the trails without issue."

To help make experiences like this possible, Wilderness Inquiry has received support from the Reeve Foundation Quality of Life Grants program for many years. Previous grants have supported projects ranging from accessible kayak purchases to travel scholarships for families with children living with SCI.



"To have the Reeve Foundation's support and belief in the value of what we do is huge," said Lais. "It keeps us inspired and it keeps us connected with hundreds of people living with spinal cord injuries who can now get active, engaged and enjoy life."

With the most recent grant, the organization redesigned their Little Sand Bay Base Camp, a sea kayaking gateway to Lake Superior's Apostle Islands National Lakeshore, to serve as a national model for access for people living with disabilities.

"If you live with a spinal cord injury and want to go outdoors, call us and we'll figure it out, that's what we do," said Lais. "If we don't have it, we'll build whatever you need to make the outdoors accessible."

## QUALITY OF LIFE GRANTS

### *Chanda Plan Foundation Lakewood, Colorado*

At the age of 21, Chanda Hinton Leichtle was near death. Living with quadriplegia from an accidental gun shot in the neck at age nine, she relied solely on medication for pain and was placed in hospice care.

“I was 59 pounds and desperate to survive. Massage therapy and acupuncture saved my life,” said Hinton Leichtle. “I couldn’t believe that no one had suggested integrative therapies before, and I wanted to be sure others didn’t suffer the same fate.”

In 2005, Hinton Leichtle founded the Chanda Plan Foundation to provide people with physical disabilities access to preventative and integrative therapies including acupuncture, massage, chiropractic, adaptive yoga and adaptive exercise on a local and national basis. Funded through grants, individual donors and special events, all services provided by the Chanda Plan Foundation are available at no cost based on eligibility.

“A 2007 Reeve Foundation Quality of Life Grant to support integrative therapies provided the seed money to get our program off the ground and help us grow,” said Hinton Leichtle. “We would be nowhere near where we are today without it and support from others. The grant was a true investment in the future, the ROI on the support is indescribable. In 2016, we provided 4,875 individual treatments, saving participants an estimated \$324,840 in out-of-pocket costs.”

In 2016, the Chanda Plan Foundation reached out to the Christopher & Dana Reeve Foundation again to help support a full-time care coordinator position for their newest undertaking, a completely accessible health center that is eight-times larger than the current location. Designed specifically for people living with physical disabilities, the center offers a one-stop-shop for primary care, behavioral health and care coordination in addition to acupuncture, massage, chiropractic, and adaptive yoga in a collaborative environment, all



under one roof.

“We hope the center will serve as a new model for medical services for this community, to foster independence and offer direct access to providers who are trained in spinal cord injuries and other disabilities,” said Hinton Leichtle. “We really thought through all the details down to including a service-dog relief area. All providers will share one office to allow for organic and constant collaboration, and all providers will participate in quarterly care plan reviews with the patient as the driver. The direct impact we are making on people’s lives is made possible thanks to Reeve Foundation support.”

## QUALITY OF LIFE GRANTS

### *Miracle Flights* *Las Vegas, Nevada*

Distance can be an enormous barrier to life-changing healthcare. For a child born with a rare or congenital disease, the best resources and treatment could be hundreds of miles away.

“The opportunity to gain medical knowledge and access to the best healthcare should not be a limiting factor for families,” said Christina Moon, director of programs and development for Miracle Flights. “The development of advanced therapies doesn’t matter if you can’t reach the care you need. That’s where we step in.”

Founded in 1985, Miracle Flights is the nation’s leading nonprofit health and welfare flight organization, providing financial assistance for medical flights on commercial airlines. Their mission is to help seriously ill children and their families, as well as adults and their caregivers, reach life-altering, life-saving medical care and second opinions from experts and specialists throughout the United States.

“Our services are not disease specific,” said Moon. “The key to Miracle Flights is that we are not one and done, we will fly families as many times as they need. Their ability to reach ongoing treatment can often times be the barrier to progression in care.”

In 2006, Miracle Flights reached out to the Reeve Foundation Quality of Life Grants program for the first time to request support to cover flight costs. Since then, Miracle Flights has received five grants specifically for paralysis-causing conditions.

“Through the support of the Reeve Foundation and others, we can provide flights as many times as needed to help people lead healthier lives,” said Moon.

Moon recalled the story of a 17-year-old named Jessica who was born with arthrogryposis (congenital joint contractures) and has been using Miracle Flights since birth.



“Jessica lives in Las Vegas and the best facility to treat her condition was in Washington state,” said Moon. “Because she was able to reach that care, she is living a virtually pain-free life and has the ability to walk like any other child.”

Since its inception, Miracle Flights has coordinated more than 100,000 flights and counting.

“Many times, this access to healthcare can be what a family needs to turn a corner,” said Moon. “It is important for people to be their own advocate and never give up, and to know that there are organizations like the Reeve Foundation and Miracle Flights that will help them along their journey.”



## QUALITY OF LIFE GRANTS

### *Shane's Inspiration Sherman Oaks, California*

Getting back into the community is one of the hardest hurdles to life after sustaining a spinal cord injury.

“There is often a strong feeling of isolation and the ability to socialize is so important, especially for kids,” said Tiffany Harris, founder and CEO of Shane’s Inspiration, an organization that partners with global communities to design and develop inclusive playgrounds and social programming.

Founded in honor of Shane Alexander Williams who was born with spinal muscular atrophy and passed away two weeks later, Shane’s Inspiration built their first playground in Los Angeles’ Griffith Park in 2000. Since then, the organization has built 64 inclusive playgrounds throughout the world, including eight international playgrounds in Mexico, Israel, Canada, Ecuador and Russia, with another 75 in development.

“When we started this organization 20 years ago, there were no truly accessible playgrounds in the western United States. The original playground was a memorial project designed to allow children with disabilities to play with their peers but the playground wasn’t getting much use,” said Harris. “What we quickly realized was that we needed to add programming elements to effect change. We wanted to build inclusive playgrounds, not just accessible playgrounds.”

Over the years, the organization has created a powerful education program, which has been in over 150 schools and reached 38,000 students, and My Play Club, a free monthly program hosted by volunteers for families and children of all abilities to come together to socialize and play. They are replicating these programs now globally.

“The core of what we are doing is to create social interaction. Everyone is a child first, we are all just differently abled,” said Harris. “Our playgrounds are designed to be equally challenging for typically developing children and those



with special needs. We create a stimulating, engaging and safe place for kids of all abilities to interact.”

Shane’s Inspiration has received a number of Reeve Foundation Quality of Life Grants over the years to help support several of its programs. The most recent grants help support Together We Are Able, a social inclusion education program for grade-school students. The program includes an awareness workshop to dispel misperceptions about disabilities and an interactive field trip that pairs students with and without disabilities.

“The feedback from our education programs goes right back into the playground design so the process is full circle,” said Harris. “The parlay effect of the Reeve Foundation’s investment is profound and we are profoundly grateful.”



## NEURORECOVERY NETWORK (NRN)

### *Eden Hoelscher Louisville, Kentucky*

One-of-a-kind. That's how Kylee Hoelscher describes her daughter, Eden.

"She's a total goofball," says Hoelscher. "Rarely upset and always positive."

These are especially impressive attributes given Eden's difficult journey over the past year and a half. In December 2015, Eden sustained a spinal cord injury at the T8/T9 level from doing a backbend in her living room.

"She was in the ICU for five days, then inpatient rehab for six weeks," says Hoelscher. "But when she was discharged, we didn't know where to go."

At the end of March 2016, the family learned about the Frazier Rehab Institute, part of the Christopher & Dana Reeve Foundation's NeuroRecovery Network® (NRN) located in Louisville, KY, which recently expanded to include pediatric participants. Eden was accepted into the program in April 2016.

"Eden started to show significant improvement within the first twenty sessions of the program at Frazier," says Hoelscher. "Locomotor Training has begun to retrain her spinal cord to be active again. With the support of her therapists, she has taken her first steps. No one was giving us this kind of hope back home, so we decided to sell our house in California and move to Kentucky full time."

Since starting the NRN program, Eden has gained enough core strength to lean forward and back without falling. She has also started to recover some sensory function below the injury. She can now feel when she has a stomach ache and her body has begun to perspire. She even dropped two prescriptions and is down to taking just one daily medication.

"She has made significant, significant improvements in just the eight months here," says Hoelscher. "Before, she couldn't sit and remain steady if she lifted her hands off the ground. Now she can move herself around, transfer to and from the couch, dress herself, bathe herself, brush her own teeth and hair, and even tie her shoes. Her improved abdominal strength means she can now pass



bowel movements which is a huge weight off our shoulders because it helps to avoid other complications."

But perhaps best of all for the Hoelscher family is that Eden has been able to get back to life as a young girl. She goes to Frazier five mornings a week and attends school in the afternoon.

"She missed the social interaction. Her biggest goal now is to learn to transfer from the wheelchair to the school chair," says Hoelscher. "She also enjoys yoga and art, and she started taking tennis lessons with a friend. She also wants to join the

tennis team and the school choir."

On a recent family trip to Great Wolf Lodge, Eden was able to go down the waterslides by herself because of her improved core strength. She can also use her arms and core to pump on a swing, and she is starting to gain the ability to push the pedal on a bike.

"People don't realize how much we use our core on a daily basis and how

much else is taken away when we lose that ability,” says Hoelscher. “When we were in the hospital, everyone treated her so cautiously; they never saw the potential and hope for recovery. Frazier never gave us promises, but gave us hope that she would recover. The NRN literally changes people’s lives.”

In addition to her daughter’s improvements, Hoelscher has also benefited from the comradery the NRN offers.

“I’ve met many new friends through the NRN program,” says Hoelscher. “Knowing other parents with a child in this scary, awful situation helps a lot. Also, when asked, Eden says her physical therapist, MacKenzie, is her best friend.”

Moving forward, the family’s primary goal is to keep Eden healthy.

“The NRN has done a great job of helping us avoid other issues like worsening her slight scoliosis. Eden needs to be on her feet and bearing weight to eventually hold up an adult body,” says Hoelscher. “We want her to be comfortable in her own body, not nervous about injuring herself. Everything we do is to keep her body healthy as she grows to be an adult.”

Meanwhile, Eden is using her one-of-kind spirit to be an incredible advocate and ambassador for the paralysis community.

“Eden’s wonderful attitude and disposition make her very approachable and she is teaching others that someone in a wheelchair is not to be avoided,” says Hoelscher. “She wants to play and have fun just like everybody else. And now, thanks to the NRN, she can.”



SUZY KIM BY CHRISTOPHER VOELKER

# 3

## ACUTE CARE & REHAB

The best way to deal with the confusion and helplessness of a spinal cord injury is to be armed with reliable information. Start here.



Learning that a family member or friend has had a spinal cord injury is devastating and overwhelming news. The best way to combat your feelings of helplessness and confusion is to arm yourself with information on what a spinal cord injury is, and what it means in terms of short-term planning and long-range goals. This section of the book helps those who are beginning to locate spinal cord injury information for a loved one or friend who has been recently injured.

### ACUTE CARE AND ON TO REHAB

Navigating the world of neurotrauma can certainly be confusing. The Information Specialists at the Paralysis Resource Center specialize in answering questions about new injuries. You can speak to a member of the Information Specialist team at 1-800-539-7309, or make an appointment for a preselected time. If you have not done so already, please visit the PRC website at [www.ChristopherReeve.org](http://www.ChristopherReeve.org) for a wealth of information for the newly injured as well as for those living with SCI for years. You will find numerous links to other organizations as well as information specific to advances in SCI research. You don't have to go this alone: Join the online Paralysis Community to connect with and gain support from others whose circumstances are similar to yours. Reeve Connect: [www.ChristopherReeve.org/community](http://www.ChristopherReeve.org/community)

The following section concerns issues common to acute SCI. Since each injury is different as to its level and severity, the information is provided in general terms.

#### Acute Management

The first few hours are critical after a spinal cord injury, as life-saving interventions and efforts to limit the severity of the injury take precedence. Fewer people are coming away from accidents with complete paralysis. A generation ago, the number of spinal cord injured people considered neurologically incomplete was 38 percent; it's now well over half, an improvement attributed to more careful management of medical emergencies at the scene. Ideally, a spinally injured person should be transported to a





Level I trauma center for multidisciplinary expertise. If cervical spine injury is suspected, the head and neck are immediately stabilized. The spine should never be allowed to bend. Since SCI rarely occurs without other complications, acute management must address possible brain injury (especially for upper cervical injuries), fractures, lacerations, contusions, etc.

Beginning in 1990, most people with SCI in the United States were given large doses of the steroid

drug methylprednisolone; it was thought to preserve spinal cord tissue vulnerable to the “cascade” of biochemical responses secondary to the initial trauma. According to the National Institute of Neurological Disorders and Stroke, the steroid drug methylprednisolone appears to reduce the damage to the nerve cells if it is given within the first eight hours after injury. Cooling of the spinal cord has been tested in clinical trials and appears promising, but protocols for temperature, duration, etc. have not been determined. Other acute SCI therapies are under investigation, including Riluzole (see North American Clinical Trials Network, pages 62-63).

Once a person reaches the acute hospital, several basic life-support procedures may occur. Respiratory issues must immediately be addressed. Tracheostomy or endotracheal intubation is often done even before location of injury is established. Bladder management is begun, typically with an indwelling catheter. Commonly, SCI patients undergo MRI.

Early surgery (within hours of injury) to decompress or align the spinal canal is often done. Evidence from animal studies supports this as a means to improve neurologic recovery but the timing of this intervention is subject to debate; some surgeons wait several days to allow swelling to subside before

## WHAT IS A SPINAL CORD INJURY?

*Spinal cord injuries commonly lead to paralysis; they involve damage to the nerves within the bony protection of the spinal canal. The most common cause of spinal cord dysfunction is trauma (including motor vehicle accidents, falls, shallow diving, acts of violence, and sports injuries). Damage can also occur from various diseases acquired at birth or later in life, from tumors, electric shock, and loss of oxygen related to surgical or underwater mishaps. The spinal cord does not have to be severed in order for a loss of function to occur. The spinal cord can be bruised, stretched, or crushed. Since the spinal cord coordinates body movement and sensation, an injured spinal cord loses the ability to send and receive messages from the brain to the body's system that controls sensory, motor, and autonomic function.*

decompressing the cord.

For cervical fractures, the spine is often stabilized by a bone fusion, using grafts from the fibula (calf bone), tibia (shin bone) or iliac crest (hip). To stabilize spinal bones, a spinal fusion might be done, using metal plates, screws, wires and/or rods and sometimes small pieces of bone from other areas of the body.

A spinal cord injured patient will typically encounter several external devices including braces, traction pulleys, skull tongs, turning frames, molded plastic jackets, collars and corsets. Bracing devices are often used early on; they allow vertebral bones to heal but allow patients to be up and around, protecting them from the effects of bed rest. A halo brace is a stainless steel hoop placed around the patient's head and secured to the skull by four stainless steel pins. It can be applied in the emergency room. The brace is secured to upright pieces extending up from a pelvic girdle.

Classifying the Injury: Once physicians determine the level and extent of the injury, the patient will also undergo a thorough neurological examination. This looks for signs of sensation, muscle tone and reflexes of all limbs and the trunk. The classification of injury may differ from what is seen on the x-rays or scans because it is based on function, reflected by what is called the ASIA scale. This is a tool that assigns the spinal cord injury patient into a category: ASIA A (no motor control, no sensation); B (no motor, some sensation); C (some motor function), D (motor function incomplete with more function below lesion area); or E (normal). During an ASIA classification examination the physician looks at



### **OUTCOMES THAT OFTEN OCCUR**

*By level of injury, here are summaries of outcome expectations (remember, these are averages, not hard, cold facts): the level of injury and function may change.*

**Level C1-3:** Total paralysis of the trunk and all extremities. These folks are most likely to be ventilator dependent and typically need 24-hour attendant care with total assistance with bowel and bladder management, bed mobility, transfers, eating, dressing, grooming, bathing and transportation. They can power an electric wheelchair and can be independent communicators with the right equipment; they need to be able to explain everything an assistant needs to know about their care.

**Level C4:** Total paralysis but some respiratory reserve possible. May be able to breathe without a ventilator, otherwise, similar profile as the C1-3 group: total assistance needed for all tasks except power wheelchair use. Some neck and shoulder movement.

**Level C5:** Possible shoulder flexion, elbow flexion, weak hands and wrists. Low respiratory endurance; may need help clearing secretions. These people can eat independently if meals are set up for them but still need some assistance for grooming, bed transfers and dressing. Personal care assistance needed daily. Some people with a C5 injury can drive a vehicle with the right specialized equipment and training.

**Level C6:** Total paralysis of trunk and legs but more independent. Some help may be needed for bowel care, uneven transfers, and bathing. No wrist flexion or hand movement but can push a manual chair and do weight shifts. Personal care needed but on a limited basis; getting up in the morning, grooming, going to bed. Driving is very doable.

**Level C7/8:** Paralysis of trunk and legs but with greater arm and hand dexterity, including elbow, wrist and thumb extension. Still some limits to respiratory endurance and reduced vital capacity. Mostly independent for bladder and bowel self-care, eating, grooming, etc. Personal care attendant may be needed on limited basis.

**Level T1-9:** Lower trunk paralysis but full arm and hand function. Some compromised vital capacity but independent for almost all functional self-care activities. Minimal assistance needed for daily living, work and homemaking.

**Level T10-L1:** Paralysis of legs but good trunk stability; intact respiratory system. Independent in functional activities. Minimal help needed in the home.

**Level L2-S5:** Partial paralysis of legs, hips, knees, ankles and feet, good trunk support. Independent for all functions of wheelchair life. No assistance in the home.

Get a copy of Expected Outcomes, What You Should Know, (choose the one for your level of injury). Free download from [www.pva.org](http://www.pva.org).

a variety of determinants such as muscle movement and range of motion, and notes whether or not the person can feel light touch or sharp and dull sensations.

The location and severity of the spinal cord injury determines what parts of the body are affected. The doctor will also determine if the injury is complete or incomplete. An incomplete injury means that the ability of the spinal cord to convey messages to or from the brain is not completely lost. A complete injury is indicated by a total lack of sensory and motor function below the level of injury. But the absence of motor and sensory function below the injury site does not necessarily mean that there are no remaining intact axons or nerves crossing the injury site; just that they do not function appropriately following the injury.

Extra care must be given to protecting the skin; as many as half of new SCI patients get some degree of pressure ulcer in the first month post-injury. Pressure relief is needed at least every 30 minutes.

The first days after a SCI are also the most crucial to begin formal rehabilitation. It is essential to optimal recovery to initiate rehab interventions immediately after injury to prevent secondary complications, including thromboembolism, skin breakdown, and respiratory issues. Bowel and bladder care must also be managed.

It is also important to immediately begin addressing psychosocial issues related to SCI, paying attention to family issues, depression, social supports, coping strategies and suicidal ideation. This is also the key time to discuss assistive devices and information services, insurance issues, Internet resources, etc.

Depending on other medical issues related to the injury, most people leave the acute hospital within days and enter into rehabilitation.

See “Early Acute Management in Adults with Spinal Cord Injury,” a guide from the Consortium for Spinal Cord Medicine. This publication, along with eleven Clinical Practice Guidelines, can be downloaded at no cost; go to [www.pva.org](http://www.pva.org).

### **CHOOSING A REHABILITATION SETTING**

**How can you predict the quality of care** you or a loved one will receive when entering a rehabilitation program? How do you know what facility to choose? Is there really a choice? Does rehab really matter?

Most people have no experience with rehab or the effects of paralysis, so assessing the quality of a rehab program can be stressful and complex. The final choice may come down to which program is covered by insurance or by which one is closest to the support systems of one’s family and community, but it is possible to make an informed decision. Rehabilitation centers are not

### **I HAVE NO HEALTH INSURANCE**

*Being uninsured or underinsured does not mean there are no avenues to get health coverage. Hospitals that accept federal money must provide a certain amount of free or reduced-fee care. Check with the hospital's financial aid department to see if you qualify for reduced cost or charity care. To start the process, meet with a caseworker at the hospital to gather relevant paperwork and begin applying for Medicare/Medicaid and Social Security. Not everyone will qualify for Medicaid, a state-administered program established to provide healthcare to low-income individuals and families. Applications and rules vary from state to state, so contact your local Medicaid office directly or work with the hospital caseworker. Be aware of any deadlines or required documentation. Contact relevant benefit offices to set up any appointments or interviews needed to expedite the process; confirm the documentation needed. Be sure to keep accurate and thorough records of everyone you are in contact with. If you are doubtful of your eligibility, it is best to apply and have a caseworker or lawyer review your application. Caseworkers or social workers are sometimes assigned by your hospital (though you may have to ask for one). They are there to assist you in managing your family member's care.*

**Medicaid** is an assistance program. Medical bills are paid from federal, state and local tax funds. It serves low-income people under the age of 65. Patients usually pay no costs for covered medical expenses, although a small co-payment may be required. For more, call the Centers for Medicare and Medicaid Services (CMS), 1-877-267-2323.

**Medicare** is an insurance program. Medical bills are paid from trust funds into which those people covered have paid. It mainly serves people 65 and over, whatever their income, and serves younger disabled people after they have received disability benefits from Social Security for 24 months. Patients pay part of costs through deductibles for hospital and other costs. Small monthly premiums are required for non-hospital coverage. Medicare is a federal program. For more information on Medicare call 1-800-MEDICARE.

**Children:** If the patient is under 18 year of age, look into your state's health insurance program for children (SCHIP). SCHIPs provide low-cost insurance coverage to families and children. Eligibility is determined by each state and is income- and disability-based. Each state's SCHIP program may have a different name. It is important to note that your child may qualify for SCHIP coverage even if denied Medicaid. Children may also be eligible for some disability benefits from Supplemental Security Income.

To help you navigate the Medicaid/Medicare process or SCHIP program: Center for Medicare and Medicaid Service: [www.cms.gov](http://www.cms.gov) or [www.medicaid.gov](http://www.medicaid.gov)

all the same; they can be compared.

At the top of the list of qualifying factors is experience in rehabilitation for your specific needs. Medical rehab is increasingly specialized; the more patients a facility regularly treats with needs similar to yours, the higher the expertise of the staff. How do you know what a facility is best at? Ask the facility how many beds are dedicated to your rehab situation. For example, if 85 percent of a unit's beds are dedicated to stroke survivors, this may not be the ideal place for a young person with a spinal cord injury. Get a sense of the facility's reputation and standing. Ask around; connect to others by way of support groups (e.g., Reeve Connect, American Stroke Association, National Multiple Sclerosis Society; turn to page 375 for a list of online communities).

High-quality programs are often located in facilities devoted exclusively to providing rehabilitation services or in hospitals with designated units.

#### **Here are a few questions to consider in choosing a facility:**

- ***Is the place accredited, that is, does it meet the professional standards of care for your specific needs?*** Generally speaking, a facility with accredited expertise is preferable to a general rehabilitation program. For example, recognition by the Commission on Accreditation of Rehabilitation Facilities (CARF) for spinal cord injury indicates that the facility meets a minimum standard level of care, has a wide range of specialized services and is well connected in the local community. CARF also accredits programs in assisted living, mental health and substance abuse, brain injury, and pediatric rehab.

For those with a spinal cord or brain injury, there are groups of specialized hospitals called Model Systems Centers. These are well-established facilities that have qualified for special federal grants to demonstrate and share medical expertise (see pages 12 and 54-55).

- ***Does the place offer a wide variety of specialized personnel who offer therapies with a coordinated team approach?*** Rehab teams should include doctors and nurses, social workers, occupational and physical therapists, recreational therapists, rehabilitation nurses, rehabilitation psychologists, speech pathologists, vocational counselors, nutritionists, respiratory experts, sexuality counselors, rehab engineering experts, case managers, etc.

- ***Does the facility offer connections to peer support and contact with others with a similar disability?*** Peer support is often the most reliable and encouraging source of information as people make their way in the new world of rehab and recovery.

*You might also ask these types of questions: What have been the results for people like me who have used your services? How will services be individualized? How much can my family participate in the program? Are you close to public transportation? Are there bilingual staff or sign language interpreters?* The ultimate measure of good rehab is the breadth and quality of the professional staff on hand. The professions you can expect to find represented on a rehabilitation team are as follows:

### Physiatrist

A physiatrist (pronounced fizz-ee-AT-trist, or more commonly, fizz-EYE-a-trist) is a doctor with a specialty in physical medicine and rehabilitation. Physiatrists treat a wide range of problems from sore shoulders to acute and chronic pain and musculoskeletal disorders. Physiatrists coordinate the long-term rehabilitation process for people with paralysis, including those with spinal cord injuries, cancer, stroke or other neurological disorders, brain injuries, amputations and multiple sclerosis. A physiatrist must complete four years of graduate medical education and four years of postdoctoral residency training. Residency includes one year spent developing fundamental clinical skills and three years of training in the full scope of the specialty.

### Rehab Nurse

Rehab nurses begin to work with individuals and their families soon after the onset of injury or illness. They have special training in rehabilitation and understand the full range of medical complications related to bladder and bowel, nutrition, pain, skin integrity and more, including vocational, educational, environmental and spiritual needs. Rehab nurses provide comfort, therapy and education and promote wellness and independence. The goal of rehabilitation nursing is to assist individuals with disabilities and chronic illness in the restoration and maintenance of optimal health. Nurses are the hands-on people who carry out the directives of the medical team.

### Occupational Therapist

Occupational therapists (OTs) are skilled professionals who have studied the social, emotional and physiological effects of illness and injury. An OT helps individuals learn—or relearn—the day-to-day activities they need for maximum independence. OTs offer treatment programs to help with bathing, dressing, preparing a meal, house cleaning, engaging in arts and crafts or gardening. They recommend and train people in the use of adaptive equipment to replace lost function. OTs also evaluate home and job environments and recommend

### **MONEY FOR REHAB**

***How can I locate funding for rehabilitation and equipment?** Depending upon the cause and the nature of the injury, you should seek out various insurance policies that may cover medical emergencies (homeowners, auto, and worker's compensation) in addition to your health insurance. If you still need assistance, there are some non-profit organizations that provide grants for individuals. However, funding levels and guidelines vary from organization to organization. Please call the Reeve Foundation at 1-800-539-7309 for more information on organizations that provide grants to individuals as well as those that provide wheelchairs and other equipment. Fundraising is another option to consider. An organization called Help Hope Live assists individuals with raising funds from their communities and social networks for uninsured expenses related to catastrophic injury. Donors receive tax deductions and recipients protect their ability to receive income-dependent benefits. Help Hope Live: Toll-free 1-800-642-8399; [www.helphopelive.org](http://www.helphopelive.org)*

adaptations. The occupational therapist guides family members and caregivers in safe and effective methods of home care; they will also facilitate contact with the community outside of the hospital.

### Physical Therapist

Physical therapists (PTs) treat people with motor and/or sensory impairments, helping to increase strength and endurance, improve coordination, reduce spasticity and pain, maintain muscles, protect skin from pressure sores, and gain greater control of bladder and bowel function. PTs also treat joints and help expand their range of motion. PTs use a variety of equipment including weights, pools and bikes (including the functional electrical stimulation types). When pain is an issue, physical therapy is often the first line of defense; therapists use a variety of methods including electrical stimulation and exercise to improve muscle tone and reduce contractures, spasticity and pain.

PTs will also demonstrate techniques for using assistive devices such as wheelchairs, canes or braces. Physical therapy is not a passive activity that is “done” to you; a PT program requires active participation from both practitioner and patient—it’s hard work to restore body function lost to injury or disease. Once a maintenance program has been developed by a physical therapist, it is the client’s responsibility to follow it at home.

### Recreation Therapist

Recreation therapists help people discover the wide range of options for

### **STAYING IN TOUCH**

*Staying in touch with loved ones and friends while also managing a healthcare challenge can be difficult. But staying connected is a crucial component to getting and staying well—for both patients and caregivers. One very good way to stay connected with family, friends and colleagues before, during and after hospitalization and rehabilitation is by way of a private, personalized website such as Caring Bridge or Lotsa Helping Hands. These free websites allow you to post entries on the condition and care of your loved one in the care of a hospital or rehabilitation center. You can also receive messages of encouragement to help sustain you during this difficult transition in your life. [www.caringbridge.org](http://www.caringbridge.org), [www.lotsahelpinghands.com](http://www.lotsahelpinghands.com).*

active living in their community. It has been well established that exercise, fitness and relaxation reduce stress and contribute to improved cardiovascular and respiratory function, and increased strength, endurance and coordination. Activity clearly reduces secondary medical complications related to paralysis. Skin sores and urinary tract infections, for example, are significantly reduced in wheelchair athletes, as compared to non-athletes. Rec therapists push physical activity for social as well as medical reasons. Active involvement in recreation leads to improved life satisfaction, better social relationships and lower levels of depression.

### **Vocational Counselor**

Vocational counselors perform many of the same functions that career counselors do—they assess a client’s job skills and help with a smooth reentry into the workforce or school. Then they work with various government agencies to obtain equipment, training and placement. Vocational therapists also educate disabled individuals about their rights and protections under the Americans with Disabilities Act, which requires employers to make “reasonable accommodations” for disabled employees. Vocational therapists may mediate between employers and employees to negotiate reasonable accommodations.

### **Speech-Language Pathologist**

Speech-language pathologists help people with aphasia or other communication problems relearn language or develop alternative means of communication. They also help people improve their ability to swallow. Sometimes, changing body position and posture while eating can bring about improvement. The texture of foods can be modified to make swallowing easier.

Speech-language pathologists help people with paralysis develop strategies for language disabilities, including the use of symbol boards or sign language. They also share their knowledge of computer technology and other types of equipment to enhance communication.

### **Neurologist**

A neurologist is a doctor who specializes in the diagnosis and treatment of disorders of the nervous system (brain, spinal cord, nerves and muscles). A neurologist makes an initial evaluation, diagnoses the injury and consults on one’s immediate care.

### **Rehabilitation Psychologist**

A rehab psychologist helps people deal with life-changing injury or disease, offering tools to cope with the effects of disability. A psychologist offers support for families as well. Therapy might be offered individually or in a group to speed the adjustment to changes in physical, cognitive and emotional functioning. The psychology team also offers marital and family therapy and sexual or family planning counseling. Biofeedback and relaxation techniques may be included.

### **Case Manager**

A case manager oversees many aspects of rehab, including preparing a discharge plan and working with insurance companies to communicate the rehab team’s goals. A case manager may arrange for purchases of special equipment and/or home modifications.

### **Social Worker**

A rehab social worker connects many aspects of the recovery process, delving into a patient’s personality, lifestyle, emotional behavior, past relationships, education, work history, special interests and financial background in order to help the rehab team create an optimal rehabilitation program within the hospital and back home in the community.

### **SOURCES**

American Occupational Therapy Association, American Physical Therapy Association, American Academy of Physical Medicine and Rehabilitation, Commission on Accreditation of Rehabilitation Facilities, Association of Rehabilitation Nurses, American Therapeutic Recreation Association



## REHABILITATION RESOURCES

**American Academy of Neurology (AAN)** is a medical specialty society established to advance the art and science of neurology and to promote the best possible care for patients with neurological disorders. Toll-free 1-800-879-1960; [www.aan.com](http://www.aan.com)

**American Academy of Physical Medicine and Rehabilitation** is the national medical society for physicians who are specialists in the field of physical medicine and rehabilitation (physiatrists). The website includes a physician directory. 847-737-6000; [www.aapmr.org](http://www.aapmr.org)

**American Congress of Rehabilitation Medicine** serves people with disabling conditions by promoting rehabilitation research and the transfer of technology. 703-435-5335; [www.acrm.org](http://www.acrm.org)

**American Occupational Therapy Association (AOTA)** is a professional society that advances the field of occupational therapy through standard setting, advocacy, education and research. 301-652-6611; [www.aota.org](http://www.aota.org)

**American Physical Therapy Association** is the main membership organization for the PT profession, furthering the prevention, diagnosis and treatment of movement dysfunction. Toll-free 1-800-999-2782; [www.apta.org](http://www.apta.org)

**American Speech-Language-Hearing Association (ASHA)** is the professional association for audiologists, speech-language pathologists, and speech, language and hearing scientists. Toll-free 1-800-638-8255; [www.asha.org](http://www.asha.org)

**American Therapeutic Recreation Association (ATRA)** represents the interests of recreational therapists and promotes recreation as a means of improving health and well-being. 703-234-4140; [www.atra-online.com](http://www.atra-online.com)

**Association of Rehabilitation Nurses** promotes and accredits rehab nurses and sets forth the philosophy of care of the nursing professional. Toll-free 1-800-229-7530; [www.rehabnurse.org](http://www.rehabnurse.org)

**Christopher & Dana Reeve Foundation** and the **Shepherd Center** produced “*Restoring Hope: Preparing for Rehabilitation After Spinal Cord Injury*,” a booklet designed to prepare families for the initial urgent care of spinal cord injuries and guide them through the transition to rehabilitation centers. Call the Reeve Foundation at 800-539-7309 for a free copy.

**Commission on Accreditation of Rehabilitation Facilities (CARF)** is an independent, nonprofit accrediting body that establishes rigorous standards to



*Christopher Reeve and his rehab entourage, getting therapy in the pool.*

assure the quality, value and outcome of rehab services. Toll-free 1-888-281-6531; [www.carf.org](http://www.carf.org)

**National Center for Medical Rehabilitation Research (NCMRR)**, a component of the National Institute of Child Health and Human Development (NICHD), supports research on enhancing the functioning of people with disabilities in daily life. [www.nichd.nih.gov/about/org/ncmrr](http://www.nichd.nih.gov/about/org/ncmrr)

**National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR)** supports research aimed at improving the lives of individuals with disabilities from birth through adulthood. 202-795-7398; <https://acl.gov/about-acl/about-national-institute-disability-independent-living-and-rehabilitation-research>

**Spinal Cord Injury Model Systems and Traumatic Brain Injury Model Systems** are federally funded medical and/or rehabilitation centers across the United States. These centers research best practices for SCI and TBI. For a list see [www.msctc.org](http://www.msctc.org)

# 4

## ACTIVE LIVING

Challenge the world, explore the boundaries, escape the ordinary, take risks. Most of all—have fun, stay fit, with friends and family.



*Christiaan Bailey drops in.*

**Recreation. What a relief to get away from our day-to-day routines, to recreate mind and body with fun activities, sports and games with friends and family, or in solitude. Paralysis is a ready excuse to stay indoors and inactive. But the benefits of escaping the ordinary, of being challenged, of exploring the boundaries of limitation, and sharing this with people you like to be with is all very fulfilling and meaningful.**

The physical benefits of active living promote health and wellness, reduce stress and help us think more creatively. The social and psychological reasons add balance to life with disability. We need to do things that focus on activity and not limits. Recreation and adventure enable people to explore themselves, to take risks, to get the blood going, to gain a fresh perspective.

We're here to discuss fun, though, not therapy. Many recreational activities, sports and competitions are inclusive and accessible. Here's the real bottom line: no matter your level of function or your physical limitations, if you want to try something—anything—there's almost always a way to do it. Jump out of an airplane ... hooked up to a ventilator? Been done. Climb the rock face of El Capitan in Yosemite, with just arm power? Done. Bag an elk with a large caliber rifle, by a high quad sitting in a wheelchair? Sure, if that fits your notion of recreation. Surf the waves off Malibu, with no hand or leg power? Of course. Bungee jumping, swimming the English Channel, riding the rapids in the Grand Canyon, skiing the black diamonds in Vail, sailing or flying solo around the world—all have been done by people living with paralysis.

The point isn't to raise the recreation bar to the level of the extreme achiever. Recreation doesn't have to be measured or scored, or even noticed by anyone but the participants. There is recreation for everyone. Find your own rec groove. Below is a list of some popular individual activities that for the most part can be shared with family and friends (see also team sports listed on page 221). Some require adaptive gear, such as cycles, skis and clubs. Some require a bit of fitness going in. All require a spirit of fun and a readiness to recreate.



## RECREATION SPORTS

### Billiards

This is a great game for wheelchair users. The rules and regulations are basically the same as in the stand-up game; individuals with upper body limitations must stay seated (one bun on the chair at all times) during play and are allowed to use adaptive devices for shooting control. Modified pool cues or a roller attachment at the end of a cue stick allow players with limited hand use to enjoy the sport and be competitive with the best players. Some wheelchair players compete quite well against nondisabled players. Contact the National Wheelchair Pool Players Association; [www.nwpainc.org](http://www.nwpainc.org)



Rozanna Quintana

### Bowling

Wheelchair bowling, like basketball, emerged as part of social and physical rehab programs for disabled World War II vets. The sport is easy to learn and does not require enormous strength. It is played just as the stand-up version, with the exception of special push tools and ball-drop ramps for bowlers with limited arm mobility. Special snap handle balls are available for those who can't get a good grip on the ball. Can you do well against nondisabled bowlers? Ask George Holscher, a para from Virginia Beach, or Shawn Beam from Fort Worth. They both rolled perfect 300s in 2012. To find out about leagues and adaptive gear, contact the American Wheelchair Bowling Association: 713-444-7588; [www.awba.org](http://www.awba.org)

### Camping

Some people's idea of roughing it is being far enough from home that WiFi will no longer work. While "rough" is a relative term, there is more to camping than getting out of the city service area. It's a way to be close to nature, to simplify, to cut the electronic umbilical cords and conveniences we take for granted. Getting away might mean car or motorhome camping within a designated site. It might mean getting off the beaten path and deep into the woods. Wheeling into the wilderness isn't easy for people who are paralyzed, but it's not impossible with a bit of preparation and determination.

### CHAIR BOWLER'S PERFECT GAME

*"I know I said I can't feel my knees, but let me tell you, they were weak." So says George Holscher as he rolled the last ball in the 10th frame for the first 300 of his bowling career.*

*For George and his team, it was just another Monday night of bowling league, November 26, 2012, at Indian River Lanes in Virginia Beach, VA. Little did he know how special this night was going to be for him and all those who watched as the 12th ball rolled down the lanes and George rolled into wheelchair bowling history. He became only the second person in the American Wheelchair Bowling Association's 50+ year history to throw a perfect game. Shawn Beam of Fort Worth, TX was the first in May of 2012.*



George Holscher

*"When you're on a streak like that, the whole house gets quiet," Holscher says. "Everyone else stops bowling. It gets tense." With a deep breath to steady his nerves, he let the last throw leave his fingers. "The 60 feet to the pins seemed like 60 miles. Everyone just went crazy. It was amazing."*

Where to go? State and national parks are a good place to start. As mandated by the Americans with Disabilities Act, these parks have accessible accommodations, bathrooms and level ground—usually. Progress toward accessibility continues but you can find many camp areas that are already inclusive. Be prepared and be creative. To get started, check with your state's outdoor recreation or state parks agency. You may need to make reservations.

What to bring? There may be no way to avoid the necessities of mobility, medications and hygiene. But go lightly—you don't need the handheld satellite TV or the Swiss Army microwave. Remember, the idea is to escape the mundane and the routine.

Resources: U.S. National Parks are visited by more than 275 million visitors

every year and they include 43,162 miles of shoreline. [www.nps.gov](http://www.nps.gov). Residents of the United States with disabilities can obtain a free Access Pass, a lifetime entrance pass to over 2,000 national parks, monuments, historic sites, recreation areas and wildlife refuges. The Pass also provides a 50 percent discount on fees for camping, swimming, parking, boat launching and tours. <https://store.usgs.gov/access-pass>

## Flying

By its very nature, flight is restrictive—by gravity, of course, and by licensing agencies and cost, but not necessarily by paralysis. If a person has normal health and has either quick reflexes or a suitable alternative control, most likely he or she can fly. Flying does not require great strength although good headwork is a must. Hundreds of paraplegics, quadriplegics and amputees have successfully flown over the years, even as commercial pilots, having proven their abilities to the FAA and other licensing authorities throughout the world.

**Able Flight** is a non-profit organization which offers flight and aviation career training to people with disabilities. They train people to become pilots and offer various types of scholarships. Able Flight: 919-942-4699; [www.ableflight.org](http://www.ableflight.org)

**Freedom's Wings International**, a New Jersey organization, has a fleet of adapted motorless sailplanes. Gliders are towed into the sky by a regular airplane and then released for a quiet ride back to the airport. When conditions permit, sailplane pilots ride the natural thermal currents to stay aloft for hours. People with disabilities can come along either as passengers or by joining the flight training program. FWI: 848-227-1957; [www.freedomswings.org](http://www.freedomswings.org)

## Gardening

Digging in the dirt, planting seeds and growing flowers or food is pleasurable and rewarding. Gardening provides exercise and mental stimulation. Many people claim it's also therapeutic—there's an organization called the American Horticultural Therapy Association (see <http://ahta.org>) that promotes physical and mental health through gardens and plants. Gardening can relieve tension. With its clear cause-and-effect nature, it can foster a sense of expectation, accomplishment, self-reliance and responsibility. Moreover, with some adaptations (raised beds and special tools, for example), gardening can be barrier-free and fully inclusive.

## Golf

Such a simple game. Maddeningly simple. Simply maddening. Hit the ball down the grassy fairway, get it on the green, and sink it in the hole. Easier to say than do, but that's part of the fun of it. The game is quite adaptable to the seated player. Custom clubs and special carts, some with single-passenger swivel seats and tires that won't damage the greens, open the game to players who have limited leg function.



Tim Gilmer tees off

Golf is growing in popularity among players with disabilities, not only because of equipment innovation but also because of the changes in law. The Americans with Disabilities Act requires all public accommodations, including golf courses, to provide goods and services to people with disabilities on an equal basis with the rest of the general public. Public entities, such as states and local governments,

must make golf courses and other facilities accessible to people with disabilities and all new golf course facilities must be accessible. The ADA also requires removal of architectural barriers in existing facilities when “readily achievable” or when it can be done without much difficulty or expense for that facility. Before you show up at a golf club expecting an equal basis experience, check ahead. You may need to work with the management and perhaps enlist the help of organizations such as the United States Golf Association, 908-234-2300; [www.usga.org](http://www.usga.org); or American Disabled Golfers Association, 772-888-7483; [www.usgtf.com/teaching-the-paraplegic](http://www.usgtf.com/teaching-the-paraplegic)

## Hand Cycling

Hand cycling really took off once the technology came of age with sophisticated three-wheel, multi-gear cycles. Hand cranking has become quite popular across the country and abroad, and for good reason. It's fun, fast and family-oriented. It's great for fitness, too. A rider can move the three-wheelers along at a steady 20 mph pace, enough to keep up with nondisabled bike riders. Many riders have hand-powered through the thin air of Colorado's



SAM MADDOX



Sarah Cantor handcycling in San Diego

highest mountain passes, or even around the world. Hand cycling has emerged as an elite competitive sport too; it's included in the Paralympics. The handcycle is used in triathlons for the cycling portion of the competition and in cycling events like century rides. There are several variations on the hand-power theme: some cycles clamp on to a standard manual wheelchair, with a chair-driven front wheel to more or less pull the

chair along. Clamp-ons are best for cruising around the neighborhood. Serious road travel or competition requires a trike: they are lighter and deliver more power to the drive wheel, have greater stability at speed, and offer much less wind resistance. The big wheelchair companies Invacare and Sunrise Medical offer handcycle lines. For information about bikes, see [www.bike-on.com](http://www.bike-on.com), [www.varnahandcycles.com](http://www.varnahandcycles.com) or [www.freedomryder.com](http://www.freedomryder.com).

### Hunting

There are very few limits to this sport. If you can exhale a puff, you can fire a gun. Here are some connections to hook up with others who like to shoot.

Buckmasters American Deer Foundation offers a hunt wish-granting service for children and young adults with critical illnesses and severe disabilities. BADF also provides information on adaptive hunting equipment.

[www.buckmasters.com/resources/disabled-hunters/badf-life-hunts](http://www.buckmasters.com/resources/disabled-hunters/badf-life-hunts)

Outdoors Without Limits breaks down barriers and removes stereotypes.

[www.outdoorswithoutlimits.net](http://www.outdoorswithoutlimits.net)

Be Adaptive, manufactures sip'n puff triggers, gun mounts, etc.

[www.beadaptive.com](http://www.beadaptive.com)

### Pinball

The game of pinball has always been out of reach to many players. The machines are usually too high for wheelchair users, and for those with less than normal hand function, there just isn't any way to activate the flippers. However a New Jersey company has made pinball accessible. Ron Kochel and Gene Gulich created a game that a disabled player and nondisabled player



CHRISTOPHER VOELKER

**Ron Scanlon** is a master of Kung Fu San Soo, an ancient fighting art. He teaches others, including people in wheelchairs, to be prepared. When Ron was nine, he was in an auto accident that injured his spinal cord. However, he did not let this stop him from achieving his dreams. "We all suffer from traumas, maybe it's a disability, maybe it's a divorce maybe it's losing a family member, but at some point when you get through the grief you have to wake up and say 'time to get on with my life!'"

can share on equal terms. Using the U Can Do controls, players can become wizards whether they use one hand or two, or one foot or two. Players can use fists, elbows, head switches or even a sip and puff method, moving the steel ball around the game by blowing or sucking air out of a straw. Every independent living center and accessible recreation program should have one. Toll-free 866-822-6362; [www.ucandocentral.com](http://www.ucandocentral.com)



## Racing

Wheelchair racing can take place anywhere there is running, on the track or on the road. The racing wheelchair has three wheels, one small one up front and two larger wheels that the person sits between; it looks like a mini dragster. Almost all running road races from 5K to marathon length have wheelchair divisions. The Summer Paralympics features a wheelchair marathon and numerous track races. Click on U.S. Paralympics at [www.teamusa.org](http://www.teamusa.org)

## Riding

Horseback riding is an exhilarating recreation that's doable for many people who are paralyzed, using padding or specially made saddles and a mounting ramp. While riding can be done simply because it's pleasurable, for some people the activity is therapeutic. The rhythmic motion and warmth of a horse can be helpful; riding can facilitate cognitive as well as sensory and motor development. Moreover, it can help foster a sense of responsibility and self-confidence while reducing spasticity and improving strength, and stimulating good posture, balance and flexibility for more functional independence off the horse. The equestrian event dressage, where horse and rider perform a series of predetermined movements, has been included in the Paralympics since 1996. There are many programs across the US that cater to riders with disabilities. The best source of information is the Professional Association of Therapeutic Horsemanship International, toll free 1-800-369-7433; [www.pathintl.org](http://www.pathintl.org)

## Sailing

Sailing can be a peaceful and relaxing way to explore and enjoy the world of water. The sport also offers great adventure and challenges to instincts we forgot (or never knew we had). It's a lot of fun if you're along for the ride, but it is especially so if you're the skipper, reading the wind, setting the course and piloting the boat. Sailboats can accommodate people with varying degrees of paralysis. There are boats that are quite accessible for the wheelchair sailor (a transfer box helps with the hardest part—getting aboard). In fact, there are boats that can be single-handed by people with no hand function whatsoever. A sip 'n puff control has been adapted to a fleet of boats called Martin 16s. These were originally designed to be quad friendly, with inspiration from Sam Sullivan, a high-quad sailor from British Columbia and former mayor of Vancouver. These boats are affordable, comfortable, safe and accessible to anyone. For more information, visit [www.martin16.com](http://www.martin16.com)

The Sail to Prevail program out of Rhode Island creates opportunities for children and adults with disabilities to overcome adversity through therapeutic sailing. [www.sailtoprevail.org](http://www.sailtoprevail.org) Shake-A-Leg Miami offers sailing programs for people with disabilities. Their children's program "We Can Sail" matches up children with disabilities with high-school aged mentors who are trained and focused to make sure the kids have fun and learn. [www.shakealegmiami.org](http://www.shakealegmiami.org)

For some, the most fulfilling way to enjoy sailing is to see who's got the fastest boat. Sailing is something of an aquatic equalizer—nondisabled sailors have no particular advantage when it comes to boat handling and navigation skill.





SAM MADDOX

There are also many disabled-only races, including the Paralympic Games. For information on racing: The United States Sailing Association, 1-800-877-2451; [www.ussailing.org](http://www.ussailing.org)

There are numerous sailing programs across the country that offer boats and instruction for people with disabilities. Check your local marinas; many programs are listed on the USSA website.

## Scuba

Scuba diving opens a fantastic new world to the gravity-bound. And for those with limitations of mobility, underwater sports offer an exhilarating “aquatic equality” unsurpassed on land. With training and some assistance getting in and out of equipment, even high quads can enjoy scuba diving, and perhaps the clear, 85-degree water of the beautiful reefs of the Caribbean. There are dive programs all over the US that specialize in getting divers with disabilities trained and certified. There are special tour companies that target the wheelchair diver, and there are even resorts in such exotic places as Bonaire in the Caribbean that offer fully “walk ‘n roll” accessible dive vacation packages.

Many divers have been trained by instructors certified by the Handicapped Scuba Association (HSA), a California nonprofit that’s been running scuba and underwater education programs for nearly 30 years. HSA bases diving proficiency on one’s ability to assist another diver in the water. Level A divers are certified to dive with one other person; a Level B diver must dive with two other nondisabled divers. Level C divers require two dive buddies and one must be trained in diver rescue. Says HSA founder Jim Gatacre, “Virtually everyone I’ve ever trained will tell you that their lives have been changed by the diving. Just about anybody can do it; if a person has fair respiratory function, even if he or she can’t move at all, there are ways to teach diving so anyone can have a wonderful diving experience.” HSA International, 949-498-4540; see [www.hsascuba.com](http://www.hsascuba.com). Site includes a list of dive instructors across the United States. The Cody Unser First Step Foundation also supports a robust scuba program. See [www.codysfirststep.org](http://www.codysfirststep.org)



CHRISTOPHER VOELKER

**Cody Unser** was diagnosed with transverse myelitis when she was 12; two years later, after having already started the Cody Unser First Step Foundation, she learned to scuba dive. Says Cody, “You’re free in the water, you’re not dependent on your wheelchair to move you around. With scuba diving, I realized that life does go on and I didn’t have to get swallowed up in what was happening to me.” These days Cody spreads the word on the benefits of diving, with Operation Deep Down, and Cody’s Great Scuba Adventure programs that will offer expense-paid trips to wounded military veterans to get certified in scuba diving.

## JOIN TEAM REEVE

Run or push a marathon, or maybe half of one. Complete a triathlon, bike a trail, swim the tides, host a bake sale, plan a party, or organize any kind of event that interests you—all to benefit Team Reeve and the Reeve Foundation. Turn your passions into a mission to help others. Team Reeve is a charity participant in several major marathons, including the Virgin London Marathon, Bank of America Chicago Marathon, Marine Corps Marathon and the ING New York City Marathon. Team Reeve runners get coaching and personalized training advice, fundraising assistance and, most of all, tremendous satisfaction both for themselves and for helping the Foundation. See [www.ChristopherReeve.org/TeamReeve](http://www.ChristopherReeve.org/TeamReeve)



Hall of fame mono-ski racer Sarah Will in 2002

## Skiing (Alpine)

This is a sport that's been well adapted for people with disabilities, thanks to technology. Depending on one's level of function, there are three ways a person can get from the top of the mountain down the snowy trails to the bottom. At the highest end of the tech scale is the mono-ski, best for those with good upper body strength and trunk balance. The skier sits in a molded shell mounted to a frame

above a single ski with a shock absorber linking the frame to the ski. Two outriggers are used for balance and turning. Mono-skiing closely resembles stand-up skiing—the skier can become highly skilled, carving turns in tight formation and taking on the deep and the steep. Ski all day without anyone's help: the mono-ski self-loads onto the chairlift.

The bi-ski, a bucket seating system similar to the mono ski, sits atop two heavily shaped skis and can be balanced with attached or hand-held outriggers. Bi-skis are used by individuals who have more significant physical limitations and are tethered or skied from behind by an instructor. A definite thrill ride!

The sit-ski, akin to a toboggan, works for people with even more significant limitations. Those with some hand function can steer the sit-ski with short ski poles and by leaning. The sit-ski is tethered to an instructor.



WALLY MARSH

Candace Cable

There are many disabled ski programs across the United States. Among the largest is the National Sports Center for the Disabled, which runs recreation programs year-round, at Winter Park in Colorado. NSCD, 970-726-1518; [www.nscd.org](http://www.nscd.org). Another big Colorado program is the Breckenridge Outdoor Education Center: [www.boec.org](http://www.boec.org). See the National Ability Center, Park City, UT, 435-649-3991; [www.discovernac.org](http://www.discovernac.org). Achieve Tahoe, a full-scale California program can be found at Alpine Meadows: [www.achievetahoe.org](http://www.achievetahoe.org). The Adaptive Sports Foundation at Windham Mountain runs a large program on the East Coast: [www.windhammountain.com/lessons-programs/asf](http://www.windhammountain.com/lessons-programs/asf)

Skiing has a very active competitive and Paralympic side too. Contact [www.paralympic.org/AlpineSkiing](http://www.paralympic.org/AlpineSkiing)

## Skiing (Cross Country)

This manner of sit-skiing imitates the experience of hiking in the wilderness and is a great aerobic and strength workout. Cross country sit-skis have molded or canvas seats mounted on frames that are simple and lightweight, creating more independence. The frames are attached to two cross country skis for snow skiing or a mountain-board for summer trails. The skier propels along the course using cross country ski poles that have straps to support any limited hand function. There are no chair lifts to ride, no tickets to buy, and this sport will really work your muscles, including some you didn't know you had.





CHRISTOPHER VOELKER

**Patrick Ivison** was 14 months old when a car backed over him and injured his spinal cord. Currently, he is a film director and an advocate for active living. He's an avid surfer and inveterate optimist: "It is important to get back out there and live life to the fullest, with or without an injury."



ALEX GENTRY

Pro surfer Christiaan Bailey rides the surf

### Surfing

Well, dude, it's bitchin, that's why. Jesse Billauer, a quad after a surfing accident, started Life Rolls On to raise awareness about quality of life and spinal cord injury. Jesse, of course, got back on his board, riding huge waves on his stomach, with help from some stand-up surfers to get in and out. To share the joy, he started They Will Surf Again, a program that gets people in wheelchairs out riding the waves, on surfboards, at beaches across the United States. LRO also features They Will Skate Again, showing how wheelchair users can have fun at the skatepark. LRO: [www.liferollson.org](http://www.liferollson.org)

### Tennis

Wheelchair tennis is played with the same rules as stand-up tennis, except the wheelchair player is allowed two bounces of the ball. Decent wheelchair players can actively compete against stand-up players, making this one of the best activities to share with friends and family. In wheelchair tennis, the player must master the game as well as the wheelchair. Learning mobility on the court is exciting



and challenging, and it helps build strength and cardiovascular fitness. The competitive side of tennis is robust and international in scope. Tennis is also a Summer Paralympic sport. International Tennis Federation, [www.itftennis.com](http://www.itftennis.com)

### Tennis (Table)

This is not your daddy's ping pong game. This is a fast and fun indoor/outdoor option. For information on competitive action (this is a Summer Paralympic sport), contact USA Table Tennis, [www.teamusa.org/usa-table-tennis.aspx](http://www.teamusa.org/usa-table-tennis.aspx)

### Triathlon

The sport of triathlon is expanding for people with disabilities. Triathlon distances include the shorter course (half mile swim, 12 mile bike, 3.1 mile run), or the longer Ironman course (2.4 mile swim, 112 mile bike, 26.2 mile run). The adaptive division completes the same courses. The 2016 Summer Paralympics debuted the triathlon event with the Olympic distance of swimming, biking and running. Sit-down athletes use a handcycle for the bike and a racing wheelchair for the run portions of the Triathlon. [www.usatriathlon.org](http://www.usatriathlon.org)

### Video games

Modern video games, with various controller options, movement integration, and virtual reality are more immersive and interactive than ever before. This is great for anyone with decent hand function, but can a high quad play? If you can sip and pu, the answer is yes. A company called QuadStick makes various input devices for quadriplegics that are compatible with console and PC games. It takes a bit of practice to become skillful with their accessible devices, but if a gamer is motivated, this popular activity is still wide open to them.

[www.quadstick.com](http://www.quadstick.com)

Many modern games that depend on analog-only control, which is the mushroom thumb stick controls on a regular gamepad, can be problematic for individuals with limited hand function. However, most driving games, sports games, and many other popular titles don't require analog control to be played effectively, or the controls can be modified within a game's options menu.

Organizations such as the Game Accessibility Project have taken up the torch of addressing concerns of disabled gamers about the availability of accessible video games by providing resources for developers, publishers, and researchers with the goal to increase accessibility in games. They also provide news and reviews on the latest accessible games. [www.game-accessibility.com](http://www.game-accessibility.com)

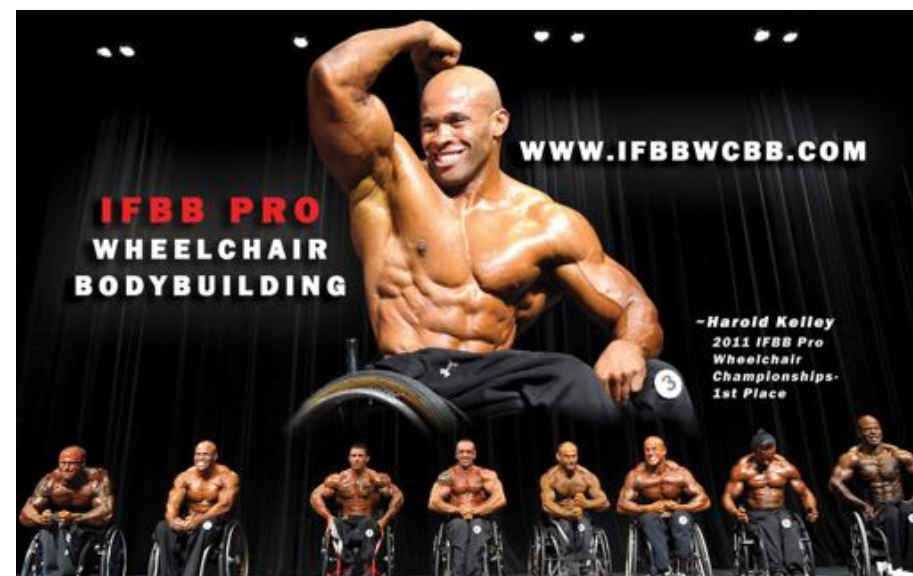
Finally, the Able Gamers Foundation also aims to improve the overall quality of

life for those with disabilities through the power of video games by providing outreach and grants to those living with a disability. [www.ablegamers.com](http://www.ablegamers.com)

### Water Skiing

Water skiing is a terrific heat-beating summer sport that's been adapted so that skiers of almost all abilities can participate with family and friends. If skiers get good at it and have the urge to compete, there are various water ski meets around the United States. The sit-skis are varied in width of 10 to 15 inches, depending on the skier's ability; some skis have outriggers or short ski tips attached to either side of the sit-ski for balance. The towropes have a modified handle so individuals with hand disabilities can hook up to a boat and thrill to the speed and wake-crashing fun of water skiing. Skis are available commercially; many have been added to recreation programs in many communities across the country.

Water ski tournaments for skiers with mobility limitations include slalom, tricks and jumping events. Competition is organized by the Water Skiers with Disabilities Association (WSDA), a division of USA Water Ski, the national governing body for the sport in the United States. WSDA promotes the recreational aspects of the sport with clinics, teaching materials, equipment development and by way of a network of water ski resources. Contact WSDA, 863-324-4341; <http://usawaterski.org>





### Weightlifting

Granted, many don't hear the calling for this strenuous, get-pumped recreation, but it is not hard to adapt lifting weights to people with lost function due to paralysis. The activity has clear benefits for fitness but lifting has also emerged as a very competitive activity at the international level.

Online, check out powerlifting under the Paralympics section at [www.teamusa.org](http://www.teamusa.org)

### Wheelchair Bodybuilding

This sport has come a long way with numerous competitions across the U.S., and internationally, even sporting a professional division. Want to oil up, pump and pose? See Wheelchair Bodybuilding (WCBB) at

[www.wheelchairbodybuilding.com](http://www.wheelchairbodybuilding.com)

## TEAM SPORTS



### Basketball

Basketball is probably the most well-developed sport for wheelchair users in the United States, for good reason. The game has been played for almost 70 years, originated by World War II vets in rehab on the East and West coasts. There are teams and divisions all over the country for men, women and juniors. Some colleges suit up wheelchair hoops teams. The game is fast and fun, and quite entertaining to watch. Contact the National Wheelchair Basketball Association, telephone 719-266-4082; [www.nwba.org](http://www.nwba.org)

### Quad Rugby

Quad rugby, or murderball, is a combination of soccer, keep-away and demolition derby that emerged from the cold northern winters of Winnipeg, Manitoba to become an international sport. Rugby fans say it's the fastest growing wheelchair sport in the world. There are dozens of competitive teams in the United States; each team utilizes four players, mostly quads (players must have all four limbs affected by disability). A player has 15 seconds to



LEON BOSTICK BY CHRISTOPHER VOELKER





advance the ball into the opponent's half-court. The player with the ball must pass or dribble every ten seconds or a turnover is awarded. The idea is to cross the end line on the court and score a point. The other players do what they can to stop you. It's not a game for polite recreation. U.S. Quad Rugby Association; [www.usqra.org](http://www.usqra.org)

### Sled Hockey

Sled hockey is played by people who use their arms to propel themselves by digging picks on the ends of two short hockey sticks into the ice. Players are seated on sleds, which are affixed to two hockey skate blades under the seat. The sleds are about three inches off the ice and are anywhere from two to four feet long, depending on the size of the player. There are few differences between this and the stand-up game. The puck is the same, as are the pads. Protection is needed, as there is a lot of checking. International competition is fierce, including the Paralympic Games. USA Hockey, 719-576-USAH (8724); <https://teamusa.usahockey.com/usnationalsledteam>

### Softball

It's not easy to field full teams of wheelchairs for a Saturday afternoon pick-up game. The best chance for action occurs at an annual tournament sponsored by the National Wheelchair Softball Association, where 30 or so teams show up to compete. The game is much the same as slow-pitch softball, using a 16-inch slow-pitch ball with base paths shortened to 50 feet. There is no adaptive equipment. For more, contact NWSA, [www.wheelchairsoftball.org](http://www.wheelchairsoftball.org)

### Volleyball

Volleyball has been adapted to include seated persons with many types of disabilities. The net is about three feet high and the court is smaller than a standard volleyball setup. Bump, set, spike—the major differences between the standing game and the sitting game are that players can block the serve and that one bun must be in contact with the floor when a player makes contact with the ball. USA Volleyball, 719-228-6800; [www.usavolleyball.org](http://www.usavolleyball.org)

### RECREATION RESOURCES

**Achilles International**, with chapters in more than 65 locations in the United States and abroad, encourages people with disabilities to participate in long-distance running. ATC provides support, training and technical expertise to runners with all kinds of disabilities. Achilles has programs for children and war veterans. Achilles Track Club, 212-354-0300; [www.achillesinternational.org](http://www.achillesinternational.org)

**BlazeSports America**, an outgrowth of the 1996 Paralympic Games held in Atlanta, empowers children and adults with physical disabilities through sport, health enhancement, and the promotion of universal human rights. The program is named after the Atlanta Paralympics mascot, Blaze. 404-270-2000; [www.blazesports.org](http://www.blazesports.org)



**Challenged Athletes Foundation** steps in where rehabilitation and health insurance end by funding sports wheelchairs, handcycles, mono-skis and sports prosthetics, as well as expenses for training and competition. Based in San Diego. 858-866-0959; [www.challengedathletes.org](http://www.challengedathletes.org)

**Move United** was created by the merger of Adaptive Sports USA with Disabled Sports USA. Move United focuses on one goal: to improve the lives of wounded warriors, youth and adults with disabilities by providing sports and recreation opportunities. Their structure as a community-based chapter network allows them to reach people across the country, through a grassroots approach that supports local chapters in identifying the needs of the communities they serve. 301-217-0960; [www.moveunitedsport.org](http://www.moveunitedsport.org)

**National Center on Health, Physical Activity and Disability (NCHPAD)** offers

multimedia information on accessible fitness, recreation and sports programs, stress management, nutrition, equipment vendors, etc. NCHPAD, toll-free 1-800-900-8086; [www.nchpad.org](http://www.nchpad.org)

**Paralympics: United States Olympic Committee** manages the U.S. Paralympic team. With minor exceptions, services provided to athletes with disabilities are comparable to those provided to nondisabled Olympic athletes. The USOC is dedicated to the integration and advancement of elite athletes with disabilities into open competition whenever possible. The Paralympics are open to elite athletes who meet the rigid qualifying standards of their sport. Athletes are categorized by a combination of functional and medical determinations. The Paralympic Games have been contested since 1960 and now feature competition in 28 sports. The Paralympic Winter Games showcase five sports. For more, contact U.S. Paralympics, 719-632-5551; [www.usparalympics.org](http://www.usparalympics.org). Also see International Paralympic Committee, [www.paralympic.org](http://www.paralympic.org)

**Sports 'N Spokes** is a magazine about sports and recreation for people with paralysis published by the Paralyzed Veterans of America; SNS offers details on wheelchair athletics and competition, recreation, exercise, training, nutrition, event schedules and other topics of interest to the active wheeler. Toll-free 602-224-0500; [www.pvamag.com/sns](http://www.pvamag.com/sns)

**Turning POINT** teaches people with mobility impairments the skills necessary to fully enjoy the outdoors. The organization sponsors opportunities for people living with paralysis of all shapes, sizes and ages to camp, fish, sail, scuba dive, hunt, water ski or take pictures from a pontoon boat in the scenic swamps of East Texas. 972-524-4231; [www.turningpointnation.org](http://www.turningpointnation.org)

**World T.E.A.M. Sports** brings individuals with and without disabilities together in unique athletic events (mountain climbing, white water rafting, biking, rides around the world, rides through Vietnam, etc.). The program promotes diversity and increased awareness, acceptance and integration of those with disabilities. 855-987-8326, [www.worldteamsports.org](http://www.worldteamsports.org)

## ARTS AND CREATIVITY

The arts enrich our lives in countless ways, whether we create art or appreciate its beauty, truth or abstraction. The worlds of creative endeavor and artistic expression are inclusive; there are no limitations on imagination. There are only a few restrictions on accessing the tools of art; musical instruments,

paintbrushes, pencils or video cameras are fairly adaptable. Because art is infinite and unconditional, people with disabilities are free to express themselves without physical, social, or attitudinal barriers. The arts are not recreation, per se, but they can be uplifting, refreshing and socially involving.

The arts provide unlimited possibilities for personal, academic, and professional success. By engaging in the arts, people with disabilities are able to greatly contribute to their communities, help extinguish old stereotypes regarding disability, and create a culture truly representative of all people. The arts help forge a collective identity. People with disabilities share common experiences through the expression of their struggles and histories—in art, dance, music and other performing arts, including motion pictures and television.

## ARTS AND CREATIVITY RESOURCES

**Association of Foot and Mouth Painting Artists** is an international organization that offers significant financial support to painters accepted in the group. American affiliate is Mouth and Foot Painting Artists Inc., Atlanta. 770-986-7764; [www.mfpausa.com](http://www.mfpausa.com)

**AXIS Dance Company** has become an internationally known resource for physically integrated dance and is one of several companies setting a standard for professionalism in this emerging field. AXIS Dance Company, Oakland, CA, 510-625-0110; [www.axisdance.org](http://www.axisdance.org)

**Ballroom Dancing:** This graceful, dramatic style is catching on with wheelchair dancers. Among U.S. programs are Philadelphia-based American Dance Wheels, see [www.americandancewheels.com](http://www.americandancewheels.com), and San Diego's Wheelchair Dancers Organization, [www.wheelchairdancers.org](http://www.wheelchairdancers.org)

**Coalition for Disabled Musicians** introduces musicians with disabilities to each other, offers an accessible rehearsal and recording studio, helps with adaptive techniques for pain, and endurance, etc. Bay Shore, NY. [www.disabled-musicians.org](http://www.disabled-musicians.org)

**Creative Growth Art Center** offers art programs, independent living training, and vocational links for adults who have physical, mental and emotional disabilities. Oakland, CA. [www.creativegrowth.org](http://www.creativegrowth.org)

**Disabled Drummers Association** is an organization dedicated to serving drummers with disabilities and helping them to be a positive part of the music industry. [www.disableddrummers.org](http://www.disableddrummers.org)



CHRISTOPHER VOELKER

**Ruben Rios** was 18 when he was shot in the neck at close range. He was dependent on a ventilator 24-hour a day. Ruben was a painter and a member of the prestigious Association of Foot and Mouth Painting Artists. "I create art mostly the same way I did when I started, a kind of pointillism. I use fine point felt tip pens and I "stipple" or dot my way through the piece. First, I draw an outline with pencil and then I'll color in the sketch, dropping in different colors and layers. It takes anywhere from 20 to 60 hours to complete a piece from beginning to end with this method. My art has been the biggest thing in my life that has kept me goal-oriented and not just stagnant. Now I have something to achieve. And if it weren't for the opportunity I was given to pursue a career as an artist, I don't think I'd be where I am today. I wouldn't have the same quality of life."

Ruben passed away on February 10, 2014. He had been an ambassador for the Reeve Foundation and Paralysis Resource Center (PRC) since 2007.

**Full Radius Dance** explores the human experience in a world of diversity in attitude, action and outcome. Atlanta, GA. [www.fullradiusdance.org](http://www.fullradiusdance.org)

**Media Access Office** promotes the employment and accurate portrayal of persons with disabilities in all areas of the media and entertainment industry, ensuring that people with disabilities are part of the cultural diversity.

<http://mediaaccessawards.com>

**National Arts and Disability Center (NADC)** is an information, technical assistance and referral center dedicated to the full inclusion of children and adults with disabilities into the visual, performing, media, and literary arts. NADC, Tarjan Center for Developmental Disabilities; [www.semel.ucla.edu/nadc](http://www.semel.ucla.edu/nadc)

**Nurturing Independence Through Artistic Development (NIAD)** is a visual arts center that serves adults with developmental and physical disabilities.

[www.niadart.org](http://www.niadart.org)

**ReelAbilities Disabilities Film Festival** presents award-winning films by and about people with disabilities in multiple locations. [www.reelabilities.org](http://www.reelabilities.org)

**That Uppity Theatre Company** produces the Disability Project, an ensemble of conversation, writing, sound, movement and theatrical exercises to empower individuals, honor their stories, and enhance awareness about disability. St. Louis, MO; [www.uppityco.com](http://www.uppityco.com)



# 5

## TRAVEL

It's a big planet. You should see it. Here's how to get ready to explore, to relax, and to savor exotic cultures.



ASHLEY OLSON

*Bags packed, ready to go.*

### Travel in the Age of COVID-19

The CDC has a checklist of questions to ask yourself before traveling during the pandemic. They also provide tips on how to protect yourself while traveling, considerations by the type of travel (air, train, etc.), anticipating your travel needs, information on various local, state and country restrictions, and how to protect yourself when using transportation. You may want to check with your physician before traveling in order to discuss your own situation and risks.

Source: [Centers for Disease Control and Prevention](#)

Whether you're a tourist or a traveler, or even if you don't know the difference, there is great appeal in getting away from home to experience the world—on a road trip to the state next door or off to some far-flung place across land and sea. For our purposes, it's the trip that counts, not the purpose, or the destination, or the scenery. Travel is a process; sometimes it's familiar and comfortable, sometimes random or even unsettling. Unless you have an unusually high threshold for the unpredictable, the best travel plan is to have a plan. That does not necessarily mean a packaged trip with a cookie-cutter itinerary. But planning is especially important for people who use adaptive gear or need to get around with reduced mobility. No plan is bulletproof, of course, especially when it comes to transportation, lodging, scheduling, weather, and all the unforeseen tribulations that remind you that travel is an art, not a science. We'll break the planning into three steps: getting ready, getting there, and being there.

### GETTING READY

For those who haven't done a lot of travel with wheelchairs, walkers, and all the paraphernalia of paralysis, it's a good idea to enlist the help of someone with a lot of personal experience or perhaps a travel agent who specializes in the disability travel market. Travel professionals know how to get you where you want to go and pretty much what to expect once you get there, matching your level of adventure with your need for creature comfort. In many cases, it's best to make your maiden voyage to a destination that is familiar with people with disabilities. This would include, among many other places, San Diego, Las Vegas, Disney World in Orlando, New York, and Washington, D.C.

Your agent may also recommend a cruise—this is a very relaxing way to see exotic ports of call in an accessible, well-fed, and friendly environment including, in many cases, cabins with roll-in showers. As a whole, the cruise business does a good job anticipating the needs of travelers with disabilities, especially on the most modern sailing vessels.

Your expert friend or travel agent should know a few basic tricks (see a list of tips from veteran wheelchair travelers, including those who use mechanical ventilation, page 237). It's not an absolute requirement, but let the airline know you're coming by wheelchair. Advance notice may not be such a big deal if you're hopping a one-hour shuttle from Los Angeles to San Francisco, but if your flight is long and involves plane changes, always let them know. If the plane has fewer than sixty seats, powerchair users may also be required to give a two-day notice. Air carriers may require up to forty-eight hours advance notice if you plan to use oxygen or the plane's power supply to

### **LAVATORY ISSUES**

*How about bathroom issues on a long airplane ride for someone who uses a wheelchair? Bob Vogel, a paraplegic who has been pushing nearly thirty years and half a million air miles has this to say:*

*First, unless you're in a big, wide body aircraft, an accessible onboard lavatory is not a given; according to the Air Carrier Access Act, "Aircraft with more than one aisle must have at least one accessible lavatory (with door locks, call buttons, grab bars, and lever faucets) available, which will have sufficient room to allow a passenger using an onboard wheelchair to enter, maneuver, and use the facilities with the same degree of privacy as other passengers." I've used an aisle chair to get to "inaccessible" bathrooms—the transfer was "expert only," to say the least, but doable.*

*Most regional flights are not on two-aisle planes; some have an aisle chair, some don't, so it's a good idea to limit fluid intake before the flight. Use the restroom and catheterize immediately before boarding. Avoiding dehydration is a balancing act—the dry air in an airplane cabin can add to dehydration. I do drink water on the flight to stay hydrated—just not a lot. If you are worried about a long flight, consider using an indwelling catheter and leg bag. Alas, some folks wear pads or Depends—just in case. So here's hoping you get bumped to first class, with plenty of free drinks on a plane with an aisle chair and accessible bathroom. Safe travels!*

### **PASSENGERS WITH SERVICE ANIMALS**

*Dogs are fine onboard. Ask about the airline's policy on advance seat assignments for people with disabilities. Airlines are not permitted to automatically require documentation for service animals other than for emotional support animals, but you may want to carry documentation from your physician or other licensed professional confirming your need for the service animal. Passengers with unusual service animals also may want to carry documentation confirming that their animal has been trained to perform a function or task for them.*

operate a respirator. A note on oxygen: Most U.S. airlines can accommodate passengers requiring oxygen, although the FAA requires a physician's statement. Also, regulations prohibit the use of passenger-provided oxygen equipment during flight. Airlines will charge extra for their oxygen, and it's not cheap, so check with the carrier.

Book a direct flight whenever possible. Changing planes is a nuisance and can be unnerving, especially if your connection is tight—you have to make absolutely sure your wheelchair and other gear make the connecting flight. Airlines may try to seat you in one of their one-size-fits-all wheelchairs at the gate. In the name of comfort and safety, insist that your personal equipment be brought forth. On the subject of missing baggage, here is another pro tip: Keep your meds, catheter supplies, etc. in your carry-on bag. Never pack them in your checked luggage.

The airline industry in the United States must by law accommodate passengers with disabilities. The compliance record for all airlines is not spotless, although it has been much improved in recent years. But here's another rule of thumb experience has taught the veteran traveler with a disability: Despite federal regulations and many years of ADA sensitivity, don't assume that anyone who wears the airline's uniform knows what to do with you or your gear. It may not be necessary to pack a copy of the Air Carrier Access Act (get a summary online at [www.transportation.gov](http://www.transportation.gov)), but you may have to tap into the deep reserves of your patience.

Agents should know to get their mobility-restricted clients assigned to a bulkhead seat on the airplane; it is much easier to transfer in and out. Your travel pro should also know about general accessibility of your destination,





ASHLEY OLSON

*Mendocino, California trail.*

public transportation, rental cars with hand controls, and other details once you arrive. Book your van well ahead of time. An agent is going to be most helpful in arranging lodging on the other end. Just because a hotel's brochure has the little wheelchair symbol that says it has accessible rooms doesn't mean you can get in the bathroom. In many cases, the agent has been there ahead of you with a tape measure and knows what to expect, including accessibility of shops, restaurants, and the hotel pool. There are agencies listed at the end of this chapter.

Do you need to bring an attendant? No, unless you are on a stretcher or the air carrier cites a safety issue, which you should get in writing. As the rule reads, an attendant may be required for "a person with a mobility impairment so severe that the person is unable to assist in his or her own evacuation of the aircraft."

How about bringing your service dog? No problem. Any public or private accommodation, including restaurants, hotels, stores, taxis, and airlines, must allow people with disabilities to bring their service animals with them wherever customers are normally allowed. You and your dog can't be denied any seat, either, unless the animal obstructs an aisle or other areas that would impede an emergency evacuation. When booking your ticket, tell your travel

or ticket agent that a service dog is coming along. Bring the dog's health certificates with proof of vaccinations.

You hope your chair or scooter will survive the ride in the cargo hold. Usually there's no problem, especially for manual chairs. If you use a power wheelchair there are more reasons for concern for the well-being of your equipment. Airlines prefer that you use gel or dry-cell batteries as opposed to the more common liquid (spillable, corrosive lead acid) ones. Also, the spillable battery's regular vent caps may be replaced with spill-proof vent caps. Be sure the handlers replace the regular vent caps before reconnecting the battery so dangerous pressure does not build up in the battery during later use.

Some powerchair or scooter users remove their joystick controls and carry them on board. These devices are sensitive to abuse and difficult to repair away from home.



ASHLEY OLSON

*Sedona, Arizona.*



### PRO PARA TIPS

**Here are a few tips for wheelchair travelers from well-seasoned Ashley Olson, proprietress of [www.wheelchairtraveling.com](http://www.wheelchairtraveling.com)**

**Tools:** Bring a portable set of Allen wrenches—very handy for brake and caster adjustment.

**Tires:** Check the air in your tires before leaving; consider packing a portable pump. Solid rubber wheels are an option.

**Immunity:** Boost your immune system; I swear by On Guard Essential Oil, a blend of wild orange, clove bud, cinnamon, eucalyptus, and rosemary. Hand sanitizer is helpful too.

**Compression socks:** Good for circulation and for preventing leg swelling; helps the body stay warm in colder weather.

**Packing:** A backpack is an essential carry-on luggage item but is also a crucial daypack throughout the trip to hold water, clothing, souvenirs, etc.

**Medical supplies:** Bring extra supplies because you never know—flights get delayed, cars break down, bad weather brews.

**Flying:** Check-in at the desk instead of a kiosk to arrange for boarding and on-flight wheelchairs; gate-check your wheelchair; remove everything that can fall off the wheelchair—side-guards, seat cushion, etc.

**Gloves:** These are a good idea to protect your hands along the sometimes bumpy, dirty road.

**Reservations:** When booking anything—a plane flight, train ride, hotel, restaurant, etc.—notify the other party that you are in a wheelchair.

**Food:** Let your system adjust to new foods and spices. Don't shock your system—it could lead to indigestion and an irregular bowel.

**Public restrooms:** Sometimes finding an accessible public restroom can be challenging; try looking for shopping centers, chain coffee shops, hotel lobbies, train/subway stations, airports, government buildings, banks, and fast food restaurants.

**Attitude:** Be open to the new things that come your way, whether cuisine or access features, but also when situations don't go according to plan. Roll with it and you'll be guaranteed to have a more pleasant and eye-opening experience.



Bodega Bay, Northern California.

ASHLEY OLSON

### Getting There

It's important to get to the airport early to check in. As you are transferred to one of those skinny aisle chairs to get you to your seat (first to board, last to deplane), your chair will be tagged so the destination ground crew knows to bring it to the gate when the plane arrives. A lot of wheelchair users keep their seat cushion with them and use it on the plane. Bigger planes (more than thirty seats) must have movable armrests, so you can slide in easily.

Once onboard, the travel experience is pretty much like that of everyone else, except for using the lavatories. Newer, two-aisle planes have accessible lavatories, as long as you can maneuver yourself in the little onboard chair or have an attendant standing by. The cabin crew is not required to help you once you reach the lavatory. According to federal rules, the accessible lavatory “shall afford privacy to persons using the onboard wheelchair equivalent to that afforded ambulatory users.” Still, it's a rather conspicuous and indiscreet hassle to use the toilet on a plane. It's common for people with dysfunctional bladders to restrict fluid intake before boarding the plane

### PRO QUAD TIPS

**Here are a few tips for wheelchair travelers from well-traveled Mark Willits, a lawyer with C2-C3 quadriplegia who uses a respirator, and who is former president of the California support organization Ralph's Riders.**

- *This is true: Hope for the best, plan for the worst.*
- *Always carry on the equipment you need to survive 24 hours at your destination; for me that's an ambu-bag, suction machine, extra batteries and charger for the ventilator, medications, etc. Airlines cannot limit the amount of medical equipment that a passenger carries on to the airplane.*
- *Always remember to do regular weight shifts.*
- *Locate ground transportation at your destination. Rental vans with a ramp or wheelchair lift and wheelchair tie-downs can be found in most major cities. (Two national rental companies are listed at the end of this chapter.)*
- *If you plan to use public transportation, taxis, hotel shuttles, etc., know your options before you get there. The subways of New York or Paris are great but not always available—that's completely the opposite in Washington, D.C. or Los Angeles.*
- *Transfers from a wheelchair to an aisle chair and then to the airplane seat are crucial; understand how this works and prepare for it. You will have to speak up and explain how to keep this process safe.*
- *Plan for a broken chair. Always locate the closest wheelchair repair shop before arrival in case it happens. You can often find this by contacting the manufacturer of your chair.*
- *Make sure all electrical equipment is compatible with the voltage in foreign countries. Bring a transformer or adapter if necessary.*
- *Chair: Remove and carry onboard everything that you can: headrest, armrest, foot rest, cushion, cords, and backpacks. Instruct airline employees on how to properly handle the wheelchair; the more explicitly and simply you explain everything, the better.*
- *You are not required to remove the batteries or disconnect them from the wheelchair if the batteries are gel cell or dry cell batteries.*
- *Stay positive. Even with perfect planning, problems will occur. Be polite and courteous to the airline employees. They are always more helpful that way.*

### HOTLINE

*The U.S. Department of Transportation (DOT) has established a toll-free hotline to assist travelers with disabilities. The hotline provides general information to consumers about the rights of air travelers with disabilities, responds to requests for printed consumer information, and assists air travelers with time-sensitive disability-related issues. Call 1-800-778-4838 (voice) or 1-800-455-9880 (TTY) to obtain assistance.*

and to use airport facilities right before going aboard.

Air travel is an overwhelmingly positive experience for most passengers with disabilities. But if you are treated as cargo by insensitive personnel, or if your own cargo is mangled, always be prepared to assert your rights. Anyone who feels an airline has violated any provision of the access rules may report the incident to the Aviation Consumer Protection Division, C-75, Department of Transportation, 1200 New Jersey Ave., SE, Washington, DC 20590. 202-366-2220, [www.transportation.gov/airconsumer](http://www.transportation.gov/airconsumer). You can be sure that complaints are taken seriously.

### Being There

Public transportation may work out fine. Some cities are better set up with fixed route systems than others, but most transit systems are sensitive to travelers using wheelchairs, so do a bit of research to obtain maps and schedules ahead of time. A rental car affords flexibility and independence. Most of the major car rental companies can supply hand controls, but it's best to give them a few days notice. Several accessible van rental companies are found in major cities. These offer daily and weekly rates on a variety of accessible, full-size cars and minivans. Check ahead with the companies, listed at the end of the chapter, to make sure their rigs are configured to meet your specific needs.

Once you check in and make sure the accommodations are what you expected at the hotel or aboard the cruise ship, go do what travelers do: eat, shop, relax, go to a museum, or just watch humanity pass by. You're on holiday time now.

So, what are you waiting for? There is nothing so invigorating as travel. It renews the spirit, recharges the imagination. Travel can be a challenge no



Mark Willits, the one in the chair, in Hawaii for a helicopter tour.

matter your level of function. But the hassles and even the horror stories supply the contrast to make the good parts all the more special. When you're ready to hit the road or the high seas, be well informed. Know what you're getting in to and to some degree, what you can expect once you get there.

You might have heard that the most important piece of luggage is a joyful heart. Or that the heaviest baggage is the empty purse. Italian writer Cesare Pavese said it well: "If you wish to travel far and fast, travel light. Take off all your envies, jealousies, unforgiveness, selfishness and fears." The best advice is to take all advice with a grain of salt, to be prepared as best you can, and be open to the adventure. Bon voyage!

## **TRAVEL RESOURCES**

**Accessible Journeys**, based in Pennsylvania, has nearly three decades of experience making vacations across the world accessible and comfortable. 610-521-0339, toll-free 1-800-846-4537; [www.disabilitytravel.com](http://www.disabilitytravel.com)

**Airbnb** lets people rent rooms and private homes. They have accessibility filters to find accessible rentals. [www.airbnb.com](http://www.airbnb.com)

**Amtrak** has many trains and stations that accommodate travelers with disabilities. For information on reservations, accessible coaches and sleeping accommodations, boarding, use of oxygen, service animals, etc., see [www.amtrak.com/accessible-travel-services](http://www.amtrak.com/accessible-travel-services)

## **REVISED ADA RULES FOR LODGING**

*Ever get there and find the room you booked as accessible wasn't even close? The good news is that this is not supposed to happen anymore. ADA regulations regarding hotels, motels, and inns were revised in 2012. By law, individuals with disabilities must be able to make reservations for accessible guest rooms during the same hours and in the same manner as others. Places of lodging must identify and describe accessible features of the facility and guest rooms in enough detail to reasonably permit those with disabilities to assess independently whether a given facility or guest room meets his or her accessibility needs.*

*Customer service staff should know accessible routes to and through the facility; details about the configuration of accessible guest rooms and bathrooms; availability of accessibility equipment or features such as bath benches or visual alarm and alert devices; and the accessibility of common spaces such as meeting rooms, lounges, restaurants, swimming pools, or fitness centers.*



Madonna Inn, San Luis Obispo, CA.

*When a reservation is made for an accessible guest room, the specific accessible guest room reserved must be held for the reserving customer and the room must be removed from the reservation system.*

*Places of lodging that rely on third parties (e.g., travel agents, including online travel reservation services) must provide accessible rooms to at least some of the third parties and must provide information about the accessible features of the facility and the guest rooms.*

*Newly built lodging facilities now must comply with the 2010 ADA Standards, which include recreational spaces, such as swimming pools and spas, exercise equipment, golf courses, boating facilities, and play areas. For more, call toll-free 1-800-949-4232; <http://adata.org>*



## GOING OUTSIDE THE UNITED STATES?

- Learn some of the local language and keep a list of keywords so others can help you.
- Contact your insurance company; make sure you know what is covered while you're abroad.
- Make sure you research foods and their ingredients for the countries on your itinerary.
- For your power or other electrical equipment: Know what transformers, voltage converters, or plug adapters you will need.

**Craig Hospital** offers tips on airline travel for people with disabilities, including traveling with service dogs and mobility equipment.

[www.craighospital.org/resources/Airline-Travel](http://www.craighospital.org/resources/Airline-Travel)

**Emerging Horizons** is a publication about accessible travel. It contains access information, resources, news, and travel tips. Editor Candy Harrington has also written several books, including *Barrier-Free Travel, Inns and B&Bs for Wheelers and Slow Walkers*, and *22 Accessible Road Trips* (<http://22accessibleroadtrips.com>); Candy's point is, you don't have to go far away to get far away. For more visit <http://emerginghorizons.com>

**Mobility International USA (MIUSA)** is a clearinghouse to empower people with disabilities to achieve human rights through international exchange and international development. [www.miusa.org](http://www.miusa.org)

**Northwest Regional SCI System at the University of Washington** offers a video and information on traveling with a spinal cord injury.

[http://sci.washington.edu/info/forums/reports/travel\\_2011.asp](http://sci.washington.edu/info/forums/reports/travel_2011.asp)

**Rick Steves' Europe** offers tips for travelers with disabilities.

[www.ricksteves.com/travel-tips/trip-planning/travelers-with-disabilities](http://www.ricksteves.com/travel-tips/trip-planning/travelers-with-disabilities)

**Rolling Rains Report**, from travel promoter Scott Rains, provides resources on inclusive tourism, promoting a global disability community that both enjoys and asserts the right to full inclusion. [www.rollingrains.com](http://www.rollingrains.com)

**ScootAround** offers scooter and wheelchair rentals in dozens of North American destinations. [www.scootaround.com](http://www.scootaround.com)

**Society for Accessible Travel & Hospitality (SATH)** is a clearinghouse for accessible tourism information; dedicated to a barrier-free environment across the travel industry. [www.sath.org](http://www.sath.org)

**Travability** is a travel agency in Australia that offers itinerary planning, flight and hotel bookings, attractions, cruising holidays, private yacht charters, escorted group tours, and can hire cars or vans with or without hand controls. <http://travability.travel>

**TSA Cares** is a dedicated helpline for passengers with disabilities regarding questions about Transportation Security Agency screening policies, procedures, and what to expect at security checkpoints. Toll-free: 1-855-787-2227, [www.tsa.gov/travel/passenger-support](http://www.tsa.gov/travel/passenger-support)

**Wheelchairtraveling.com** is an international online community of wheelchair travelers sharing experiences and tips on everything from hotels to transportation to activities and attractions. Whether you are looking for something exotic or close by, let the community help you find what is out there. <http://wheelchairtraveling.com>



Yosemite National Park

ASHLEY OLSON

### **GIMP ON THE GO**

Adam Lloyd took a passion for wanderlust and transformed it into his life platform. Lloyd, from Bethesda, Maryland, was injured during a high school swim practice in 1983 and is a C4 quad. He has never been one for sitting on the sidelines. The powerchair, of course, adds another challenge. “The amount of research, planning, and coordination that goes into every trip makes it a chore. That’s really why I started Gimp on the Go. Each of us was reinventing the wheel.”

Cruising is one of Lloyd’s recommended escapes: “The opportunity to see the world without having to make a plethora of travel arrangements or constantly worrying about finding accessible lodging and activities makes for a wonderfully convenient, stress-free trip,” he says.

Favorite destination? Las Vegas. “It’s incredibly accessible and loads of fun.” Any transformative experiences? “Germany was my first trip outside the Americas, and traveling through Bavaria — the topography, architecture, history, food, people — I felt like I was in a Grimm’s fairytale. In Costa Rica, after almost twenty years in a chair, I was almost moved to tears at being able to trek through a genuine rainforest! It was such a unique experience, and one I never would have dared to dream could be a reality for me after my accident.” See [www.gimponthego.com](http://www.gimponthego.com)

### **NATIONAL ACCESSIBLE VEHICLE RENTALS**

#### **Wheelchair Getaways**

Toll-free 1-800-642-2042;  
[www.wheelchairgetaways.com](http://www.wheelchairgetaways.com)

#### **Wheeler’s Accessible Van Rentals**

Toll-free 1-800-456-1371;  
[www.wheelersvanrentals.com](http://www.wheelersvanrentals.com)



Adam Lloyd gets around.



# 6

## NAVIGATING THE SYSTEM

Get what you need and what you are entitled to.  
Understand how the system works.  
Know your rights.



On July 26, 1990, President George H.W. Bush signed the Americans with Disabilities Act into law. With him on the South Lawn of the White House are (from left to right, sitting) Evan Kemp, Chairman of the Equal Employment Opportunity Commission, and Justin Dart Jr., Chairman of the President's Committee on Employment of People with Disabilities; and (left to right, standing) Rev. Harold Wilke and Sandra Swift Parrino, Chairperson, National Council on Disability.

Coming to grips with “the system” is a fact of life in the world of paralysis. This system is a complex and formidable weave of regulation, red tape and mostly good intentions; it directly affects people who want to exercise their rights as citizens, get an education, find jobs or access medical care.

**What it really comes down to** is getting what you are entitled to, getting what you paid for, getting what you deserve. Forewarned is forearmed: Federal and state policies regarding disability must be understood and sometimes challenged in order for people to succeed. Know your rights.

This chapter focuses on the policies, legalities and practicalities of surviving paralysis; it also looks at the agencies that write and enforce the rules. Underpinning much of the discussion are the basic civil rights of people with disabilities set forth by the Americans with Disabilities Act.

The healthcare benefits section looks at Medicare, Medicaid and the effect of the Affordable Care Act (aka Obamacare), in both the private and public sectors. We will look at how Medicare Part A (hospital insurance) works, and when Medicare Part B (medical insurance) comes into play. We will consider the basics of Medigap and state programs, including Medicaid, and Children's Health Insurance Program (CHIP). Also, the steps for filing an appeal of a denial will be outlined.

The section on Social Security makes sense of the rather complex rules for getting and keeping benefits under the entitlement of federal law, for both Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI). We will also look at the appeals process.

If getting a job is your goal, there are programs to help. Vocational rehabilitation programs exist to help people with disabilities train for or find work. Also, there are government programs that allow people to work and keep healthcare benefits: PASS (Plan for Achieving Self-Support) and Ticket to Work help people join the workforce without fear of losing health insurance.



Education benefits are the cornerstone of public policy regarding children with disabilities. Herein is a primer. Also, resources are listed for college-age individuals with disabilities.

Lastly, we list the best contacts to help explain disability policies and assure that the laws are fairly enforced.

## BASICS OF THE ADA

**The Americans with Disabilities Act (ADA)**, which became law in July 1990, is the cornerstone of civil rights for people with disabilities. The law guarantees full participation in American society for all people with disabilities, just as the Civil Rights Act of 1964 guaranteed the rights of all people regardless of race, sex, national origin or religion.

The ADA covers every person with a disability, defined as a person who has a physical or mental impairment that substantially limits one or more major life activities, has a record of such an impairment, or is regarded as having such an impairment.

The law is written in several sections, or titles. Title I of the ADA prohibits private employers, state and local governments, employment agencies and labor unions from discriminating against qualified people with disabilities regarding job applications, hiring, firing, advancement, pay scale, job training, and other conditions and privileges of employment. A qualified employee or applicant with a disability is someone who, with or without reasonable accommodation, can perform the essential functions of the job in question.

Reasonable accommodation may mean making existing facilities accessible and usable by persons with disabilities. It may also include job restructuring, modifying work schedules, acquiring or modifying equipment or devices, modifying training materials or policies, and providing readers or interpreters.

An employer is required to make an accommodation for the known disability of a qualified applicant or employee unless it imposes an “undue hardship” on the operation of the business. Undue hardship would indicate significant difficulty or expense, considering an employer’s size, financial resources and the nature of its operation. An employer is not required to lower quality or production standards to make an accommodation.

Employers are not allowed to ask a job applicant about the existence, nature or severity of his or her disability. Applicants may be asked about their ability



LYDIA GANS

*Ed Roberts, the principal architect of the independent living movement help found the Center for Independent Living in Berkeley, CA in the 1972. He died in 1995.*

to perform specific job functions. A job offer may be conditional based on the results of a medical examination, but only if the examination is job related and required for all employees entering similar jobs.

Title II of the ADA prohibits discrimination against qualified individuals with disabilities in all programs, activities and services of public entities. This applies to all state and local governments, their departments and agencies, and any other special districts of state or local governments, including public transportation.

Title III of the ADA prohibits discrimination on the basis of disability by “private entities” operating places of “public accommodation.” Businesses governed by Title III include banks, restaurants, supermarkets, hotels, shopping centers, privately owned sports arenas, movie theaters, private daycare centers, schools and colleges, accountant or insurance offices, lawyer and doctor offices, museums and health clubs.

If you feel you have been discriminated against by an entity covered by the ADA, contact the U.S. Department of Justice. For job-related discrimination, contact the U.S. Equal Employment Opportunity Commission. To protect your rights you must know what they are.

### **SOURCES**

U.S. Equal Employment Opportunity Commission, U.S. Department of Justice, National Institute on Disability and Rehabilitation Research

## ADA RESOURCES

**ADA National Network** provides technical assistance on the ADA.

Toll-free 1-800-949-4232; [www.adata.org](http://www.adata.org)

**Disability Rights Advocates** is dedicated to protecting and advancing the civil rights of people with disabilities. [www.dralegal.org](http://www.dralegal.org)

**Disability Rights Education & Defense Fund (DREDF)** is a national law and policy center for disability rights. DREDF offers advocacy, education, training and technical assistance to persons with disabilities, lawyers, service providers and policy makers about disability civil rights laws and policies. [www.dredf.org](http://www.dredf.org)

**Disability Rights Legal Center** advances the rights of people with disabilities through education, advocacy, and litigation. <https://thedrlc.org>

**U.S. Access Board** (Architectural and Transportation Barriers Compliance Board) is an independent federal agency devoted to accessibility for people with disabilities. It offers technical assistance on the ADA Accessibility Guidelines. Toll-free 1-800-872-2253; [www.access-board.gov](http://www.access-board.gov)

**U.S. Department of Justice (DOJ)** enforces the laws, including the ADA. Businesses, state and local governments, or others can ask questions about general or specific ADA requirements, including questions about the ADA Standards for Accessible Design. ADA specialists are available daily. Spanish language service is available. Includes full instructions for filing complaints. Toll-free 1-800-514-0301; [www.ada.gov](http://www.ada.gov)

**U.S. Equal Employment Opportunity Commission (EEOC)** enforces the laws against employment discrimination. If you believe you have been discriminated against by an employer, labor union or employment agency when applying for a job or while on the job because of race, color, sex, religion, national origin, age, or disability, you may file a charge of discrimination with the EEOC. Toll-free 1-800-669-4000; [www.eeoc.gov](http://www.eeoc.gov)

**World Institute on Disability** promotes independence and inclusion of people with disabilities in society, and works to strengthen the disability movement through research, training, advocacy, and public education. [www.wid.org](http://www.wid.org)

## SOCIAL SECURITY AND DISABILITY

There are two main Social Security programs that support people who live

with disabilities: Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI).

**SSDI: Social Security Disability Insurance** benefits are available to workers who have “medically determinable” impairments that prevent them from staying on the job or from performing any “substantial gainful activity.” SSDI is the safety net for workers who cannot be helped by adjustments and adaptations called “reasonable accommodations” set forth by the Americans with Disabilities Act (ADA).

Disability under Social Security is based on one’s inability to work. Under the rules, you are considered disabled if you cannot do the work you did before injury and it is concluded that you cannot adjust to other work because of your medical condition. It must be expected that your disability will last for at least one year or result in death. In addition, depending on what age the disability was acquired, you must have worked long enough and recently enough under Social Security to qualify for disability benefits. For example, this means that a person who became disabled after the age of 31 must have worked at least 5 of the 10 years immediately before the disability and paid FICA taxes during that time.

A high percentage of initial SSDI claims are denied by Social Security, but there are various levels of the appeals process. To win a claim at any level, an applicant must provide medical evidence of a disabling condition. The best source of this evidence is the applicant’s doctor, not the applicant.

**SSI: Supplemental Security Income** is a program that provides monthly payments to people who have limited income and resources if they are 65 or older or if they have a disability. SSI benefits are not based on your work history or that of a family member. Depending on the state where you live, the benefits and services that come with SSI include food stamps and paid Medicare premiums (all states). In most states, SSI recipients can also get Medicaid coverage for hospital stays, doctor bills, prescription drugs, and other health costs.

### The Appeals Process

Social Security, ever vigilant toward waste and fraud, does not always make it easy to get or keep benefits. If the agency decides that you are not eligible or are no longer eligible for benefits, or that the amount of your payments should be changed, you will receive a letter explaining the decision. If you don’t agree, you can ask them to look at your case again. If

you wish to appeal, you must make your request in writing within 60 days of the date you receive the letter. There are four levels of appeal:

- A reconsideration is a complete review of your claim by someone who didn't take part in the original decision. This person will look at all the evidence submitted when the original decision was made, plus any new evidence.
- If you disagree with the reconsideration, you may ask for a hearing. The hearing will be conducted by an administrative law judge who had no part in either the first decision or the reconsideration of your case. You and your representative, if you have one, may come to the hearing and explain your case. You may review anything in your file and provide new information.
- If you disagree with the hearing decision, you may ask for a review by the Social Security's Appeals Council. The Appeals Council looks at all requests for review, but it may deny a request if it believes the hearing decision was correct. If the Appeals Council decides to review your case, it will either decide your case itself or return it to an administrative law judge for further review.
- If you disagree with the Appeals Council's decision or if the Appeals Council decides not to review your case, your final option is to file a lawsuit in a federal district court.

Because the rules are complicated, many applicants hire lawyers who specialize in Social Security law. The National Organization of Social Security Claimants' Representatives may be able to suggest local referrals; see [www.nosscr.org](http://www.nosscr.org). For any questions about SSI, SSDI or other disability benefits programs, contact the nearest Social Security office.

### **SOURCE**

Social Security Administration

### **SOCIAL SECURITY RESOURCES**

**Social Security Administration:** All the rules and applications are here. From the home page click on "Disability" at [www.ssa.gov](http://www.ssa.gov)

### **MEDICARE AND DISABILITY**

**You are eligible for healthcare coverage** from Medicare if you or your spouse worked and paid taxes for at least 10 years, you are at least 65 years old, and

are a citizen or permanent resident of the United States. You might also qualify if you are a younger person with a disability.

**Note:** Medicare is not the same as Medicaid, which is a joint federal and state program that helps with medical costs for people with low incomes and limited resources. Over 10 million people qualify for Medicaid based on a disability. Most are eligible because they receive cash assistance through the SSI program. The remainder generally qualify for Medicaid by incurring large hospital, prescription drug, nursing home, or other medical or long-term care expenses. Medicaid is the only national program that pays for the complete range of services that enable many persons with disabilities to live in their own homes and communities. However, nationally, Medicaid covers over 60 percent of nursing facility residents.

Medicaid is means-tested; it has extensive rules for determining an individual's income and resources. Furthermore, because it is not a uniform federal program like Medicare, Medicaid coverage and eligibility varies from state to state. In an effort to encourage more states to provide Medicaid to working individuals with disabilities, Congress permitted states to expand their Medicaid programs through a Medicaid "buy-in." This allows people with disabilities to continue to receive Medicaid services even if they return to work. Most states allow waivers for some eligibility restrictions. Check with your state's Medicaid office (see page 259).

Medigap policies are Medicare supplement insurance policies sold by private insurance companies to fill "gaps" in what is called Original Medicare Plan coverage, such as out-of-pocket costs for Medicare coinsurance and deductibles or services not covered by Medicare. These policies can reduce out-of-pocket costs if those costs exceed the monthly Medigap premiums.

Medicare Part A (hospital insurance) is available when you turn 65. You don't have to pay premiums if you are already receiving retirement benefits from Social Security or the Railroad Retirement Board and you or your spouse had Medicare-covered government employment. Most people get Part A automatically when they become 65. If you (or your spouse) did not pay Medicare taxes while you worked and you are age 65 or older, you still may be able to buy Part A.

If you are not yet 65, you can get Part A without having to pay premiums if you have received Social Security or Railroad Retirement Board disability benefits for 24 months.

Medicare Part B (medical insurance) is an option that helps pay for doctors



and related services, outpatient hospital care, and some things Part A does not cover, such as physical and occupational therapy and home healthcare when it's medically necessary.

The standard Part B premium amount in 2020 is \$144.60 (or higher depending on your income). If you pay your Part B premium through your monthly Social Security benefit, you'll pay less.

If you choose not to enroll in Medicare Part B and then decide to do so later, your coverage may be delayed and you may have to pay a higher monthly premium for as long as you have Part B. Your monthly premium will go up 10 percent for each 12-month period you were eligible for Part B, but didn't sign up for it, unless you qualify for a "Special Enrollment Period."

It is important to know that Medicare does not cover everything; it does not pay the total cost for most services or supplies that are covered. Talk to your doctor to be sure you are getting the service or supply that best meets your healthcare needs.

The Original Medicare Plan usually pays 80 percent of the approved amount for certain approved pieces of medical equipment. Ask your supplier, "Do you accept assignment?" This could save you money. Medicare pays for some home healthcare costs. Benefits are available if people meet four conditions: Their doctor says they need medical care in their home and makes a plan for that care; they need intermittent skilled nursing care, physical therapy, speech language services, or occupational therapy; they are homebound; and the home health agency caring for them is Medicare-approved.

Medicare does not pay for all services, including 24-hour a day care at home; meals delivered to the home; homemaker services such as shopping, cleaning and laundry; or personal care given by home health aides such as bathing, toileting or dressing when this is the only care needed. It also does not pay for all prescription drugs.

Find a Medicare approved home health agency by asking your doctor or hospital discharge planner, using a community referral service, or searching online or in the telephone directory under "home care" or "home healthcare." You are free to choose any agency that meets your medical needs.

If you have questions about your home healthcare benefits and you are in the Original Medicare Plan, contact Medicare to get the number for your regional home health intermediary. If you have questions about home healthcare and you are in a Medicare managed care plan, call your plan.

Although the Original Medicare Plan does not provide prescription drug coverage, your state may offer discounted or free medications programs. Check with your state's Department of Aging or local Area Agency on Aging. For those numbers, contact Medicare. Your state also has programs that pay some or all of the Medicare premiums for people with limited incomes. Call your state's Medical Assistance Office to learn about Medicare Savings Programs (or contact Medicare).

You have the right to file an appeal for any unsatisfactory decision about your Medicare services. Ask your provider for any information related to the bill that might help your case. Your right to appeal is detailed on the back of the Explanation of Medicare Benefits or Medicare Summary Notice mailed to you from the company that handles bills for Medicare.

If you are in a Medicare managed care plan (also known as Medicare Advantage plans), you can always appeal if your plan does not pay for, does not allow, or stops a service that you think should be covered. If you think having to wait for a decision could seriously harm your health, request a fast decision. The plan must answer you within 72 hours. A Medicare managed care plan must tell you in writing how to appeal. After you file an appeal, the plan



will review its decision. If your plan does not decide in your favor, the appeal is reviewed by an independent group that works for Medicare, not for the plan.

Medicare Part D is a program that provides assistance for prescription drugs. The drug benefit is not provided within the traditional Medicare program. Instead, beneficiaries must enroll in one of many Part D plans offered by private companies. Medicare drug benefits are available through two types of private plans: beneficiaries can join a Prescription Drug Plan (PDP) for drug coverage only or they can join a Medicare Advantage plan (MA) that covers prescription drugs (MA-PD). The drug plans control drug costs through a system of tiered formularies; lower cost drugs are assigned to lower tiers and thus are easier to prescribe.

Beneficiaries who have both Medicare and Medicaid are automatically enrolled into a Prescription Drug Plan (PDP) in their area. Dual eligible beneficiaries are automatically removed from the MA plan upon enrollment in the PDP.

Dozens of Medicare prescription drug plans are available. Plans cover different drugs, or classes of drugs, at various co-pays, but may not cover certain drugs at all. Medicare has made available an interactive online tool called the



*The Reeve Foundation and Life Rolls On commemorated the 20th anniversary of the passage of the Americans with Disabilities Act by breaking the Guinness World Record for wheelchairs in a moving line, with 193 people, pictured at Dodger Stadium, July 26, 2010.*

GIL GARCETTI

Prescription Drug Plan Finder (see [www.medicare.gov](http://www.medicare.gov)) that compares drug availability and costs for all plans in a geographic area.

The Annual Enrollment Period for Part D opens for roughly seven weeks a year (see [www.medicare.gov](http://www.medicare.gov) for dates). Only during this period can people with Medicare enroll in a plan or change from one plan to another. Those who are already in a plan should reassess whether it will be right for them in the following year; if they do not choose to switch, they will remain in their current plan. Plans will have different costs and benefits from year to year; beneficiaries should consider their options.

Medicare Part D will provide a full drug subsidy with lower co-payments to beneficiaries with incomes up to 135 percent of the federal poverty level (FPL). Part D will also provide a partial subsidy of premium, deductible and coinsurance to beneficiaries with incomes up to 150 percent of FPL. Unlike rules for Medicare Savings Programs, which allow for a family unit of only one or two, Part D recognizes larger family units and extends coverage.

### **Medicare Advantage versus Original Medicare**

Assessing individual health needs is important when choosing between Medicare, the traditional federal health insurance program administered by the Centers for Medicare & Medicaid Services (CMS,) and Medicare Advantage, alternative health plans from private companies who contract with the CMS to offer coverage.

In 2020, 36% of Medicare beneficiaries enrolled in Medicare Advantage whose plans typically offer additional benefits beyond traditional Medicare, including prescription drug, dental and vision coverage. Analyzing federal data, the Kaiser Family Foundation found that more than three-quarters (78%) of Medicare Advantage enrollees in 2020 are in plans with quality ratings of 4 or more stars, an increase from 2019 (72%).

Medicare Advantage's emphasis on preventative care and cost controls, including caps on out-of-pocket costs for physician and hospital services, may be a good fit for relatively healthy seniors. Individuals with more complicated health concerns should carefully investigate and compare Medicare Advantage with traditional Medicare to determine which offers best options for personal needs and preferences. For example, Medicare Advantage enrollees may need to receive prior

**The Affordable Care Act (ACA) brings the country one step closer to ensuring that people living with disabilities have access to high quality, comprehensive and affordable care that meets their individual needs and enables them to live as independently as possible.**

authorization before certain services, such as inpatient hospital and skilled nursing facility stays, and Part B drugs are covered. Some plans can also require enrollees to use step therapy for Part B drugs: Only after a patient first tries, and fails to see improvement, on a less expensive drug can they be approved for other, more expensive options. Traditional Medicare does not usually require prior authorization for services and does not require step therapy for Part B drugs.

In a 2017 report about Medicare Advantage, the U.S. Government Accountability Office identified some contracts in which individuals in poor health were much more likely to voluntarily leave the health plans. Those contracts generally had lower quality scores, and their enrollees often cited problems getting access to care. A 2019 study by Brown University researchers determined that Medicare Advantage beneficiaries were significantly less likely than traditional Medicare beneficiaries to receive treatment from high-quality home health agencies.

Medicare Advantage does not cover hospice care. Once you start getting hospice care, Original Medicare will cover everything you need related to your terminal illness, even if you choose to remain in a Medicare Advantage Plan or other Medicare health plan. If you were in a Medicare Advantage Plan before starting hospice care, you can stay in that plan, as long as you pay your plan's premiums. You can choose to get covered services for any health problems not related to your terminal illness from either your plan or Original Medicare. (Source: CMS' Medicare Hospice Benefits booklet)

Taking time to comprehensively map out current health issues and anticipate future needs can help determine which insurance plan might best suit an individual or family member.

## **EFFECTS OF THE AFFORDABLE CARE ACT**

*The Affordable Care Act (ACA) includes important changes that impact the disability community. Among others, these include:*

**Pre-Existing Conditions**—Prior to the passage of the ACA, many people living with disabilities were often denied coverage, charged higher premiums, or had their coverage rescinded following an injury. Under the ACA, most insurance plans cannot deny or exclude coverage to any American based on a pre-existing condition, including a disability.

**Lifetime and Annual Benefit Caps**—One of Christopher Reeve's greatest fears was that he would exceed the lifetime or annual cap on his insurance coverage. No population is more affected by these caps than those dealing with catastrophic injury. Under the ACA, lifetime and annual caps on benefits are prohibited.

**Medicaid Expansion**—The Medicaid program provides health coverage to some of the country's most vulnerable populations, including people with disabilities. While the ACA mandated expansion of state Medicaid programs for all Americans under 65 with incomes up to approximately \$15,000, the Supreme Court decision in 2012 made state expansion optional. For information on Medicaid eligibility in your state, please visit [www.medicaid.gov](http://www.medicaid.gov)

**Health Insurance Marketplaces** were established in all states by 2014. Individuals can use the "Marketplaces" to shop for health insurance—much in the same way they currently shop online for airline tickets or hotel rooms. Marketplaces provide information on insurance options, including eligibility for public coverage programs, as well as tax credits and premium assistance to help make insurance more affordable.

**Home and Community-Based Services**—The ACA expands home and community-based services offered through state Medicaid programs, making it easier for people with disabilities to live at home, rather than being forced to receive services in an institutional setting. Among others, improvements include programs such as the "Community First Choice Option," which provides home and community-based attendant services and supports for people who are eligible for an institutional level of care.



## **SOURCES**

Social Security Administration, Medicare

## **MEDICAID AND MEDICARE RESOURCES**

**Affordable Care Act** coverage information is available from Healthcare.gov which provides information on health insurance options, as well as changes under the ACA that impact all Americans, including people living with disabilities. [www.healthcare.gov](http://www.healthcare.gov)

**Center for Medicare Advocacy, Inc.** provides education, advocacy and legal assistance to help elders and people with disabilities with Medicare-related issues. [www.medicareadvocacy.org](http://www.medicareadvocacy.org)

**Centers for Medicare & Medicaid Services** provides health insurance for more than 100 million Americans through Medicare, Medicaid and State Children's Health Insurance Programs. Toll-free 1-877-267-2323; [www.cms.gov](http://www.cms.gov)

**Insure Kids Now** is a national campaign connecting children under age 18 to free and low-cost health insurance. Toll-free 1-877-KIDS-NOW; [www.insurekidsnow.gov](http://www.insurekidsnow.gov)

**Medicaid** is a federally supported healthcare program administered by each state. For information on Medicaid eligibility in your state, see [www.medicaid.gov](http://www.medicaid.gov)

**Medicare:** For information about healthcare options under the Medicare program, or to locate your state's *Health Insurance Assistance Program*, which can guide you in choosing a Medicare plan, dealing with denials or appeals, or filing a complaint, call toll-free 1-800-MEDICARE; [www.medicare.gov](http://www.medicare.gov)

**Medicare Rights Center (MRC)** works to insure that people with disabilities get affordable healthcare. Toll-free 1-800-333-4114; [www.medicarerights.org](http://www.medicarerights.org)

**Medigap** is Medicare supplemental insurance, sold by private companies, which can help pay some of the costs that Original Medicare doesn't cover, such as copayments, coinsurance and deductibles. Toll-free 1-800-MEDICARE or click on "Supplements & other insurance" at [www.medicare.gov](http://www.medicare.gov)

## **GETTING WORK**

It used to be that people with disabilities who received Social Security benefits were effectively penalized for taking a job. Any income above certain limits set by the government was deducted from one's benefits, thus jeopardizing

the only source of health insurance available to people with long-term health conditions.

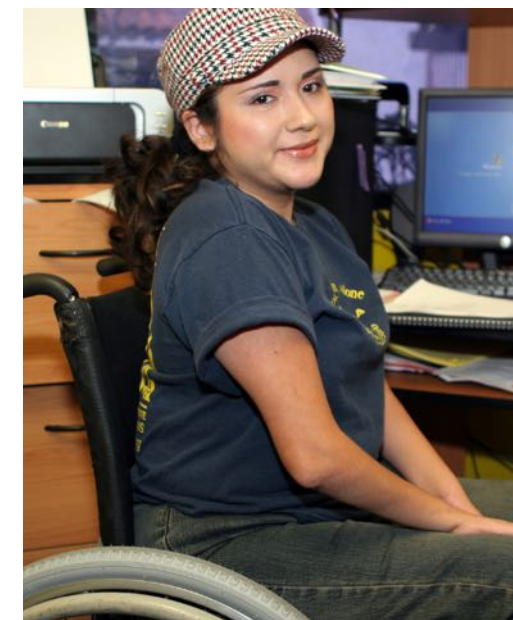
While many continue to see disincentives to working (few of the people who get Social Security and SSI disability benefits leave the rolls each year to go to work), policies have improved. Want to get a job without worrying about losing health insurance? It can be done. Below are details on two Social Security programs designed to encourage people with disabilities to enter the job force without fear of losing benefits. One is the Ticket to Work program, the other the Plan to Achieve Self-Support (PASS).

### **The Ticket to Work**

The Ticket to Work and Work Incentives Improvement Act of 1999, revised in 2008, increases choices for people with disabilities to obtain rehabilitation and vocational services while removing barriers that require a choice between healthcare coverage and earning money.

Social Security sees the Ticket as a good fit for people hoping to improve their earning potential and who are committed to preparing for a long-term career in the workforce. Ticket to Work offers improved access to employment with the help of specialized providers and a variety of free employment support services. Keep benefits while you explore employment, get vocational rehabilitation, or gain on the job experience. Cash benefits often continue throughout your transition to work and are eliminated only when you maintain a certain level of earnings.

Here's how it works: Beneficiaries of Social Security and Supplemental Security Income (SSI) receive a "Ticket" to obtain vocational rehabilitation and other employment support services from an approved provider of their choice. The Social Security Administration (SSA) contracts with providers



(employment agencies, independent living centers, state vocational rehab offices, community nonprofits, churches, etc.) to become Employment Networks (ENs). These providers work with beneficiaries to provide support and employment-related assistance. Beneficiaries with a Ticket may choose any EN to design an employment plan. Both you and the EN agree to work together and develop a plan that describes your employment goal and outlines what the EN will provide to help you reach that goal. A Ticket can also be used to obtain services and supports to help you become self-employed or start a business. For self-employment, tell the EN early on in the process; some ENs might not accept the Ticket assignment from someone who has self-employment as a goal. You are free to talk with as many ENs as you want before assigning your Ticket. You can always un-assign your Ticket and take it to another EN. For help choosing an EN, call the Ticket to Work hotline toll-free, 1-866-968-7842; visit [www.ssa.gov/work](http://www.ssa.gov/work) or go to [www.choosework.net](http://www.choosework.net)

### Preparing a PASS

The PASS (Plan to Achieve Self-Support) is a work incentive plan that allows people to work and keep Social Security healthcare benefits. Under regular Supplemental Security Income rules, your SSI benefit is reduced by any other income you have. But income you set aside for a PASS does not reduce your benefit: You get a higher SSI benefit when you have a PASS.

A PASS lets you use your income or other things you own to help you reach work goals, such as going to school or getting special training. The job that you want should allow you to earn enough to reduce or eliminate your need for benefits provided under both the Social Security and Supplemental Security Income (SSI) programs.

A PASS must state a specific work goal. “Getting a degree” or “buying a car” are not acceptable goals. You have to demonstrate a reasonable chance of



achieving your goal, within a reasonable time frame with beginning and end dates, and milestones to mark progress. One’s plan is submitted to Social Security, usually with the help of a counselor, stating what the work goal is, what is needed to achieve it, and what it will cost. The work goal can be anything you realistically expect to accomplish that will generate adequate income. It can be part- or full-time, at home or not, working for wages or starting a business of your own.

The things you buy must be related to the goal and can include training, testing or tuition; a car or van; computer, tools and supplies of your trade or business; daycare for a child while you work or attend school; and other sorts of adaptive technology, etc.

To start, ask your local Social Security office for a copy of PASS form SSA-545-BK. This has most of the information needed to review your plan. Next, choose a work goal for a job you want to do. Figure out what steps you need to take to reach your goal and how long it will take you to complete each step. Find out how much money you’ll need to set aside each month to pay for items or services you will need to reach your goal. Get several cost estimates for the things you need.

If you’re planning to set aside income for your plan, your SSI benefit will usually increase to help pay your living expenses. Contact Social Security; the agency can estimate what your new SSI payment will be. Keep any money you save for your goal separate from any other money you have; open a separate bank account for the PASS money.

If you intend to start a business, you will also need a business plan describing what kind of business you want to start, hours of operation and location. You should also explain how you will pay for your business, how you will market your product or service, who your suppliers and customers will be, and your expected earnings.

It may be a good idea to get help writing your PASS from a vocational rehabilitation counselor, an organization that helps people with disabilities, or the people at your Social Security office. After you submit your plan, Social Security will review it and decide if there is a good chance that you can reach your goal, if the things you plan to buy are necessary and reasonably priced, and if any changes are needed. They will discuss any changes with you. If your PASS is denied, there is an appeals process. If your plan is approved, Social Security will contact you from time to time to make sure that you are following

your plan and on the way to your goal. Make sure that you keep receipts for the items and services you buy for the plan.

### **Vocational Rehabilitation (VR)**

Every state has a federally funded agency that administers vocational rehabilitation, supported employment, and independent living services. VR assists people in finding jobs through local searches and by promoting self-employment and telecommuting opportunities. VR services vary widely by the state, but typically include: medical, psychological and vocational assessments; counseling and guidance; vocational and other types of training; interpreter and reader services; services to family members; rehabilitation technology; placement; post-employment services; and other goods and services necessary to achieve rehab objectives. In some cases, VR pays for transportation and vehicle modification.

#### **SOURCES**

Social Security Administration, Rehabilitation Services Administration

### **EMPLOYMENT RESOURCES**

**ADA National Network:** National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) has established 10 regional centers to provide information, training and technical assistance to employers, people with disabilities and other entities with responsibilities under the ADA. Toll-free 1-800-949-4232; [www.adata.org](http://www.adata.org)

**AgrAbility Project** assists people with disabilities employed in farming and ranching. The Project features a database of assistive technology for the agricultural industries, including adaptive tractors and other modified gear. [www.agrability.org/](http://www.agrability.org/)

**Consortium for Citizens with Disabilities** is a coalition of about 100 national disability organizations working toward the self-determination, independence, empowerment and inclusion of children and adults with disabilities in all aspects of society. [www.c-c-d.org](http://www.c-c-d.org)

**Council for Disability Rights (CDR)** believes that people should be encouraged and accommodated to live independently and to participate fully in community life. [www.disabilityrights.org](http://www.disabilityrights.org)



**Job Accommodation Network (JAN)** is a free consulting service that provides information about job accommodations, the Americans with Disabilities Act (ADA), and the employability of people with disabilities. Toll-free 1-800-526-7234, <http://askjan.org>

**Model Systems Knowledge Translation Center (MSKTC)** provides information on employment after spinal cord injury; [www.msktc.org/sci/factsheets/Employment-After-Spinal-Cord-Injury](http://www.msktc.org/sci/factsheets/Employment-After-Spinal-Cord-Injury)

**National Business & Disability Council** is a resource for employers seeking to integrate people with disabilities into the workplace and also for companies hoping to reach them in the consumer marketplace;. 516-465-1400; [www.nbdc.com](http://www.nbdc.com)

**National Collaborative on Workforce and Disability for Youth (NCWD/Youth)** works to ensure that youth with disabilities have full access to services in order to maximize opportunities for employment and independent living; toll-free 1-877-871-0744; [www.ncwd-youth.info](http://www.ncwd-youth.info)

**Office of Disability Employment Policy (ODEP)** is a federal agency that works to increase job opportunities for adults and youth with disabilities while striving to eliminate barriers to employment. Toll-free 1-866-487-2364; [www.dol.gov/odep](http://www.dol.gov/odep)

**Rehabilitation Services Administration (RSA)** administers grant programs and projects that serve individuals with disabilities in the areas of vocational rehabilitation, supported employment and independent living. 202-245-7488; <http://rsa.ed.gov>

**Social Security Administration** operates the Ticket to Work and PASS programs; toll-free 1-800-772-1213. Visit [www.ssa.gov](http://www.ssa.gov) for details on all SSA programs. Use the search function on the home page and type in "Ticket" or "PASS." For the Ticket, see [www.choosework.net](http://www.choosework.net)

**U.S. Office of Personnel Management** provides information on the hiring of people living with disabilities into federal jobs. [www.opm.gov/about-us/careers-at-opm/individuals-with-disabilities](http://www.opm.gov/about-us/careers-at-opm/individuals-with-disabilities)



## FINANCIAL PLANNING

A sudden stroke, spinal cord or brain injury can be devastating not only emotionally and physically, but also financially. This is true also for families with children with disabilities. Gaining control of the financial future is difficult for people who may be preoccupied with day-to-day disability issues. While situations vary, there are some basic steps to take to reduce anxiety about paying bills and affording necessary equipment and care down the road.

Get organized: ask for help; talk to your employer about disability benefits, if any; locate important financial and legal papers; estimate as best you can your medical expenses; prioritize your bills; and keep good records. Consider all sources of funds for medical care and equipment, including your health insurance, VA benefits, auto insurance, workers comp, lawsuits, etc. Try to keep your current insurance policy in force. If you lapse in coverage for two months or more, you could be denied coverage for up to a year in your next group plan. A program called COBRA allows for continuation of coverage in some cases including if your employment ends (voluntarily or involuntarily) for reasons other than gross misconduct or your work hours are reduced to the point you no longer qualify for your employer's healthcare plan.

It is important to understand Social Security and federal healthcare benefits (see information earlier in this chapter). It is also important to know and advocate for your rights.

### Special Needs Trust

If you receive an inheritance or settlement, this could reduce or stop benefits you may be receiving from Medicaid, SSI, or a VA pension (benefits that are paid based on your financial need). SSDI and VA compensation benefits are not based on financial need and therefore are not affected by an inheritance or settlement.

With careful planning, a person with a disability can receive an inheritance that will supplement the government assistance but not replace it. A financial tool called a special-needs trust can be established to provide funds for quality-of-life items—therapy, classes, or a computer—that are not covered elsewhere. A trust is sometimes funded with an initial cash payment, with additional funds added later through a structured settlement that makes guaranteed payments irrevocably into the trust; payments are exempt from federal and state income taxes. A trust can hold cash, stocks,

### TAP YOUR NETWORK

*What do you do when there is no insurance money, no settlement, not enough coverage from Medicaid and still great need? You might turn to churches or service organizations (Kiwanis, Elks, etc.) for help. Less than half the people with spinal cord injuries have insurance at the time of trauma.*



*Even when there is insurance, it is usually limited. Many turn to their own community network for help. A nonprofit called **Help Hope Live** offers a step-by-step framework to raise medical funds locally; because the program is approved by the IRS, all funds raised are tax-deductible to donors.*

*Help Hope Live collects and manages funds in the name of persons with spinal cord trauma or any other major injury. The funds are disbursed as needed, with some restrictions. Some expenses must be paid directly to vendors, including those for home or vehicle modifications, durable medical equipment, and insurance co-pays. Some things cannot be paid from these funds, including rent, mortgage, tuition, electronics or personal items, or taxes.*

*“At the time of my accident, I was very fortunate to have people in my life with the means and desire to offer financial support for my recovery,” says Lyena Strelkoff, a T11 paraplegic from Los Angeles. “But their generosity was limited by the fact that no deduction could be taken. My relationship with Help Hope Live allowed my donors to make sizable contributions and receive a tax deduction for their kindness.”*

*Help Hope Live also helps coordinate fundraising efforts. “They gave us ideas for fundraisers, shared sample materials, created flyers, and gave us valuable feedback on our fundraising materials,” says Strelkoff. Help Hope Live, toll-free 1-800-642-8399; [www.helphopelive.org](http://www.helphopelive.org)*

personal property and real property. It can own and/or be the beneficiary of life insurance.

A person with a disability might also be able to use his or her own income to set up a similar type of trust, called an income cap trust, in order to meet Medicaid income limits. There are restrictions on what the trust can pay. Money paid directly to the individual from the trust reduces the SSI payment. Setting up a special-needs trust requires careful planning. Work with a lawyer familiar with estate planning and the rules governing assistance programs for which you may qualify now or in the future.

In 2014, the Achieving Better Life Experience (ABLE) Act was signed into law. The ABLE Act allows people with disabilities (with an age of onset up to 26-years old) and their families the opportunity to create a tax-exempt savings account that can be used for maintaining health, independence and quality of life.

## **FINANCIAL PLANNING RESOURCES**

**ABLE National Resource Center** provides information on the benefits of ABLE accounts. [www.ablenrc.org](http://www.ablenrc.org)

**COBRA:** The Consolidated Omnibus Budget Reconciliation Act (COBRA) provides certain former employees, retirees, spouses, former spouses, and dependent children the right to temporary continuation of health coverage at group rates. [www.dol.gov/general/topic/health-plans/cobra](http://www.dol.gov/general/topic/health-plans/cobra)

**National Multiple Sclerosis Society** offers a free 85-page book, “Adapting: Financial Planning for a Life with Multiple Sclerosis.” Go to their website: [www.nationalmssociety.org](http://www.nationalmssociety.org) (search “financial planning”) or call toll-free 1-800-344-4867 to be mailed a copy.

**Veterans:** You may qualify for medical care and services from the Department of Veterans Affairs (VA). Even if you have other healthcare coverage, apply for VA benefits. Call toll-free 1-800-827-1000; [www.va.gov/vaforms](http://www.va.gov/vaforms)

## **FIND RESOURCES IN YOUR AREA:**

### **RESOURCE MAP**

*The Christopher & Dana Reeve Foundation's resource map places local information at your fingertips.*

*Simply type your zip code, and our resource map will show you numerous nonprofit organizations, agencies, groups, medical facilities, and government offices that serve the needs of people living with disabilities in your area.*

*Entries for our Quality of Life grantees are marked with a gold star next to their name. These organizations received funds from the Reeve Foundation's Quality of Life Grants Program to benefit people living with paralysis in your area.*

Visit the Resource Map at: [www.ChristopherReeve.org/map](http://www.ChristopherReeve.org/map)

**CHRISTOPHER & DANA REEVE FOUNDATION** | **RESOURCE MAP**

1199 Pleasant Valley Way, West Orange, NJ 07052  
Tel: (973)731-3600 · Fax:  
<http://www.kessler-rehab.com/programs/spinal-cord-injury-rehab/Default.aspx>  
[Rehabilitation](#), [Rehabilitation](#), [CARF](#)

**Cheshire Home, Inc.** ★  
4.6 miles away  
Cheshire Home is formed to establish and operate not for profit residential specialized care facilities, services, and homes for physically disabled adults, providing them with such medical, social and rehabilitative services as will permit each resident to achieve his/her maximum independence compatible with his/her disability.  
9 Ridgedale Avenue, Florham Park, NJ 7932  
Tel: (973) 966-1232 · Fax: (973)966-6153  
<http://www.cheshirehome.org>  
[Assistive technology](#), [Tools and Tech](#)

**Arts Unbound, Inc.**  
4.8 miles away  
Arts Unbound (AU) is a non-profit organization dedicated to the artistic achievement of youth and adults living with physical, developmental or mental disabilities.  
542/544 Freeman St, Orange, NJ 07050  
Tel: (973)675-2787 · Fax: (973)678-4408  
<http://www.artsunbound.org>  
Lifestyle, Arts and Creativity

# 7

## TOOLS & TECHNOLOGY

With the right gear, gadgets, and equipment, people living with paralysis can open the doors of opportunity, self-sufficiency, employment, or recreation.

*The RoughRider Wheelchair is targeted for use in areas of rugged terrain and poor infrastructure. Ralf Hotchkiss, who began redesigning wheelchairs after he became disabled in a motorcycle accident in college, co-founded Whirlwind Wheelchair International in order to design sturdy wheelchairs that could be easily built and repaired in developing countries from locally available materials. The RoughRider frame is made from thin-walled steel tubing, available almost anywhere. The back wheels are bicycle tires. The chairs are now made in Mexico, Turkey, South Africa, Vietnam, and Indonesia. Please see [WhirlWindWheelchair.org](http://WhirlWindWheelchair.org)*



Welcome to the wonderful world of assistive technology, all the tools, gear and gadgets that can profoundly affect the lives of people who have lost function due to paralysis. Innovation and product design offer much more than convenience, of course. There are many people thriving in their communities who would have been locked away in institutions a generation or two ago.

### MOBILITY ASSISTANCE

For many people living with paralysis, mobility is a primary concern. Being mobile means being able to function at home and away from home, whether it's work, social pursuits, or travel. Mobility is a critical factor in maintaining a good quality of life and some level of independence and in continuing one's life to the fullest degree possible. The right assistive device can hold the key.

The "right" device might be a simple cane, or it might be a power stand-up wheelchair that can climb a stair or two when necessary. The gamut of mobility-assistive devices also includes walkers, crutches, prosthetics and orthotic devices, manual and motorized wheelchairs, and scooters. Specialized chairs are available for children, sports enthusiasts, and off-road use. Technology is advancing rapidly, and sci-fi scenarios like exoskeletons and eye-gaze controls are gradually becoming more than science fiction (though still not commercially available).

There is no one-size-fits-all answer to the mobility needs of people living with paralysis. Determining what will work best for any individual must take into account the nature of their injury and degree of functional capacity as well as their lifestyle and day-to-day activities. Other considerations include:

- Mobility goals: what are they and what will it entail to meet them?
- Your needs both today and in the short-term future
- Your living and work environment, inside and outdoors
- Planned usage of a wheelchair or other mobility device
- Travel plans, e.g., as a driver or a passenger in motor vehicles



**This chapter provides information on:**

- Crutches, Canes and Walkers
- Manual Wheelchairs
  - To Fold or Not to Fold
  - Shock Absorbers
  - Lightweight Models
  - Wheels and Rims
  - Propulsion Alternatives
- Power-Assist Devices
- Power Wheelchairs
  - Next-Generation Power Chairs
- Chairs for Children
- Seating and Positioning
  - Tilting and Reclining Chairs
  - Stand-Up Chairs/Stations
  - Cushions
- Scooters
- Batteries
- Reimbursement Considerations

**CRUTCHES, CANES AND WALKERS**

Ambulatory assistive devices such as canes, crutches and walkers can help some people retain or regain the ability to walk. The capacity to ambulate even short distances or a few steps can make a world of difference to one's ability to live independently and maintain basic activities of daily living. Choosing these devices takes time and research, and is best done in collaboration with an Occupational Therapist (OT) or Physical Therapist (PT) – preferably one who specializes in assistive technology – or a Rehab Technology Supplier who can guide the selection and fitting process. Crutches, canes and walkers need to be carefully fitted to the individual user. If they fit, these devices offer support and critical mobility, but if they don't fit, they can be uncomfortable and even unsafe.

**INTRODUCTION TO WHEELCHAIRS**

The common saying has it all wrong: People are not “confined” to their wheelchairs; they are in fact liberated by their wheels. A person with paralysis can get around as quickly in a wheelchair as anyone else can walking, or faster. A wheelchair offers people access to work, shopping, appointments, or any other travel outside the home. For those who are so inclined, a wheelchair accommodates participation in races, basketball, tennis, and other sports.

In some ways a wheelchair is like a bicycle: There are many designs and styles to choose from including manuals, lightweights, racing models, rugged-wheeled models, and so on. Distinct styles of chairs fit special purposes, just as a bicycle is specialized for street or trail use. As with bicycles, if the fit of a wheelchair isn't just right, the user may be unable to get comfortable and therefore not achieve maximum function. An ill-fitting wheelchair can increase the risk of pressure injuries, which can be painful and even life-threatening if not identified early and treated properly.

Modern wheelchairs are a different breed than they were even a decade ago. Innovations in materials and engineering have made them lighter, faster, and easier to use. They offer better support for a person's back, neck, head, and legs, incorporate materials and mechanisms designed to reduce the risk of pressure sores, and employ safety features such as automatic brakes and anti-tipping devices. Many now use sophisticated computer technology and electronic controls that can be operated with a simple joystick or, for quadriplegics, a “sip-and-puff” system activated with a straw.

Selecting the right chair, especially for a first-time wheelchair user, can be confusing. The new Medicare and Medicaid guidelines require people to go to a certified seating clinic to work with an OT or PT who has experience with various kinds of wheelchairs or with a Rehab Technology Specialist who has experience with adaptive equipment. These specialized healthcare providers can offer advice on what might best meet the individual's needs – not just

physical needs, but personality needs as well, because a chair is really an extension of the person using it. Of course, insurance-coverage limits and budget constraints must also be taken into consideration. It's worth taking the time to get it right, because for a person living with paralysis, a wheelchair can be the most important tool there is.

Permobil is one of the largest wheelchair manufacturers in the United States. It is composed of three different companies which supply different products. Permobil offers power wheelchairs under that name, manual wheelchairs under the TiLite brand, and ROHO for wheelchair cushions and other accessories. <https://permobilus.com>

## MANUAL CHAIRS

Manual chairs fall into two general categories: those that are meant to be pushed by another person, and those that are propelled by the wheelchair user. People who have sufficient upper-body strength may choose a self-propelled manual chair, which typically has rims on the outside of the large rear wheels that are grabbed and pushed. Depending on the needs of the user, chairs may be adapted for propulsion with the legs, or with one arm and one leg.

Wheelchair design has come a long way since the clunkers of yesteryear. Modern chairs are designed for lighter weight and superior performance, offering greater comfort for the user and easier pushing. Whether with a rigid (non-folding) frame or a folding frame, lightweight materials make it easier to lift the chair in and out of cars for transport.

A great starting place for researching manual wheelchairs is the Reeve Foundation's online video series on "Manual Wheelchair Comparisons", which includes detailed test drives and consumer-friendly information on manual wheelchairs from leading manufacturers as well as information about wheelchair shopping, accessories, and pediatric wheelchairs. The Reeve Foundation's website also offers archived webcasts on chair selection and proper wheelchair fit.

### To Fold or Not to Fold?

Generally speaking, a rigid frame transfers more of the rider's energy into the forward motion than does a folding unit. The primary advantage of a folding chair, of course, is portability; some can even fit in the overhead bin of an airplane. The hardware and mechanisms required to enable a chair to fold up

typically add modest weight to the chair. Rigid chairs are more durable while folding chairs do not always hold up over time.

### Shock Absorbers

Suspension systems designed to make the ride smoother and minimize spasticity are an increasingly common option; they also can add weight to the chair, as well as expense. Aftermarket products such as Frog Legs ([www.froglegsinc.com](http://www.froglegsinc.com)) add suspension to the front forks, acting like shock absorbers to smooth the ride over bumpy terrain or curbs. Such add-ons are generally not approved for reimbursement by Medicare.

### Lightweight Models

The weight of the chair can be an important consideration, not just for when the chair needs to be picked up but also for ease of mobility. Lightweight chairs require less exertion to push, and therefore less strain on muscles. The use of high-tech materials such as super-light titanium in wheelchair frames has made it possible to bring the weight of chairs down considerably. Titanium is advantageous not only for its lightness, but also its strength, durability and built-in shock absorption. Titanium wheelchairs are generally more expensive, and custom-built options may take a little longer to have made. Among the many options for lightweight chairs, Permobil's TiLite ([permobilus.com/products/tilite-manual-wheelchairs-smartdrive-power-assist](http://permobilus.com/products/tilite-manual-wheelchairs-smartdrive-power-assist)) leads the pack in the U.S. Panthera, from Sweden, offers a super lightweight chair that weighs under 10 lbs. including wheels ([www.panthera.se/index\\_en.html](http://www.panthera.se/index_en.html)).

### Wheels and Rims

The options for wheels, tires and push rims have also expanded, including innovations for high performance, off-road traction, and style. A company called Spinergy ([www.spinergy.com](http://www.spinergy.com)) branched out from the bicycle business to add a high-performance line of wheelchair rims that are lightweight and steer true. The company's patented push-rim system bridges the rim and the tire, allowing for an easier, low-impact push that protects hands and arms from impact and allows the user to push without ever touching the tire.

The FreeWheel wheelchair attachment clamps onto a manual chair with certain types of foot plates to gently lift the chair's front casters off the ground and transform a standard chair into a 3-wheel, all-terrain chair that can be safely pushed over grass, curbs, or rough terrain. A special adapter enables it to fit onto any folding chair. ([www.gofreewheel.com](http://www.gofreewheel.com))

## Propulsion Alternatives

While an estimated 90 percent of all wheelchairs are push-rim propelled, this type of ambulation can be physically straining and can lead to repetitive strain injuries in the arms and wrists. A number of companies are now making alternative systems to the standard wheel-rim chair propulsion, including chairs and aftermarket systems that can be used to modify a manual chair. These systems typically incorporate either a side-lever design, or a rowing-action design.

For example, the RoChair ([www.rotamobility.com](http://www.rotamobility.com)) uses an ergonomic, compact lever drive system that mounts to the chair's front center. The user turns the handlebars like a bicycle to steer and with a rowing motion, propels the chair with both the forward and backward strokes. Extending the lever up adds more power to the propulsion and pulling it back all the way engages the powerful rear hub brake.

NuDrive Air ([www.nu-drive.com](http://www.nu-drive.com)) calls itself the world's first lever-powered system for manual chairs. Wheel adaptors attach easily to a manual chair's wheel with snap-lock technology and are driven by levers on each wheel. Force applied to the levers propel the chair forward with less muscle power than a rim-based wheel drive. NuDrive claims the system reduces the effort of propulsion by 40 percent and minimizes wear and tear on shoulders and arms.

The Willgo manual chair ([www.willgowheelchairs.com](http://www.willgowheelchairs.com)) also incorporates a lever-based propulsion system. It looks like a conventional chair but incorporates a lightweight, compact, manual-powered transmission system that boosts the user's muscle power by up to two times while enabling a more upright sitting position during movement.

The Wijit Wheelchair Lever Driving and Braking System (<http://wijit.com>) is an add-on system that propels the chair in a similar fashion, but also incorporates a reverse mode. Wijit wheels replace the standard wheels of a manual chair with a simple installation kit. The company's website says that its combination of lever drive and transmission significantly reduces the force



required to propel the chair, cutting the number of wheel pushes each day at least by half.

## Power-Assist Options

Sometimes all one needs is a boost of power. A sort of hybridization is occurring in the assisted-mobility world as manual wheelchairs are tricked out with compact power packs that can make a manual chair act like a motorized one when needed. Power assists can dramatically increase a wheelchair user's mobility range both in distance and terrain accessibility. They also reduce the physical workload of manual-chair travel to preserve one's energy and decrease wear and tear on the shoulders, arms and wrists. On the downside, the devices add significant weight to the chair (up to 50 pounds, though there are some lightweight models) and can be quite expensive (with prices typically in the \$5,000 to \$8,000 range).

The increasing number of options for a power boost range from do-it-yourself motorization kits to removable front ends that essentially turn a manual chair into a power scooter. The most common iterations rely on a small, powerful motor that typically attaches to the wheels or chair base. Some variations boost the chair user's propulsion through kinetic energy while others power the chair independent of manual effort.

### Here's a brief rundown on some of the power-assist options currently available:

- At the high end of the market is the Swiss-Trac ([www.swisstrac.ch/en/](http://www.swisstrac.ch/en/)), a four-wheeled motorized unit with a steering apparatus that is made in Sweden and available through dealers in Europe. The rugged Swiss-Trac looks like a small lawnmower that attaches to the front of the chair to power through rough terrain or ease the burden of long-distance rolling.
- The same concept in a more portable unit is behind RioMobility's (<https://riomobility.com>) snap-lock, two-wheeled power and steering unit, which fits in a trunk and attaches instantly to the front of the chair when needed.
- The Samson Power Drive PD-6A from Tzora ([www.tzora.com](http://www.tzora.com)) is designed to ease the burden of pushing a chair. Resembling an upright vacuum cleaner, it attaches to the back of any manual chair to provide a power boost via 12 volt rechargeable batteries. It weighs about 60 pounds (48 with a 9 volt battery) and is narrow enough to fit into most car trunks.



- The e-motion from Alber replaces manual wheels with a power-assisted wheel with lithium-ion batteries integrated into the wheel hub. A sensor in the wheel registers the propelling movement and activates the electrical motor. The e-motion is portable and fits most manual chairs. Available from wheelchair dealers such as Alber ([www.alber-usa.com](http://www.alber-usa.com)) and Allegro ([www.allegromedical.com](http://www.allegromedical.com)). The e-fix version of the e-motion adds an armrest joystick for controlling the motor.
- The Xtender expands the range of mobility for manual wheelchair users by adding power assisted wheels to a manual frame. Developed by Quickie and Yamaha, the Xtender features quick-release motorized rear wheels that increase the force applied to the handrims by up to four times. Weighing about 38 pounds with a seven-hour battery life, it is available from chair and accessory dealers for some Quickie models. ([www.quickie-wheelchairs.com](http://www.quickie-wheelchairs.com))

- SmartDrive is a lightweight drive wheel that hooks onto the back of the chair at the wheel axle and acts like a motorized fifth wheel with a built-in rechargeable battery. It can be paused with a tap on the wheel rim and is speed-adjustable. New models come with the PushTracker motion-sensing control wristband that communicates with the drive motor via Bluetooth technology, and a smartphone app that enables you to individualize speed and other parameters and monitor activity. The SmartDrive + PushTracker is typically priced around \$6,000, comparable to rim-based power-assist units.



*SmartDrive: portable, easy to hook up.*

- Spinergy offers the ZX-1 motorized add-on with built-in wheels and armrest that attaches to the back of a manual chair. A joystick on the armrest (adaptable to either side) controls the unit, which operates off 2-volt lead gel mat batteries or an optional lithium ion battery, which reduces the weight of the unit from 82 pounds to 75 pounds and doubles the range of the motor from 5 miles to 10. ([www.spinergy.com](http://www.spinergy.com))

- The Twion bills itself as the fastest and lightest wheel-based power drive. Compact and quiet, the wheel hub drives use built-in lithium ion batteries to ensure greater propulsion force on push-rim wheels. Suitable for almost all common active wheelchairs, the drives attach with a lightweight, quick-release bracket that is fitted to the wheelchair without removing the original wheels. A smartphone app enables remote control via Bluetooth technology. ([www.alber-usa.com/us/products/active-drives/twion](http://www.alber-usa.com/us/products/active-drives/twion))
- MagicWheels ([www.magicwheels.com](http://www.magicwheels.com)) don't use batteries or a motor, but rely on dual-gear wheels that, with a click of the hub, kick into a lower gear when needed to navigate hills or rough terrain. They generally run about a third of the cost of power-assist units.

## MOTORIZED WHEELCHAIRS

A person whose paralysis prohibits him or her from self-propulsion, or who requires mobility assistance for longer distances or special conditions (e.g., rough terrain) may require a power wheelchair. Available in many iterations, power chairs operate with an electric motor driven by rechargeable batteries. Steering and power are controlled by a joystick (most commonly), a keypad, or, for people without the use of their hands, a “sip-and-puff” system that the user controls by manipulating air flow through a straw-like tube to the mouth. There are also joystick controls operable by chins or sensors built into headrests. Newer models incorporate hands-free technologies like Bluetooth and smartphone apps that monitor activity.

Twenty years or so ago, the power-chair market was limited to just a few brands and models that were bulky, heavy and expensive. Innovation has expanded the choices toward lighter, more powerful and much faster chairs. Several basic styles are available. The traditional power chair looks like a



beefed-up standard-issue wheelchair with extra bulk comprised of batteries, motor, and control systems. There are also platform-model power chairs with a more ordinary-looking seat or captain's chair fixed atop a power base. Tilting, reclining, and stand-up chairs comprise the higher end of the power-chair market, and custom-built chairs are available from a number of manufacturers to meet special needs.

Most power chairs have rear-wheel drive, but mid-wheel and front-wheel drives have grabbed a share of the market. These are easier to turn and can be especially useful for negotiating tight spaces. Some models are rugged and built for off-road use; some are designed for portability (e.g., e-Throne makes a folding power chair that collapses to fit in the trunk of a car;

[www.goldenmotor.com](http://www.goldenmotor.com)), and some for special uses such as sports. There are ultra-lightweight three-wheelers for road racing; sporting chairs with extra camber to prevent tip-overs; heavy-duty four-wheelers for off-road use; chairs with big puffy tires for navigating sandy beaches or other challenging surfaces, and even chairs with tractor treads for those who want to negotiate the roughest terrain. Almost any chair can be customized for the individual needs of people with paralysis.

The best choice for each user is based on much more than style. The right chair maximizes the user's mobility and independence, meets every-day needs and suits his or her particular lifestyle. (See the list of considerations when choosing a chair in the introduction to this section.) The new Medicare and Medicaid guidelines require people to go to a certified seating clinic to work with an OT or PT who has experience with various kinds of wheelchairs or with a Rehab Technology Specialist who has experience with adaptive equipment. The Reeve Foundation's website offers archived webcasts on wheelchair selection and proper wheelchair fit that provide a helpful starting point, and a video series, "Power Wheelchair Comparisons" (produced by power chair user Jenni Gold), offers comprehensive information on a range of models as well as information on reimbursement, warranties, safety considerations, batteries, and custom modifications.

With so many options available, doing some research is critical to finding the right chair and supplier. Ask people with experience using chairs, including other people in the disability communities, OTs/PTs, rehab specialists, and online experts in wheelchair selection. Watch the Reeve Foundation's online videos (see above). Join online forums and make it a best practice to ask others in the community for suggestions. Read user reviews of products to

understand how the chairs function in real-world situations.

The Reeve Foundation has a team of Information Specialists available to answer questions and provide individualized support; specialists can be contacted online or by calling 1-800-539-7309.

## NEXT-GENERATION POWER CHAIRS

When it launched in 2003, the groundbreaking iBOT offered wheelchair users access to an expanded terrain. Created by Dean Kamen, inventor of the Segway, the powerful wheelchair could rumble over cobblestones, up curbs and across sandy beaches. It could also climb stairs and transform from standard to two-wheel mode, allowing individuals to move while 'standing' and interact with others at eye level. But the price tag —about \$24,000 – was high and reimbursement from insurance companies rare; Johnson & Johnson discontinued production in 2009.

A decade later, New Hampshire-based Mobius Mobility has unveiled a next generation iBOT. The new, lighter model renamed the iBOT Personal Mobility Device (PMD,) features the same capabilities as the original along with enhanced and simplified user interface and improved battery life. Significantly, the Food and Drug Administration has reclassified the iBOT PMD as a Class II medical device, expanding its options for seating systems and controller designs. The iBOT PMD's price tag, roughly \$30,000, remains steep, but Mobius Mobility is working with the Centers for Medicare and Medicaid Services, the Veterans Health Administration and private insurers to encourage reimbursement, and also with non-profits and private donors to help defray costs for users.

Meanwhile, the popularity of the old iBOT (a few of which are still in use) seems to have spawned a new generation of stand-up wheelchairs and Segway-like adaptations. A New Zealand firm, OmeoTechnology, has developed a self-balancing, hands-free chair that it calls the Omeo (<https://omeotechnology.com>) built from a Segway-based prototype. The firm's website says the chair, which is steered by body movement with a joystick option costs just under \$20,000.

The WHILL Model M power chair – though not a stand-up – is being marketed as a "next-generation" chair in terms of style and maneuverability. Approved by the FDA in 2016, the Model M features patented omni-wheel four-wheel-drive technology to tackle tough terrain outside, while its compact shape

and nimble steering easily navigate tight spaces. The high-tech chair includes advanced software that can evolve as developments in autonomous driving become more integrated with online mobility resources and mapping; a mobile app is also in development to support the user experience. ([www.whill.us](http://www.whill.us))

## CHAIRS FOR CHILDREN

Children's bodies are growing and changing, which means their chairs must be adjusted or replaced more often than adult chairs. Since chairs are expensive and insurance providers often place limitations on replacement, most manufacturers offer adjustable chairs to accommodate a growing child. Wheelchair companies also offer chairs specially designed for kids, which don't look as "medical" as traditional styles. The updated looks offer more streamlined designs, kid-friendly upholstery, and a variety of frame colors.

- Colours ([www.colourswheelchair.com](http://www.colourswheelchair.com)) offers a few children's chairs including the Little Dipper and the Chump, kid-sized chairs with a little attitude.
- Sunrise Medical makes a range of ultralightweight chairs with built-in adjustments to keep up with a growing child, including the Quickie Zippie and the Quickie Iris ([www.sunrisemedical.com](http://www.sunrisemedical.com)).
- The Invacare Orbit ([www.invacare.com](http://www.invacare.com)) is a tilting chair that features a detachable seat frame and the ability to mix and match seats and bases for multiple custom fits and results that grow with the child.
- Permobil (<http://permobilus.com>) and TiLite offer a variety of pediatric chairs including a tilt chair that are adjustable as the child grows.

A few organizations offer free or low-cost wheelchairs to children in need, including Kids Mobility Network ([www.kidsmobility.org](http://www.kidsmobility.org)), the Wheelchair Foundation ([www.wheelchairfoundation.org](http://www.wheelchairfoundation.org)), and Free Wheelchair Mission ([www.freewheelchairmission.org](http://www.freewheelchairmission.org)).



*Sunrise Quickie Zippie*

## SEATING AND POSITIONING

People with paralysis are at high risk for pressure sores and therefore usually require special cushions and seating systems to disperse the pressure of prolonged sitting and reduce the risk of skin complications, which can be serious and even life-threatening if not treated promptly. Several kinds of cushion materials are available, each with benefits for certain types of users, including air, foam, or liquid gel. No single product will be right for all people. The right cushion can help ensure correct posture, improve comfort, and prevent pressure sores, but it doesn't necessarily have to meet all of those criteria for every user. For example, an ambulatory person who only uses a wheelchair to go shopping doesn't have the same needs in a cushion as a high-level quad who spends 18 hours a day in a power chair. It's important to fully understand individual requirements and work with a seating and positioning expert to select a product that meets an individual's specific needs for comfort and well-being.

Foam is the least expensive material for a cushion. It's also lightweight and doesn't leak or lose air. It does wear out, however, losing its compression over time. Jay Cushions ([www.jaycushions.net](http://www.jaycushions.net)) offers a wide variety of foam cushions and backrests, some with air-cell inserts and specialized features to accommodate a range of needs.

Air flotation cushions provide support using a rubber bladder of evenly distributed air. These generally work well to equalize pressure over bony prominences and promote good blood circulation to reduce the danger of damaging the skin. They can, however, be prone to leaking, and they require air adjustments with changes in altitude. The BBD single-chamber air cushion (aka the "Bye Bye") was introduced in the 1950s and is still widely used for inexpensive pressure relief. ([www.randscot.com](http://www.randscot.com)) The ROHO line of cushions ([www.permobilus.com](http://www.permobilus.com)) uses a "dry flotation" approach of many individual cells that move independently to provide support while dispersing pressure and reducing shear and friction. ROHO offers models with foam coverings for added comfort, and an available "SmartCheck" system alerts the user to under- or over-inflation. Vicair ([www.vicair.com](http://www.vicair.com)) packs its seat and back cushions with many small, permanently sealed air cells to disperse pressure, and its cushions can be adjusted by unzipping the liner and removing or adding air cells.

Gel cushions are typically filled with slow-flowing, viscous gel. They are



popular and effective for skin protection, but can be relatively heavy. Many cushions combine a gel pack with foam to reduce the weight of the cushion and improve comfort. Comfort Company ([www.comfortcompany.com](http://www.comfortcompany.com)) and Drive Medical ([www.drivemedical.com](http://www.drivemedical.com)) have a number of options.

A fairly recent development in cushion technology is the pressure-changing cushion, which is based on the theory that alternating the pressure in the seat can reduce the risk of skin compression and enable the user to sit for longer periods of time without requiring “lift and shift” adjustments as frequently. Aquila is one example of this kind of dynamic cushion ([www.aquilacorp.com](http://www.aquilacorp.com)). It features an oscillating pump to change pressure at regular intervals. American Medical Equipment ([www.ame-medical.com](http://www.ame-medical.com)) and Ease ([www.easeseatingsystems.com](http://www.easeseatingsystems.com)) also make pressure-changing cushions. These cushions rely on battery power to inflate and deflate the cells, which adds weight to the wheelchair and makes this option less carefree than a static cushion.

Some users might benefit from a custom cushion, made to fit their body. Ride Design’s Custom Cushions offers a line of individualized cushions and back supports generated from a mold of the user’s body that is adjustable to growth and body changes. ([www.ridedesigns.com](http://www.ridedesigns.com))

For an overview of available cushions and seating systems, see SpinLife ([www.spinlife.com](http://www.spinlife.com)) or United Spinal Association’s Wheelchair Reviews and Views. (<https://unitedspinal.org/wheelchair-reviews-views>).

## TILT OR RECLINE OPTIONS

Specialized wheelchairs can be useful to distribute pressure and reduce the risk of pressure injuries, as well as to improve comfort and sitting tolerance. Tilting chairs change a person’s orientation while maintaining fixed hip, knee and ankle angles. In effect, the whole seat tilts to a varying degree of angles. Another option is a reclining chair, which changes the seat-to-back angle by flattening out the back of the chair and, in some cases, raising the legs to form a flat surface. Both tilt and recline options must be



*Old school: recline yes; tilt no.*

fitted and prescribed by seating and positioning experts.

A tilt system redistributes pressure from the buttocks and posterior thighs to the posterior trunk and head. The system maintains posture and prevents shearing (the friction on tissues from dragging across a surface). One drawback is that if the user sits at a workstation, tilting requires that he or she move back from the table to avoid hitting it with the knees or footrests.

Recline systems open the seat-to-back angle and, when used in combination with elevating leg rests, open the knee angle. There are some advantages to a recline system for eating, making transfers, or assisting with bowel or bladder programs. Generally speaking, the recline system offers more pressure relief than tilt, but with a higher risk of shear. Elevating the legs may be beneficial to people with edema.



## STANDING CHAIRS

Standing chairs act as normal power or manual chairs but also help the rider rise to a standing position. There are many advantages to this at home, in school, in social situations, and in the workplace. Some manual chairs come with a power assist to activate the rising mechanism. Some power chairs also enable the rider to rise to a standing position, offering the advantage of eye-to-eye contact with others. Standing also has physical benefits, helping to prevent pressure sores, to improve circulation and range of motion and, for some people, reduce spasms and contractions. VA research has shown that people who stand for 30 minutes or more per day have significantly improved quality of life, fewer bed sores, fewer bladder infections, improved



Ready Stalls Standing Frames

bowel regularity, and improved ability to straighten their legs. Standing chairs are typically priced at the higher end of wheelchairs and are heavier than an everyday chair.

The Standing Company ([www.thestandingcompany.com](http://www.thestandingcompany.com)) makes three models of its Superstand Standing Wheelchair (manual, half-power, and full-power), each of which is custom manufactured to the user's particular physicality. Levo ([www.levousa.com](http://www.levousa.com)) claims to have the most complete line of standing wheelchairs in the world, including manually propelled standers and power-driven models. Karman

([www.karmanhealthcare.com](http://www.karmanhealthcare.com)) makes standing chairs for adults and children as part of its broader line of chairs. Redman ([www.redmanpowerchair.com](http://www.redmanpowerchair.com)) makes one – and only one – customized power chair that tilts, reclines and stands. Permobil (<http://permobilus.com>) is a leader in adult standing chairs.

A standing frame (also known as a stand, stander, standing technology, standing aid, standing device, standing box, tilt table) is assistive technology that can be used by a person who relies on a wheelchair for mobility but does not double as a mobile wheelchair. Leading manufacturers of standing frames include EasyStand ([www.easystand.com](http://www.easystand.com)), and Stand Aid of Iowa ([www.stand-aid.com](http://www.stand-aid.com)). Some models are motorized to gently glide the user from a sitting position to upright, while others are more rudimentary, essentially providing a static frame to support a person in the standing position.

## SCOOTERS

Scooters are produced in a wide range of styles and formats. Most are three-wheeled but there are also four-wheeled varieties. They are similar in appearance to a lightweight riding lawnmower, with a seat, a steering column, and a platform base that serves as foot support. Scooters are becoming more popular for use among people whose mobility is limited, including older people who have difficulty walking. For people with paralysis, they can be

used to augment other mobility-assistive devices when longer-distance travel is required, or can function for some as an alternative to a powered wheelchair.

The most familiar types of scooters are those often seen at shopping centers and malls. Such scooters may be intended for indoor use only or be designed for both outdoor and indoor use. Normally, their maximum speed is from 6 to 8 mph. Off-road models are designed to navigate rougher terrain while maintaining stability, and typically incorporate a fortified base and stronger, more rugged wheels. Travel scooters are more lightweight versions that enable them to be moved in and out of a vehicle (using a ramp or power lift), and even taken onboard a plane. Many can be disassembled or folded for portability. Lighter-weight scooters usually are equipped with a smaller and less powerful motor, so top speeds will be lower.

Scooters can offer a valuable option for some people with paralysis, but they are not for all. For individuals with a degenerative form of paralysis such as ALS, MS, muscular dystrophy, cerebral palsy, or post-polio syndrome, scooters may not be the best option as their physical condition can change rapidly. They require the ability to stand, steer, sit upright, and have a degree of balance to maintain one's posture during movement. Because they are not as adaptable as most wheelchairs, scooters may not be the best option for someone whose functional capacity is subject to change.

## WHEELCHAIR BATTERIES

Battery life is a crucial issue for power-chair users. Failure to manage this power source can spell trouble, especially if you're far from home. Wheelchair batteries are 24-volt "deep-cycle" batteries; they discharge over long periods, as opposed to an automobile or lawnmower battery (12-volt), which is designed for short bursts of power. Deep-cycle batteries have to be fully discharged before recharging, and most can be recharged as many as 300 times before they lose capacity to hold power. They come in several sizes: Group-22, Group-24 and Group-27; the larger the number, the larger the battery and the more power it stores.

There are three primary types of batteries. Lead-acid or "wet" batteries create electrical energy when lead and sulfuric acid interact. Wet means just that: these battery cells need to be periodically filled with distilled water, which can be problematic for people with paralysis because it puts them at risk of chemical burns during the process. Because of the risk of chemical spills,

they may also be prohibited on airplanes or at least require special handling. Wet-cell batteries have a larger capacity and store more power, and are generally less expensive than other types of batteries, but their safety and environmental concerns have led many chair manufacturers to recommend alternatives.

Gel-cell lead-acid batteries have no liquid, so maintenance is easier and the risk of spills is eliminated. They are more expensive than wet batteries, but they have a longer life cycle and are acceptable for airline travel. Absorbent glass mat (AGM) batteries, like gel units, don't require maintenance and are fine for bringing on airplanes. They are very rugged, hold a charge better, and last twice as long as standard lead-acid batteries. They are also the most expensive.

When buying a new power wheelchair battery, it's important to have the correct charger for the given battery, as an incorrect charger can permanently damage the battery.

Wheelchair batteries are sometimes the same as those used in the boating industry, and it's possible to save money by purchasing marine deep-cycle batteries. Just be sure to check the chair manufacturer's battery specifications in the Instruction Manual.

## REIMBURSEMENT CONSIDERATIONS

Reimbursement is a key consideration for all durable medical equipment purchases, especially high-ticket items such as power chairs, some of which can outprice a small car. Because of the high costs, mobility assistance equipment is often purchased through a third-party payer, whether it is private health insurance, Medicare/Medicaid, the Veterans' Administration, or vocational rehabilitation programs. Each of these institutions has its own system for purchasing assistive devices and an individualized set of criteria it uses to determine whether and how much will be paid. Of course, people who have the resources to do so can purchase wheelchairs and other mobility options directly, which can significantly simplify the process by removing the need for prior authorization by a third-party payer.

The health benefits of power-assist add-ons for manual chairs (e.g., preventing wear and tear of the shoulders) has convinced many third-party payers, including Medicare, to cover their cost.

Increased requirements for prior authorization for such purchases stem in part from federal investigations into Medicare fraud. A 2011 government

report found that 80 percent of Medicare claims for power wheelchairs did not meet coverage requirements and should not have been paid by Medicare. Subsequently, some reimbursement rules have changed, including the requirement for prior authorization in some cases. The move, coupled with

a choice-limiting system of competitive bidding, has been met with much resistance in the disability community due to the barriers and hardships it has caused to people who rely on these devices for mobility. As a result, patient advocacy groups are working through the appropriate channels to ensure that federal reimbursement policies are responsive to the needs of the populations they serve. For example, the ITEM Coalition (Independence Through Enhancement of Medicare and Medicaid) is a consumer-led coalition of national organizations, including the Reeve Foundation, whose goal is to improve access to assistive devices, technologies, and related services for individuals with disabilities. (<https://itemcoalition.org>)

When it's time for a new chair, it's important to work with funding sources, an OT/PT and seating specialist who understands the person's functional ability and needs, and with a qualified rehab supplier to identify and secure the best suited chair and to defend the choice in the event of reimbursement denial.

## REEVE FOUNDATION RESOURCES

If you need more information on wheelchairs or have a specific question, Information Specialists with the Reeve Foundation are available, Monday through Friday, toll-free at 800-539-7309 from 9:00 am to 5:00 pm EST. Specialists can also be reached via the Foundation's website ([www.ChristopherReeve.org/Ask](http://www.ChristopherReeve.org/Ask)).

The Reeve Foundation's website ([www.ChristopherReeve.org](http://www.ChristopherReeve.org)) includes several instructional videos on wheelchair selection and use, including these topics:

- Wheelchair Selection (webcast)
- Proper Wheelchair Fit (webcast)
- Seating and Mobility (webcast)
- The Art of Wheeling (video series)
- Rick Hayden on Manual Comparisons (webcast)
- Manual Wheelchair Comparisons (video series)
- Power Wheelchair Comparisons (video series)



The Foundation also maintains a large directory of fact sheets on hundreds of topics ranging from state resources to secondary complications of paralysis, many of which are also available in Spanish.

([www.ChristopherReeve.org/Factsheets](http://www.ChristopherReeve.org/Factsheets))

#### Foundation fact sheets related to wheelchair use include:

- *Wheelchair Transfers*
- *Wheelchair Seating and Positioning*
- *Wheelchair and Equipment Donations*

### MOBILITY ASSISTANCE RESOURCES

**Better Life Mobility Center** is an online resource for wheelchair transport vehicles and mobility-assistive products including wheelchairs, scooters, adaptive-driving technology, and lifts. [www.betterlifemobility.com](http://www.betterlifemobility.com)

**Disabled World** provides news and information useful to disabled persons, including reviews and news about a range of mobility-related products. [www.disabled-world.com](http://www.disabled-world.com)

**New Mobility** is a magazine for active wheelchair users that includes resources for participating fully in life and articles concerning disability lifestyle. [www.newmobility.com](http://www.newmobility.com)

**Wheelchair Assistance** is a resource website with information on all aspects of mobility assistance. [www.wheelchairassistance.com](http://www.wheelchairassistance.com)

**Diestco** offers all manner of wheelchair accessories, including backpacks, trays, cup holders, canopies, umbrellas and other cool stuff to trick out wheelchairs. [www.diestco.com](http://www.diestco.com)

### ASSISTIVE TOOLS & TECHNOLOGY

Welcome to the wide world of assistive devices. These are the tools and technology, gadgets, gear, products, and equipment that help people with disabilities perform every-day tasks and activities – communicating, eating, getting dressed, going to the bathroom – and help them lead their lives as independently as possible. They impact every aspect of life, from basic activities of daily living to school, work, recreation, and social engagement.

This goes way beyond convenience. The right equipment can profoundly improve the lives of people with spinal cord injury and paralysis, enabling

them to thrive in their own communities and retain or regain a degree of independence that they otherwise wouldn't have. It could be something as simple as the perfect pencil gripper or as sophisticated as an eye-gaze reader that controls household lights and temperature. Assistive devices open the doors of opportunity, self-sufficiency, employment, education, travel...the list is virtually endless. Research is showing that even people living with high-level quadriplegia may be able to interact with their world using thought-controlled computers, the first rudimentary models of which are now in development. Self-driving cars are already a reality.

#### And that's just the beginning...

Take the computer, for example. For anyone, it is an essential and empowering tool. For a person with paralysis, a computer can be life-changing. It unlocks gateways to communities and social networks, information and marketplaces, recreation, even gainful employment. With the right programming interfaces, the computer becomes a control center for all manner of household systems and communications. Handheld devices such as tablets, smartphones and smartwatches put the power of the PC right at our fingertips – and on your wheelchair armrests. Voice-recognition, head-tracking and eye-gaze technology open access to individuals with even the most complex disabilities. Brain-machine interfaces that use nerve signals to power devices promise a next level of progress in overcoming disability.

In the future, one can imagine a world where a paralyzed person can direct a mere thought to turn the wheelchair to the right, or to send an email or turn on the teapot. A tiny electrical pulse in the brain would send a signal to a smartwatch or an implanted chip, which would, in turn, Bluetooth a code to a computer control



center, which would translate it and send a message to a specific device – like the chair, the laptop, or the stove. In this way, people living with paralysis could communicate and regain interaction with their environment.

That’s the future. Right here and now, a host of assistive devices help people with disabilities perform fundamental tasks such as cooking, dressing, and grooming – and most of them are very low-tech. Kitchen implements are available with large, cushioned grips to help people with limited ability to grasp or grip. Medication dispensers with alarms can help people remember to take their medicine on time. People who use wheelchairs for mobility can use extendable reaching devices to reach items on shelves.

Deciding which type of rehabilitative or assistive technology (AT) would be most helpful for any given situation takes a village: the person with a disability, his or her family and caregivers, and a team of healthcare professionals and consultants trained to match products and programs to people who need them. The team may include family doctors, regular and special-education teachers, speech-language pathologists, rehabilitation engineers, occupational therapists, physical therapists, and other specialists, including representatives from companies that manufacture assistive technology.

### **How does rehabilitative & assistive technology benefit people with disabilities?**

Appropriate assistive technology helps people with disabilities overcome or compensate, at least to some degree, for any limitations in function. Rehabilitative technology can help restore function in people who have developed a disability due to disease, injury, or aging.

#### **Rehabilitative and assistive technology can enable individuals to:**

- Care for themselves and their families
- Work
- Learn in schools and other educational institutions
- Access information through computers and reading
- Enjoy music, sports, travel, and the arts
- Participate fully in community life

**The Americans with Disabilities Act (ADA)** was passed by U.S. Congress in 1990 to ensure that individuals with disabilities have access to the same opportunities for learning, living and working that other people have. Since then, similar disability-rights laws have been passed in other countries. The

International Convention on the Rights of People with Disabilities – a kind of Geneva Convention for disability rights – has now been ratified by over 150 countries.

The ADA mandated accessibility in schools, workplaces, public spaces and transportation, and increased awareness of the need for “universal design” principles that make spaces, indoor and outdoor, accessible to people with disabilities. It has also fueled innovation in products and systems that enable people with disabilities to better control their environment.

In the classroom, for example, assistive devices such as automatic page-turners, book holders and adapted pencil grips allow learners with disabilities to participate in educational activities.

Adaptive switches make it possible for a child with limited motor skills to play with toys and games. Assistive technology also benefits employers, teachers, family members, and everyone who interacts with users of the technology. By increasing opportunities for people with paralysis to participate in all aspects of life, everyone benefits.

### ***Chapter Overview***

We’ve taken a fairly broad view of what might be considered an assistive tool or technology, but not nearly as broad as some. Our intent here is not to provide an exhaustive review of products and equipment, as that is best done by specialists in individual categories of assistive technology. Rather, we have described the primary categories of assistive devices along with a list of key resources in the last part of each category so the reader can dig deeper when necessary to learn more and find dealers.

In this chapter, we provide an overview of:

- **Environmental Control Units** (central switch boxes to run electrical functions)
- **Computing and Communicating** (harnessing the power of the personal computer)
- **Home Modification** (the design elements that make the home or workplace accommodating)
- **Adaptive Driving** (automobiles and the modifications that make them accessible)
- **Wearables** (clothing tailored for people with paralysis)
- **Service Animals** (dogs and monkeys trained to assist people with disabilities)

## WHO PAYS FOR ASSISTIVE TECHNOLOGY?

*The answer depends on the technology, the use, and the user. Many kinds of assistive devices may cost the individual little or nothing, even for some very expensive items. Some examples:*

- School systems distribute specialized materials as well as assistive technology specified in an Individual Education Plan (IEP) or a 504 plan.
- Government programs (Social Security, veteran's benefits, or state Medicaid agencies) pay for certain assistive technology if a doctor prescribes it as a medically necessary device.
- Private health insurance pays for certain assistive technology if a doctor prescribes it as a necessary medical or rehabilitative device.
- Rehabilitation and job-training programs, whether funded by government or private agencies, may pay for assistive technology and employment training to help people get jobs.
- Employers may pay for assistive technology that is a reasonable accommodation to enable an employee to perform essential job tasks.

*Other sources of funds in states or communities include private foundations, charities, and civic organizations. The Assistive Technology Industry Association offers a free Funding Resources Guide, which provides sources and resources to investigate as prospective options.*

*Source: Assistive Technology Industry Association ([www.atia.org](http://www.atia.org))*

Many of these devices are based on technology that is rapidly changing. What is state-of-the-art today may be old news tomorrow. To understand the full array of products available, check out tech guides such as AbleNet ([www.ablenetinc.com](http://www.ablenetinc.com)) and Makoa ([www.makoa.org](http://www.makoa.org)) and home-healthcare catalogs such as Sportaid ([www.sportaid.com](http://www.sportaid.com)), Performance Health ([www.performancehealth.com](http://www.performancehealth.com)), HDIS ([www.hdis.com](http://www.hdis.com)), or Allegro Medical ([www.allegromedical.com](http://www.allegromedical.com)).

## ASSISTIVE TECHNOLOGY RESOURCES

People using assistive technologies and their families and caregivers can

access information and support from a variety of organizations, including the following government-vetted sources recommended on the disability pages of the National Institute of Child and Human Development (NICHD):

- **Center for Accessible Technology (CforAT)**
- **Family Caregiver Alliance**
- **Family Center on Technology and Disability**
- **Office of Disability Employment Policy: Disability Rights**
- **U.S. Department of Education, State Tech ACT Sites**

**AssistiveTech** is an online resource providing up-to-date information on assistive technologies, adaptive environments, and community resources. <http://assistivetech.net>

**ATvisor** provides an online catalog of AT products. [www.atvisor.ai](http://www.atvisor.ai)

**Closing the Gap** is a national print and online resource guide to assistive equipment and adaptive gear. [www.closingthegap.com](http://www.closingthegap.com)

**Disabled World** has information on a large range of assistive devices and disability products for persons with a disability and seniors. [www.disabled-world.com/assistivedevices](http://www.disabled-world.com/assistivedevices)

**Edutopia** has an assistive technology resource gateway geared to helping educators and parents discover websites, blog posts, articles, and videos related to understanding, selecting, and assessing assistive technology. [www.edutopia.org/article/assistive-technology-resources](http://www.edutopia.org/article/assistive-technology-resources)

**Makoa** provides an extensive online resource of information and manufacturers of AT products in a wide range of categories. [www.makoa.org/ecu.htm](http://www.makoa.org/ecu.htm)

**National Rehabilitation Information Center (NARIC)** is the library of the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR). The Center collects, catalogs, and disseminates articles, reports, curricula, guides, and other publications and products of the research projects funded by NIDILRR. NIDILRR funds more than 250 projects each year that conduct research on a wide range of issues including technology, health and function, independent living, and capacity building. [www.naric.com](http://www.naric.com)

**RehabTool** features a comprehensive collection of links to the largest AT catalogs, databases, and vendor directories in North America. [www.rehabtool.com](http://www.rehabtool.com)

**U.S. Access Board** is a federal agency that promotes equality for people with



disabilities through leadership in accessible design and the development of accessibility guidelines and standards for the built environment, transportation, communication, medical diagnostic equipment, and information technology. Toll-free 1-800-872-2253 or 202-272-0080; [www.access-board.gov](http://www.access-board.gov)

## ENVIRONMENTAL CONTROLS

Paralysis often restricts one's ability to have control over one's day-to-day environmental comfort, such as light, temperature, and air flow. An environmental control unit (ECU) can help people regain power over their living environment in order to maximize their functional ability, independence, and safety in a given setting (usually the home).

An ECU can be defined as any system permitting remote control of electronic devices in the immediate surroundings. It enables a person to independently turn on or off any electronics such as lights, heat, air conditioning, stereo, or television; to answer or initiate phone calls; to unlock doors, and to open and close windows or window shades. Essentially any aspect of the environment can be controlled depending upon the system's complexity. An ECU could be hardware installed in the home, software allowing programmed or spontaneous control over remote appliances, or some combination of both.

The user interface – the method by which the person with paralysis operates the ECU – depends upon the user and his or her functional capacity. The interface might be an array of hardwired switches at a doorway, a remote-control joystick mounted on a wheelchair, or a touchscreen tablet with wireless Bluetooth technology. It might operate by voice command, or by “sip-and-puff,” or even by detecting eye blinks, eye direction, or head movements.

A new generation of digital assistants are emerging as powerful players in the “smart-home” market for mainstream use. Devices such as Amazon's line of Echo, Echo Dot, and portable Echo Tap; Google's Nest and Apple's HomeKit are Bluetooth-enabled devices that allow users to perform an array of tasks with voice commands. The HomeKit, in particular, was designed to let users control door locks, lights and other smart home gadgets with an iPhone or iPad.

For people living with paralysis, these smart-home devices open up possibilities that go well beyond ordering pizza or playing music – at least potentially. Much depends on the types of products and services that can be linked up to the operating systems.

Finding the right system, and an installer who will work to individualize the system

to meet the specific needs of the individual using it, is critical. Test driving various ECU or computer operating systems before purchase is recommended.

## ENVIRONMENTAL CONTROL RESOURCES

**Association of Assistive Technology Act Programs** is a federally funded system of state programs whose purpose is to promote full access to AT devices and services. Your state's Tech Act office provide AT demonstrations, loan and re-use programs, financing options, and links to high-quality resources in the disability world. [www.ataporg.org](http://www.ataporg.org)

**Home Automated Living (HAL)** makes software that turns a laptop or tablet into an ECU controllable from anywhere. HAL, Inc. Toll-free 1-855-442-5435; [www.automatedliving.com](http://www.automatedliving.com)

**Makoa** lists manufactures and dealers of ECUs, home automation, accessible telephones, and adaptive switches. <https://www.makoa.org/ecu.htm>

**Quartet Technology Incorporated (QTI)** offers a high-end “Simplicity” line of ECU units that operate by voice, switches, or computer mouse. 978-272-1800; [www.qtiusa.com](http://www.qtiusa.com)

**Reeve Foundation's Fact Sheet on Assistive Technology – Environmental Controls** includes a list of manufacturers of ECUs, as well as general information and funding services. ([www.ChristopherReeve.org/Factsheets](http://www.ChristopherReeve.org/Factsheets) and search for “assistive technology environmental controls” under Topic Resources)

## COMPUTING AND COMMUNICATING

Access to a computer can be nothing short of transformative for people living with paralysis. Not only does the personal computer open up the global gateway of information, social networking, and remote services via the world wide web, it can also be an empowering tool for communication and home management. Specialized computer software and hardware that help people with paralysis can be high-tech, like voice-recognition and other hands-free technologies, adaptive keyboards, and head-tracking mouse clickers, or relatively low-tech, like screen readers and screen-enlargement applications.

Personal tablets and the ubiquitous smartphone put the power of computing and web surfing at one's fingertips, and their portability makes them ideal for people with mobility issues. The newest adaptation of the portable computer

is smartwatches like the Apple Watch and Samsung Gear, which are just what the name implies: smartphones for your wrist, complete with Internet access and a range of apps borrowed from phone operating systems.

With ever-evolving, hands-free technology, even quads and people with upper-body limitations can operate a computer and navigate the Internet using only voice, breath, eye, or head movements. Emerging technologies like brain-machine interfaces, which read nerve signals from the brain and translate them into commands on a device, will open the world of computing to even those with severe paralysis, enabling them to not only communicate but to manage basic aspects of daily life.

The array of assistive devices for computing and communicating is vast and changing rapidly. The pace of 21st-century technology means that today's latest and greatest may be obsolete tomorrow. Below we provide an overview of the primary technologies that are commercially available now to help people with paralysis better access the power of the personal computer for communication and everything else. The Resource section at the end provides a list of sources where one can learn more about specific products or systems.

## WIRELESS CONNECTIVITY

Bluetooth ushered in the world of short-range, wireless connectivity in the mid-1990s, and computing has never been the same. A Bluetooth device uses radio waves instead of wires or cables to connect to a phone or computer, making true portability possible. Bluetooth technology allows a wide

*“No question about it, my computer is my most valuable possession. It's an incredible tool for communication, for learning, for fun, for shopping, for running one's home environment, and best of all, for making a living. There are lots of ways to operate the computer without using hands. I use a mouth stick, which I make myself. I can type fairly quickly with it.”*

*-Pete Denman, C4*

variety of devices and services to connect to each other wirelessly, silently, and automatically. Bluetooth-capable devices include smartphones and smartwatches, audio speakers, automobiles, medical devices, computers, and even toothbrushes, to name just a few.

How does it work? A Bluetooth product, such as a headset or watch, contains



Christopher Reeve and Brooke Ellison, on the set of *The Brooke Ellison Story*, directed by Reeve, 2004

a tiny computer chip embedded with software that essentially acts as a radio tower to send and receive low-power, short-range radio waves. The technology makes it possible to give commands remotely to a computer or phone within a certain distance – even through walls. When combined with voice-recognition, eye-tracking, or other hands-free technology, Bluetooth opens a world of possibilities for people living with paralysis.

### Voice recognition

A cumbersome and inefficient novelty barely a decade ago, voice-recognition (VR) technology is now used by millions of people every day on smartphones. This is, after all, the era of Siri and Google Now, smartphone apps that communicate by recognizing vocal commands and responding with information or specific actions. VR enables hands-free texting, calling, and Internet searching on most modern handheld devices, as well as laptops and PCs equipped with the right software (e.g., Windows' digital assistant called "Cortana").

Advances in voice recognition (coupled with artificial intelligence and speech-generating technology) have also driven the success of next-level virtual assistants such as Alexa, the operating system behind Amazon's Echo and

““ I do a lot of work on the computer. I spend hours and hours every day on the computer. I use a voice-activated system called Dragon: Naturally Speaking, which works very well for me. For me to move the mouse, which I use pretty extensively, it works through the wheelchair system. The mouse is infrared, and it sends a signal from my wheelchair to the computer. I have a little remote control that sits on the roof of my mouth, and I hit little buttons with my tongue. ””

-Brooke Ellison, C2

second-generation Echo Dot. These wireless devices function like two-way speakers, listening to voice commands even from a relative distance and responding accordingly, whether it be to order a pizza or look up something on the Internet. They perform as a kind of wireless command-and-control center for the home, and as technology progresses, are being fitted with an ever-increasing array of software interfaces to enable a broad range of uses. Consumer electronics companies are now racing to develop products based on the Alexa operating system, including home appliances, lamps, robots, car infotainment systems, and next-generation smartphones.

It's easy to imagine how voice-recognition systems can improve the lives of people whose mobility or motor function is limited. Currently, VR software is available in wheelchairs to direct movement; phones and computers; interfaces for home-control systems, and automobiles. As technology progresses, individualized interfaces will make it possible to control virtually any electronic device with a simple voice command.

### Eye-Gaze Technology

Eye-gaze technology is designed to track the movement of the eyes by recording and analyzing the position of the pupils. Marketers use eye tracking to assess, for example, where on a computer screen a user's eyes are focused, or to determine how long a banner ad catches the eye's attention. For people with paralysis who are unable to move their arms, eye-gaze technology can be combined with the right software interface to enable use of a computer, phone, home-control unit, or basic communications device.

For example, one current iteration of eye-gaze technology (the "EyeGazer" by LC Technologies; [www.eyegaze.com](http://www.eyegaze.com)) is an eye-operated communication and control system that empowers people with disabilities to communicate

and interact with the world. By looking at control keys or specific areas on a screen, a user can generate speech either by "typing" a message one letter at a time or selecting pre-programmed phrases. Customized screens and programs for tablets and computers enable users to check, compose and send emails, browse the web, listen to music, operate remote electronics, read an e-book, or do just about anything else other computer users can do.

Tobii ([www.tobii.com](http://www.tobii.com)) offers a variety of eye-gaze products including eye tracking systems. Tobii Dynavox provides speech-generating devices which can be used by those with speech issues such as people with ALS and CP. Tobii also has eye-gaze products for video gaming ([www.tobiigaming.com/products](http://www.tobiigaming.com/products)).

### Mouse Alternatives & Pointing Devices

Several products are available to augment or replace the standard computer mouse to make point-and-click computing possible for people who have impaired arm and hand function or difficulty with fine motor control. The possibilities include touchpad-, joystick- or trackball-based controllers, foot-controlled mice, and controllers driven by head or body movements.

### Sip-and-Puff

Sip-and-Puff (SNP) is assistive technology used to send signals to a device using air pressure by "sipping" (inhaling) or "puffing" (exhaling) on a straw, tube or "wand." It is primarily used by people who do not have the use of their

““ If you have access to a computer, you're able to communicate with the outside world. They won't even know you have a disability unless you tell them. I use Morse code and a sip-and-puff. I tried a lot of ways to do this and this seems to work the best. Once you memorize the codes, it's just automatic. ””

-Jim Lubin, C2

hands. The mouth-controlled input provides users a simple and effective way to control mouse movement as well as other devices such as wheelchairs.

### COMPUTING AND COMMUNICATING RESOURCES

**AbleNet** offers a range of assistive technology, curriculums, and services to



help individuals with disabilities lead productive and fulfilling lives.

[www.ablenetinc.com](http://www.ablenetinc.com)

**Accessibility Clearinghouse** is an information hub from the Federal Communications Commission (FCC) about phones and innovative ways to communicate, especially for people who may have a disability.

<https://www.fcc.gov/general/accessibility-clearinghouse-0>

**Makoa** has a comprehensive listing of products, services, and resources to make computing accessible to people with disabilities.

[www.makoa.org/computers.htm](http://www.makoa.org/computers.htm)

**Reeve Foundation** has a **Fact Sheet on Assistive Technology – Computers**, which includes a list of manufacturers and resources for assisted computing and communicating. ([www.ChristopherReeve.org/Factsheets](http://www.ChristopherReeve.org/Factsheets) and search for “assistive technology computers” under Topic Resources)

**RJ Cooper & Associates** offers dozens of assistive technology solutions, including custom adaptations for the iPad. [www.rjcooper.com](http://www.rjcooper.com)

**VOICE-RECOGNITION SYSTEMS** (Source: [www.makoa.org](http://www.makoa.org))

- **Discrete Speech**

- **Nuance** Dragon Dictate
- **e-Speaking** Speech recognition software
- **tazti speech recognition** Free speech recognition software - free download

- **Continuous Speech**

- **Nuance** Dragon NaturallySpeaking
- **Synapse** AP Universal and UNIX voice recognition

**EYE-GAZE TECHNOLOGY** (Source: [www.makoa.org](http://www.makoa.org))

- **DynaVox Mayer-Johnson**
- **LC Technologies, Inc** Eyegaze Communication System
- **VisionKey Computer Controller** Eye control input
- **Tobii Eye Control Systems** Tobii PCEye and CEye and Eye Trackers for PC Gaming

**MOUSE ALTERNATIVES & POINTING DEVICES** (Source: [www.makoa.org](http://www.makoa.org))

- **Cirque GlidePoint** touchpad controllers
- **Camera Mouse** hands-free mouse gives computer control without headgear
- **Logitech** Trackballs
- **NaturalPoint trackIR** control of your computer by tracking your body motion
- **Nohands Mouse** foot-controlled mouse
- **Origin Instruments** HeadMouse Head-Controlled Pointing Systems
- **PI Engineering** X-keys Switch Interface; Ymouse - attach 2 mice to 1 port
- **Prentke Romich Company** HeadMaster, Jouse
- **RJ Cooper’s Special Needs** Switch-Adapted Mouse devices
- **QuadLife** mouse for quadriplegics
- **TetraMouse** alternative computer mouse for people who cannot use their hands

## HOME MODIFICATION & ACCESSIBILITY

It’s no secret to anyone living with paralysis that, at least for the most part, no one was really thinking about people with mobility challenges when they designed our streets, public buildings, and homes. Still, things are changing as people with disabilities – joined by the largest ever U.S. generation now solidly in its senior years – have pushed to improve access for all people, including those with paralysis or mobility problems.

The Americans with Disabilities Act (ADA), passed by U.S. Congress in 1990, was a landmark achievement for improving accessibility for individuals with disabilities. The ADA instituted a set of regulations for making schools, transportation, housing, public accommodations, and sidewalks fully accessible in every city. In the decades since, substantial improvements in accessibility have been made in many aspects of public life. Technologies like push pads for opening doors and key fobs that unlock doors with a swipe are a common sight, for example.

For most people with disabilities, “accessibility” has more to do with getting in and out of the house, working in the kitchen, or using the bathroom. Home modifications that improve accessibility can be as simple as a doorknob that’s easy to work, a grab bar in the right place, or a ramp to get in through the back door. It may involve widening a door or installing a special sink or elevator. Many accessibility challenges have simple solutions that are



PHOTOS: SAM MADDOX

Mark is a heavy computer user. He works his rig two ways: with a Jouse joystick he can operate with his mouth ([www.compusult.com](http://www.compusult.com)); this input is synced with an onscreen keyboard ([www.imgpresents.com](http://www.imgpresents.com)). He can also write, send and receive email or surf the web by voice activation (Dragon NaturallySpeaking software, [www.nuance.com](http://www.nuance.com)).

### **A MAN AND HIS GEAR**

Mark Willits recently celebrated what he called his 50-50 day: half his life walking, half as a vent-dependent C3 quadriplegic. He had a big party at his house outside Los Angeles, with lots of family and friends to share the day; he gives this support system credit for his success. Mark broke his neck as a teenager on his family's farm in Iowa; he went on to college, first in Iowa and then in Arizona. He then went to law school at UCLA. "In May 2008, I graduated from the UCLA School of Law," says Mark, "while my girlfriend graduated from Pepperdine University one week later. At our joint graduation party, she got down on one knee and proposed to me. We were married in November 2008 at our home."

Mark is a practicing attorney; he is the former president of the L.A. area peer network Ralph's Riders. He and his wife, Sheila, travel extensively (see page 237 for his tips for vent trekking). Says Mark, "Your limitations can only limit you if you let them."

Here is a glimpse of the gear Mark uses to work and stay connected.



Exercise is a major part of Mark's lifestyle. To get a workout he straps into a functional electrical stimulation device from Restorative Therapies ([www.restorative-therapies.com](http://www.restorative-therapies.com)). He can work his lower extremities, or arms and legs simultaneously.



Left: Mark uses an Invacare power chair with tilt, and relies on a Pulmonetics LTV 1100 ventilator.

Below: he hooks either phone or iPad to a flexible mount from Loc-Line Modular Hose (see [www.modularhose.com](http://www.modularhose.com)). He activates the capacitive touch screens with mouthsticks from iFaraday.



inexpensive and relatively easy to implement; others may require extensive renovations associated with high costs.

## UNIVERSAL DESIGN

The late Ron Mace, founder of the Center for Universal Design at North Carolina State University, is credited with coining the term “universal design.” He defined it this way: “Universal design is the design of products and environments to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design.”

The concept of universal design goes beyond ramps and wider doorways – though those are two important adaptations. It isn’t just about accessibility either; it is a way of looking at the world with an eye toward careful planning at the design stage to accommodate any user across his or her lifespan – whether it’s getting to the office, the ballpark, or to the toilet in one’s home. Universal design seeks to create environments that are intrinsically accessible to all individuals regardless of disability status.

Still, home accessibility and ease-of-use modifications, are for the most part, still viewed as an exception rather than a rule. Architects and builders generally don’t include them in home design unless consumers ask for them, and consumers generally don’t ask for them unless they have a current need. It’s useful to be an informed consumer, to know what one’s options are and how to achieve a level of accessibility appropriate to one’s needs, lifestyle and functional capacity. The resources below can help people with paralysis assess needs, weigh the many options, and locate contractors and vendors to make the home or work environment accessible and efficient.

## UNIVERSAL DESIGN RESOURCES

**AARP** features an array of informational guides and resources about universal design and making homes accessible for people of all ages and abilities.

[www.aarp.org](http://www.aarp.org) (search for “universal design”)

**Center for Inclusive Design and Environmental Access (IDEA)** is a program of the State University of New York – Buffalo that is dedicated to making environments and products more usable, safer, and healthier in response to the needs of an increasingly diverse population. <http://idea.ap.bu.edu>

**Home Wheelchair Ramp Project** offers an inexpensive, modular, reusable, easy-to-build wheelchair ramp design. The manual, “How to Build Wheelchair

Ramps for Homes,” is a manual of design and construction for modular wheelchair ramps, including information about modular ramps and long-tread low-riser steps to improve safe home accessibility.

[www.klownwerkz.com/ramp/default.htm](http://www.klownwerkz.com/ramp/default.htm)

**Institute for Human Centered Design (IHCD)**, founded in 1978 as Adaptive Environments, is an international organization committed to advancing excellence in design, balancing expertise in legally required accessibility with best practices in universal design. <http://humancentereddesign.org>

**Mac’s Lift Gate** designs and engineers vertical lifts for everyday use in the home and for travel; <http://macshomelift.com>

**MAX-Ability** specializes in products and consultation services for accessibility accommodation in the home, school, and healthcare facilities. National coverage; <http://max-ability.com>

**National Resource Center on Supportive Housing and Home Modification**, based at the University of Southern California, promotes independent living for people of all ages and ability levels; [www.homemods.org](http://www.homemods.org)

**RAMPS Across America** is a non-profit foundation that provides individuals with mobility restrictions a safe ramp for their home. Volunteers provide free design and construction. [www.rampsacrossamerica.org](http://www.rampsacrossamerica.org)

**Shower Bay** is a portable shower designed for wheelchair users, without requiring dangerous wet-environment transfers or expensive home renovations; <http://showerbay.com>

**Visitability** works to make all homes “visitible,” that is, accessible to all – based on minimum standards of at least one entrance, with zero steps, 32-inch passages through interior doors, and at least a half-bath on the main floor. [www.visitability.org](http://www.visitability.org)

## ADAPTIVE DRIVING

There’s more to having a set of wheels than getting from here to there. For people living with paralysis, driving can be a ticket to freedom, independence, and adventure.

But can it be done? Can a paralyzed person get behind the wheel and handle the machine and the traffic? A wide range of adaptive equipment and vehicle modifications – from the simple addition of a left-side accelerator to fully



customized vehicles equipped with motorized lifts – are available to make driving possible for many people who are paralyzed, including people with very limited hand and arm function.

Driving with a disability often means relearning to drive. The rules of the road don't change, but the controls do. Depending on one's specific needs, an adapted vehicle may include hand controls for braking/accelerating, power-assist devices for easy steering, touch ignition pads and gear shifts, adjustable driver's seats, automatic door openers, or joysticks for people with extremely limited hand function. For a person who has had a stroke, a spinner knob might be attached to the steering wheel for one-hand steering. Steering-wheel-mounted brake and gas pedals open driving to people with paraplegia. People who sit in their wheelchair while driving or riding require either a manual tie-down or power lockdowns to ensure safety. Manual systems usually require assistance getting in and out of while power units allow for more independence – the user just rolls his or her chair into place and the chair automatically locks down. Operating a vehicle from a scooter is not possible, so scooter users must be able to transfer to the vehicle seat to drive. Special electronic seats are available to assist transfer.

### Getting Evaluated to Drive

The first step for someone with a disability who is interested in driving is to get an evaluation from a qualified driver trainer. This will help determine what specific modifications and driving equipment will match the individual's needs. An evaluation typically includes vision screening and assessment of muscle strength; flexibility and range-of-motion assessments; tests of hand-eye coordination, reaction time, judgment, and decision-making, and how well the user can handle adaptive equipment. An evaluator may also take into account medications a potential driver is taking.

Rehabilitation centers can usually provide references to qualified evaluators. If not, contact the Association for Driver Rehabilitation Specialists ([www.aded.net](http://www.aded.net)), which maintains a list of certified specialists nationwide.

As for getting a new driver's license, most states require a valid learner's permit or driver's license to receive an on-the-road evaluation. No one can be denied the opportunity to apply for a permit or license because of a disability, but a restricted license may be issued depending on the adaptive devices



necessary for driving.

Once the green light to drive is given, one can explore the kinds of vehicles that suit one's individual abilities and needs. The right car may be different than one we'd choose in the absence of paralysis, and the range of options available is likely to be more limited. Do diligent research to understand what other people with similar disabilities drive. Talk to other drivers via online forums or community groups, and fully explore the possibilities that are available. Then be sure to collaborate with the driving evaluator and a qualified vehicle modification dealer to find the best option.

### Associated Costs and Financial Aid

The cost of modifying a vehicle varies greatly. A new vehicle modified with adaptive equipment can cost anywhere from \$20,000 to \$80,000 and up. Be a well-informed shopper; explore a range of options and investigate public and private financial assistance. Contact the state department of vocational rehabilitation or another agency that provides vocational services and, if appropriate, the Department of Veterans Affairs. Also, consider the following:

- Some nonprofit groups that advocate for individuals with disabilities have grant programs that help with adaptive devices, including vehicles.

- Workers' compensation may provide coverage for adaptive devices and vehicle modification. Check with the insurance carrier in advance of any purchase to understand what is covered and what limitations exist.
- Several auto manufacturers have rebate or reimbursement plans to help offset the costs of vehicle modification (see list below, in Resources).
- Some states waive the sales tax for adaptive devices if a doctor has prescribed their use. In some cases, costs associated with medical expenses can be deducted on federal income taxes; a tax specialist can provide advice.

### WHAT KIND OF VEHICLE BEST SUITS YOU?

Here are some questions that can help people with paralysis decide which vehicle is right for them and whether adapting a car they already own is possible:

- *Does the necessary adaptive equipment require a van, or will a smaller passenger car do? In other words, will you be driving from a wheelchair or can you transfer to the car seat? If you can transfer in to drive a car, your choices are much wider.*
- *Will your wheelchair fit in the vehicle? A person may sit taller in a wheelchair and may not clear the ceiling. Purchase your wheelchair before your vehicle so that it fits the vehicle.*
- *Can the vehicle accommodate the hand controls or other needed driving equipment?*
- *Will there be enough space to accommodate other passengers once the vehicle is modified?*
- *Is there adequate parking space at home and at work for the vehicle and for loading/unloading a wheelchair or walker? Be aware that full-size vans might not fit in home or public garages, or even in certain parking spaces.*
- *If a third party is paying for the vehicle, adaptive devices, or modifications, are there limitations or restrictions on what is covered? Get a written statement on what a funding agency will pay before making your purchase.*
- *If you are adapting a used van or family vehicle, make sure the technician has lots of experience. All lifts are not created equally; some just won't fit. Also, some lifts are built only for wheelchairs and will not work for scooters.*

When searching for a qualified dealer to modify a vehicle for the specific needs of an individual with paralysis, be sure to ask questions, check credentials and references. Do they work with evaluators? Will they examine your vehicle before you purchase it? Do they require a prescription from a physician or other driver-evaluation specialist? Do they provide training on how to use the equipment? Do they provide service? What is the cost? How long will it take to do the work? What is the warranty? Be sure these questions are answered satisfactorily before committing.

### ADAPTIVE DRIVING RESOURCES



**Adapting Motor Vehicles for People with Disabilities** is a brochure available from the National Highway Traffic Safety Administration (NHTSA) that provides comprehensive information on regulations, procedures, selecting and maintaining adaptive equipment,

and financial-assistance options. [https://www.nhtsa.gov/sites/nhtsa.dot.gov/files/documents/adapting\\_motor\\_vehicles\\_brochure\\_810733.pdf](https://www.nhtsa.gov/sites/nhtsa.dot.gov/files/documents/adapting_motor_vehicles_brochure_810733.pdf)

**Association for Driver Rehabilitation Specialists (ADED)** certifies driver trainers who are experts in adaptive driving and vehicles. The organization offers several fact sheets for drivers with various types of disabilities. Call toll-free 1-866-672-9466; [www.aded.net](http://www.aded.net)

**Disabled Dealer** is a publication featuring used vehicles (and all sorts of other rehab and medical gear). Regional editions feature numerous pre-owned adapted vans and cars. [www.disableddealer.com](http://www.disableddealer.com).

**Mobility Resource** is an online hub for information related to adaptive driving, including wheelchair accessible vehicles and adaptive equipment, product reviews, and financing options. [www.themobilityresource.com](http://www.themobilityresource.com).

**Mobility Works** offers a free downloadable guide to securing funding for an accessible vehicle. [www.mobilityworks.com/financing/automotive-mobility-programs.php](http://www.mobilityworks.com/financing/automotive-mobility-programs.php)

**National Highway Traffic Safety Administration** offers advice on driver training, vehicle selection and vehicle modification. Search for “adaptive” at [www.nhtsa.gov](http://www.nhtsa.gov)

## VEHICLE DISCOUNT AND REBATE PROGRAMS

Several car manufacturers offer rebate or reimbursement discounts to help offset the costs of vehicle modification; here is what they offer and how to learn more. Other car makers may also offer discounts; ask your automobile dealer. Ford Mobility Motoring offers up to \$1,000 of assistance toward the cost of adaptive equipment on a new Ford, Lincoln, or Mercury vehicle. Ford Mobility Motoring Customer Care Center. 1-800-952-2248. [www.fordmobilitymotoring.com](http://www.fordmobilitymotoring.com)

GM Mobility Program offers up to a \$1,000 reimbursement (with qualifications) plus two years of OnStar Protection Plan when eligible adaptive equipment is installed. 1-800-323-9935. [www.gmfleet.com/overview/mobility-vehicles.html](http://www.gmfleet.com/overview/mobility-vehicles.html)

Toyota Motor Sales, USA, Inc. provides reimbursement up to \$1,000 to each eligible, original retail customer, for the exact cost they paid to purchase and install qualifying adaptive driving or passenger equipment. 1-800-331-4331. [www.toyotamobility.com](http://www.toyotamobility.com)

Driver Ability provides up to \$1,000 in financial assistance toward the installation of adaptive equipment on new Chrysler, Jeep, and Dodge vehicles. 1-800-255-9877 [www.fcausautomobility.com](http://www.fcausautomobility.com)

Hyundai Mobility Program offers \$1,000 toward the cost of adaptive equipment. See dealer for more information. 1-800-633-5151. [www.hyundaiusa.com/us/en/special-programs/mobility](http://www.hyundaiusa.com/us/en/special-programs/mobility)

Lexus Mobility Program provides reimbursement assistance of up to \$1,000 of the cost of adaptive equipment; comprehensive mobility resource information, and flexible, extended-term financing of up to 84 months for the vehicle and the adaptive equipment. 1-800-255-3987. [http://lexus2.custhelp.com/app/answers/detail/a\\_id/8229/~/\\_what-is-lexus-mobility%3F](http://lexus2.custhelp.com/app/answers/detail/a_id/8229/~/_what-is-lexus-mobility%3F)

Volvo Mobility Program reimburses up to \$1,000 toward the cost of adaptive equipment added to a new Volvo. Mobility by Volvo Center. 1-800-550-5658.

[http://volvo.custhelp.com/app/answers/detail/a\\_id/8927/](http://volvo.custhelp.com/app/answers/detail/a_id/8927/)

**National Mobility Equipment Dealers Association (NMEDA)** is a trade group of companies that sell adaptive driving equipment and vehicles. Call toll-free 1-866-948-8341; <https://nmeda.com>

**Reeve Foundation** provides information on cars and driving for people living

with disabilities as well as a fact sheet on the topic.

[www.ChristopherReeve.org/living-with-paralysis/home-travel/driving](http://www.ChristopherReeve.org/living-with-paralysis/home-travel/driving)

## CLOTHING

For a person with limited mobility or who may be sitting a great deal of the time, dressing can be a challenge. Off-the-rack clothing presents problems: seams may be placed in areas that could cause skin breakdowns; trousers may not be long enough or may bunch up in the lap; jackets bunch up; buttons and fasteners might not be handy. There are, however, options.



Several companies market to people with paralysis:

**AbleApparel** offers outerwear and accessories for children and adults.

[www.ableapparel.com](http://www.ableapparel.com)

**Adaptations by Adrian** designs capes, pants, sweatshirts, jackets with wheelchair users and the mobility challenged in mind.

[www.adaptationsbyadrian.com](http://www.adaptationsbyadrian.com)

**Easy Access Clothing** has pants, jeans, outerwear. Call toll-free 1-800-775-5536; [www.easyaccessclothing.com](http://www.easyaccessclothing.com)

**IZ Adaptive** has men's and women's clothing as well as unisex coats and capes and face masks; <https://izadaptive.com/>

**Professional Fit Clothing** features alterations, as well as a line of capes and clothing protectors. 1-800-422-2348; [www.professionalfit.com](http://www.professionalfit.com)

**Specially For You** offers a line of gowns, dresses, pants. 605-765-9396; [www.speciallyforyou.net](http://www.speciallyforyou.net)

**Wheelchair Apparel** make jeans designed for sitting so that wheelchair users can look and feel normal. The pants are specially designed to help minimize the chances of getting pressure sores that can be caused by pants designed for standing. 800-935-5170. <https://wheelchairapparel.com>

**Rolli Moden:** men's and women's fashion and accessories.

[www.rollimoden.de/en/](http://www.rollimoden.de/en/)



## SERVICE ANIMALS

Clearly an animal is not a device, but it's easy to understand how service dogs – or even less conventional animals like monkeys – can be an important assistive tool for a person living with paralysis. Service animals increase their owner's independence and enhance their quality of life. A dog can help to turn on a light switch, pull a wheelchair, pick up dropped keys or open a cupboard door. Dogs also make great social companions, and are great icebreakers when meeting new people. Increasing evidence suggests there is a valuable emotional and psychological benefit to pet companions in general, and the bond between a service animal and his or her owner is typically very strong.



SAM MADDOX

Most service dogs are mild-mannered Golden Retrievers or Labrador Retrievers, although increasingly, dogs without pedigree are rescued from shelters and trained to be service dogs. There are numerous organizations across the United States and abroad that train service dogs or provide training for people to use their own dogs.

### SERVICE ANIMAL RESOURCES

**Assistance Dogs International** maintains a list of assistance dog centers across the U.S. and abroad. [www.assistancedogsinternational.org](http://www.assistancedogsinternational.org)

**Canine Companions for Independence** is a nationwide program that provides assistance dogs at no cost to the person with a disability. Toll-free 1-800-572-2275; [www.caninecompanions.org](http://www.caninecompanions.org)

**Merlin's Kids** turns shelter dogs into service dogs. [www.merlinskids.org](http://www.merlinskids.org)

**National Education for Assistance Dogs Services** provides service dogs for people who are deaf or who use wheelchairs. 978-422-9064; [www.neads.org](http://www.neads.org)



**PAWS with a Cause** offers service dogs. Toll-free 1-800-253-7297; [www.pawswithacause.org](http://www.pawswithacause.org)

## SERVICE MONKEYS

**Helping Hands:** Monkey Helpers for the Disabled is an organization that provides capuchin monkeys at no cost to people with disabilities. These petite, intelligent animals can be trained to fetch things, turn on switches, help with grooming, and assist with other tasks around the household. Candidates for a service monkey are screened by the Helping Hands organization, and certain guidelines apply. To qualify, a person must be at least one year post-injury, must spend most of his or her time at home, and must be able to control a power chair. Monkeys are available for child-free homes only. A foster program places the animals in qualified homes for training, following the model by which many service dogs are trained. [www.monkeyhelpers.org](http://www.monkeyhelpers.org)

# 8

## MILITARY AND VETERANS

The expertise of the Reeve Foundation extends to those members of the military or veteran communities who have experienced spinal cord injury or paralysis.



In February 2007, my husband Matt, an Army staff sergeant on his second tour in Iraq, was shot in the neck by sniper fire near Ramadi. This happened exactly six weeks after our wedding day. Both of our lives changed forever. —Tracy and Matt Keil

### WELCOME LETTER FROM A MILITARY FAMILY

The bullet went through the right side of his neck, hit his vertebral artery and his left lung, and exited out his left shoulder blade. The bullet severed his spinal cord, rendering him a quadriplegic. The first thing the doctors said to me when they began to explain his injury was, “Your husband has a Christopher Reeve-type injury.” This is the only way I understood what the doctor was talking about: we knew who Christopher Reeve was, in fact Matt had always been a huge fan of Superman and even got a tattoo of the Superman logo on his right arm when he first joined the Army at eighteen.

When the doctor said those words to me I thought about what would happen to us, how would Matt live in a wheelchair, how would we possibly cope with the chaos and uncertainty? Matt was first transferred to Germany, then to Walter Reed Army Medical Center in Washington, D.C.; once stabilized he was sent to the Department of Veterans Affairs hospital in Tampa, one of five big polytrauma units in the VA system. Because we were a military family, we got hooked up with the system of care for wounded warriors. We became well versed about TRICARE, Warrior Transition Units, and the VA, and all sorts of layers of counseling and care; we discovered many resources and many regulations.

The VA has great expertise in spinal cord injury, but we began to wonder if there were any options for a more aggressive approach. We asked, “This is what life is going to be like?” Rehab was more like a nursing home; they told us Matt would probably be there a year, living in some sort of assisted living situation, but he really wanted to get back into the community. So my sister



Tracy and Matt, with Matthew and Faith

and I did some research. We reached out to the community of vets and other organizations, including the Christopher & Dana Reeve Foundation.

I called the Foundation and asked what we were supposed to do now: How do I learn everything I need to know and how do we learn to live with my husband in a wheelchair? I spoke to a very nice woman on the phone and she told me all about this book, the **Paralysis Resource Guide**, which was sent directly to me at the

hospital. She told me to read through the guide and please call back anytime with any additional questions. She said, “You will get through this, things do get better. You can live a very happy, full life as a quadriplegic—Christopher Reeve was proof of that.” I was very encouraged after hearing that. And this book, the PRG, it was very relevant; to this day, years later, I still go back to the guide and find things that are useful.

Meanwhile, we learned that there might be options for Matt’s medical care: The Department of Defense and VA allow and pay for some injured soldiers to seek care and rehab at specialized private facilities. The military healthcare system doesn’t promote the private care option but we were able to transfer Matt from the VA to Craig Hospital near Denver. This was the right move for us; we found our future.

Today, injured soldiers and their families reach out to Matt and me. They hear, “You want to connect with the Keils. You want the life they found.” And it’s true. We know where we are going to be. We also recognize there are many past vets who fought for our benefits. We know it’s our turn. We are here to help; we are never too busy to help someone get where they need to go. We want people to know they do have options.

Our lives continue to change—for the better. We live a very full life. Matt and I were married such a short time that we had not yet tried to start a

family, but we discovered after his injury that children were still possible and through in-vitro fertilization, we welcomed our twins Matthew and Faith on November 9, 2010. We have traveled extensively to talk about our experience and we encourage people to ask us questions about our life after injury. Our lives have changed so much since before Matt’s injury, but even Matt always says he wouldn’t change a thing even if it meant he could walk again. We found a new appreciation for life, friendship, family, and each other that most people spend a lifetime learning. To me, it seemed like fate. I can’t explain why, but we both feel like this was supposed to happen and that this is how our life should be.

Take this opportunity to appreciate the life you have been given. Whether you are newly injured or have just learned about this resource guide, share your experience and knowledge with others, participate in all life has to offer. There are many options: learn about them from this book. Better yet, ask a lot of questions and connect with others who have been in your situation and who can say, “Life is what you make of it.”

From our family to yours, we wish you a long, healthy fun-filled life. With respect and encouragement, —Matt, Tracy, Matthew, and Faith Keil

## MILITARY AND VETERANS PROGRAM

The Reeve Foundation’s **Military & Veterans Program (MVP)** incorporates our expertise in spinal cord injury and paralysis into the many supports, resources, and community connections available for members of all five branches of service (Army, Navy, Air Force, Marines, and Coast Guard) including active duty, Reserves, and National Guard components, as well as veterans, whether retired through fulfilled contract or involuntarily separated. Support through the Reeve Foundation is offered to anyone who has served in uniform, regardless of whether a paralyzing injury or disease can be linked to military service (often referred to as “service connected”) or a cause unrelated to service (or “non-service connected”). This chapter can be used by family members, caregivers and commanding officers to help navigate the injured service member’s way through the acute care, rehabilitation and the recovery process.

The first part of this chapter will cover active duty service members while the second half of this chapter is for non-active duty personnel. Please see the checklist for steps to take after an SCI for active duty personnel on page 320



and the checklist for non-active duty personnel on page 336. Resources are highlighted throughout the chapter.

In this chapter, the Paralysis Resource Guide provides a comprehensive outline of federal, nonprofit, and community-based resources for those veterans or military service members who live with paralysis and their caregivers. Feeling overwhelmed when looking for help is normal as uncertainty and a lack of guidance are typical in the immediate aftermath of a debilitating crash, surgery, accident, or disease diagnosis. The MVP Helpline is here to help make this experience less stressful. Reach out to an Information Specialist dedicated to helping members of the military and veterans find the right path toward recovery. Set up an appointment to talk to a Military & Veteran Program Information Specialist at your convenience. Toll free 1-866-962-8387; email [Military@ChristopherReeve.org](mailto:Military@ChristopherReeve.org); [www.ChristopherReeve.org/MVP](http://www.ChristopherReeve.org/MVP)

## DEPARTMENT OF DEFENSE

The Department of Defense bears the primary mission of maintaining the readiness of service members among its active and reserve ranks to train, deploy, defend, and respond to national and international emergencies. Once a service member can no longer serve due to injury or a disabling condition, a transition process begins for both that member and any family involved.

Fortunately, this transition process has evolved over the last decade and now includes cooperative partnerships with other federal agencies, state programs, and nonprofit organizations that help close gaps by holistically addressing foreseen and unforeseen needs, particularly those cases involving some form of rehabilitation. This includes those members that will be medically discharged from the military due to the severity of their injuries.

Family members as well as service members may easily experience information overload due to the numerous agencies and nonprofits who serve veterans and active duty service members. Clicking through Internet-based information becomes overwhelming and a challenge. Efforts to consolidate resources, application processes, and interaction with experts have made finding help more seamless through streamlined online interfaces.

The best sources of support and resources remain other service members, veterans, and families who have lived the experiences that lie ahead of you. They can provide you with lessons learned particularly those involving coping with paralysis and transition to civilian life.

The best place to start your exploration is Military OneSource, where you have access to a 24/7 connection to information, answers and support to help you reach your goals, overcome challenges, and transition successfully. As a member of the military, you are eligible to use this Department of Defense-funded program anytime, anywhere. Resources through Military OneSource

### **ACTIVE DUTY PROCESS CHECKLIST AFTER SPINAL CORD INJURY/ DISORDERS**

*Active duty service members who incur a spinal cord injury/disorders should expect the following process:*

1. **Admission** to nearest trauma center for surgery and stabilization
2. **Rehabilitation**
  - You will be sent to either a VA SCI/D\* (longer term focus) or a private facility SCI/D (shorter term focus). Eligibility for VA SCI/D rehabilitation is determined based on a Memo of Understanding between VA and DOD.
  - Understand eligibility for VA benefits
  - Receive counsel for benefits representation from a Veteran Service Officer (VSO) if there is a potential for a willful misconduct finding, DOD evaluates return to duty potential
  - If injury is determined to be permanent, goes to Medical Evaluation Board (MEB)
3. **Medical Evaluation Board**
  - Local commander requests medical evaluation
  - Evaluation conducted at the closest military hospital (using evaluation from SCI/D center)
  - If you disagree with the evaluation you should seek counsel with the local legal unit/VSO
  - You must sign off on all evaluations
  - Meet with counsel for benefits representation
4. **Physical Evaluation Board (PEB)**
  - PEB is a committee in Washington DC (Local legal counsel will

represent your case in DC.)

- Physical evaluation from MEB
- Decision is a FINAL finding; You have 45 days to contest
- Meet with counsel for benefits representation if contesting PEB findings
- Transition Assistance Program (TAP) is military branch specific

#### 5. **Transition out of Military**

- DD214 provided at retirement
- Temporary Disability Retired List (TDRL) for five years then Permanent Disability Retired List (PDRL)

Throughout the process is it critical to be actively involved in learning and participating in decisions. Pay attention to the following resources and sections in this chapter for key areas of assistance: Military One Source, eBenefits web portal, Military Relief Organizations, Crisis and VA Helplines, Suicide and Crisis Prevention, Counsel for representation for benefits (VSO)

include tax assistance, spouse employment help, webinars and online training, relocation and deployment tools, and much more. Many of the resources in this guide can be accessed through either Military OneSource or direct links.

Each branch of service has its own programs to improve the quality of life for the military community it serves. Staff can help you locate experts on benefits, housing, transportation, and finances. These resources can also be found on the Military OneSource website.

To learn more about transitioning to civilian life after separation or retirement, visit <https://www.militaryonesource.mil/military-life-cycle/separation-transition/military-separation-retirement/transition-assistance-programs-and-resources>

#### **Military Relief Organizations**

Non-profit organizations that focus on providing relief to service members and families act as force multipliers for the government. These organizations intervene during family hardships and emergencies and play a critical role in the transition process by providing timely support, in the form of interest-free loans or grants, for financial emergencies that often lead to crisis (e.g. vehicle breakdown, overdue bills, emergency travel).

#### **MILITARY ONESOURCE**

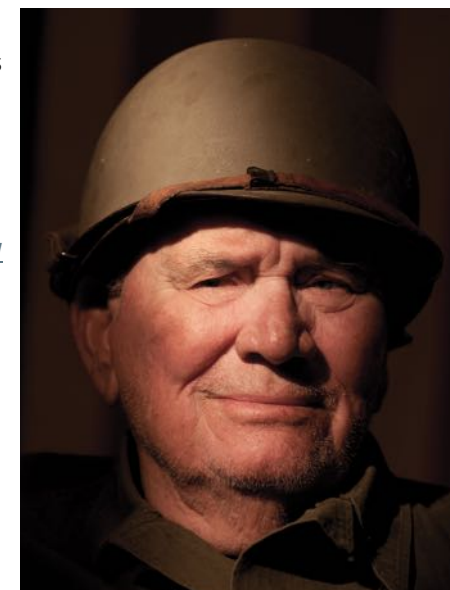
*Military OneSource is a free service from DOD to support military members and their families with centralized support for a broad range of concerns, such as money management, employment and education, parenting, relocation, deployment, and the issues of families with special needs. Military OneSource provides a wounded warrior specialty consultation service, including immediate assistance to wounded warriors and their families for healthcare, facilities, or benefits. Specialty consultants work with wounded warrior programs in each service branch (listed below) and the Department of Veterans Affairs to make sure callers are connected to the most appropriate resources. The service is dedicated to providing support—for as long as it may take—to make sure injured service members and their families achieve the highest level of functioning and quality of life. Military OneSource services are available 24 hours a day, 365 days a year. Toll-free 1-800-342-9647; [www.militaryonesource.mil](http://www.militaryonesource.mil)*

Each organization listed below has its own eligibility, application, and assistance requirements:

**Army Emergency Relief (AER)** provides funds to help soldiers with immediate financial needs with rent, utilities, emergency travel, etc. AER also provides emergency funds to soldiers' orphans and surviving spouses and offers undergraduate scholarships to spouses and children of both active and retired soldiers. You can speak with benefits experts between 9AM and 5PM EST M-F. Toll-Free 866-878-6378

<https://www.armyemergencyrelief.org>

**Navy-Marine Corps Relief Society** provides financial assistance and education, as well as other programs and services, to members of the United States Navy and Marine Corps, their eligible family members, widows, and survivors. The Society also receives and manages donated funds



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to administer these programs and services. Toll-Free - 800-654-8364;

[www.nmcrs.org](http://www.nmcrs.org)

**Air Force Aid Society** supports Airmen and enhances the Air Force mission by relieving emergency financial distress, helping Airmen's families achieve their educational goals, and improving their quality of life through proactive programs. 703-972-2650; <https://afas.org>

**Coast Guard Mutual Assistance** established and operated by Coast Guard people for Coast Guard people, CGMA provides a way to extend compassion to one another in times of need. It serves as a vital financial safety net, promoting financial stability and general wellbeing, fostering high morale and encouraging a sense of loyalty to the Coast Guard. You can speak with benefits experts between 6AM and 5PM EST Monday - Friday. Toll-Free - 1-800-881-2462, Local - 703-875-0404; <https://www.cgmahq.org>

**American Red Cross** provides emergency assistance, disaster relief, and disaster preparedness education. Find a local chapter for support through this link: [www.redcross.org/find-your-local-chapter.html](http://www.redcross.org/find-your-local-chapter.html)

**Semper Fi & America's Fund** provides direct financial assistance and vital programming for combat wounded, critically ill and catastrophically injured service members and their families during hospitalization and recovery. 760-725-3680; <https://semperfifund.org/what-we-do/family-support>

**U.S. Chamber of Commerce Wounded Warrior Transition Assistance Program** prepares wounded warriors for employment opportunities through transitional workshops, career opportunity days, internships, and mentor programs. 202-659-6000; <https://www.uschamber.com/wounded-warrior-transition-assistance-program>

**PenFed Foundation Military Heroes Fund Foundation Programs** offers financial assistance for wounded, ill, and injured post 9-11 combat veterans who are experiencing an unexpected short term (one to three months) financial setback. Local: 703-838-1200, Toll Free: 800-558-9224; <https://penfedfoundation.org/apply-for-assistance/emergency-financial-assistance>

### Navigating Military-to-Civilian Transition

The Department of Defense Transition Assistance Program (TAP) is mandatory for service members who have served 180 continuous days or more on active duty, including National Guard and reservists transitioning or upon release from active duty. Service members who are seriously injured on active duty

and require extended hospitalization may not be able to attend scheduled TAP prior to separation.

It will be up to individual commands to decide when and how a recovering service member and/or immediate family members can receive transition-related guidance. Some commands will send a representative to the hospital to do one-on-one counseling or provide the member with a web link through which relevant information can be accessed.

Veterans who did not receive TAP in person may also have the option to attend a scheduled session at the nearest base following recovery and release from the hospital. Veterans and family members should contact the nearest command to find out the local policy in such cases.

### SUICIDE PREVENTION

*The Department of Defense has established a Military Crisis Line. Toll-free 1-800-273-8255. Each branch of the military has a suicide prevention outreach. For a list see [www.veteranscrisisline.net](http://www.veteranscrisisline.net)*

### CRISIS AND SUICIDE PREVENTION

Service members and veterans in crisis, (as well as their families or caregivers), whether due to sexual assault, problems with the command, thoughts of suicide, or any other serious matter, are encouraged to contact the **Military & Veteran Crisis Line**. The number is toll free and can be reached by dialing 1-800-273-8255, then press 1, or access online chat by texting 838255. Members of the military can also click on the **Defense Suicide Prevention Office** website for more information and resources at <https://www.dsppo.mil>

Dial **911** for a more immediate response if you are in danger of imminent harm. In some cases, it will prove helpful to notify the 911 operator that a veteran is involved and either another veteran or a trained crisis intervention team member from the local police department is desired.

**Safe Helpline** - Specialized support outside the chain of command for sexual assault survivors. 24/7 Hotline: 1-877-995-5247

**Vet Center Call Center** - confidential call center where combat veterans and their families can call to talk about their military experience or any



other issue they are facing in their readjustment to civilian life. 24/7 Hotline: 1-877-WAR-VETS (927-8387)

**National Call Center for Homeless Veterans** - Veterans who are homeless or at imminent risk of homelessness are strongly encouraged to contact the National Call Center for Homeless Veterans at 877-4AID-VET (877-424-3838) for assistance. If veterans do not have access to a phone or the Internet, only then are they to visit their closest VA medical center without calling in advance. VA also urges veterans who are not homeless or at risk of homelessness to contact their VA medical center before visiting for any reason. <https://www.va.gov/homeless>

#### Other VA Helplines:

VA Health Care: 1-877-222-8387

VA Benefits: 1-800-827-1000

MyVA311: 1-844-698-2311

White House VA Hotline: 1-855-948-2311

## WOUNDED, ILL OR INJURED PROGRAMS

Comprehensive care for service members who are traumatically injured or incur seriously disabling illness requires coordination across agencies and health disciplines. Each of the individual branches of military service has specific recovery, rehabilitation, and integration goals. These programs provide lifetime support for impacted service members for which eligibility does not necessarily end when the service member is discharged from a military treatment facility, particularly for those on the Temporary Disabled Retired List (TDRL). To learn more about the wounded, ill, and injured programs for each military service, click on this link: <https://warriorcare.dodlive.mil>

**Air Force Wounded Warrior (AFW2)** works together with the Air Force Survivor Assistance Program, Airman & Family Readiness Centers and the Air Force Medical Service to provide concentrated non-medical care and support for combat wounded, ill and injured Airmen (and their families) as they recover and transition back to duty or into civilian life. The Air Force defines a wounded warrior as “any Airman who is seriously wounded, ill, or injured that may require a Medical Evaluation Board/Physical Evaluation Board to determine fitness for duty.” [www.woundedwarrior.af.mil](http://www.woundedwarrior.af.mil)

**Army Recovery Care Program (ARCP)** develops, coordinates, and integrates

care for wounded, ill, and injured soldiers, veterans and their families or caregivers to promote success in the course of civilian life. ARCP serves an essential role, not only in managing the care and recovery of soldiers evacuated from theater, but also those preparing to deploy and those who have returned from combat that require complex care management to cope with the effects of war and multiple deployments. ARCP works to ensure that everything possible is done to enable soldiers to return to duty. ARCP also plays an important role in ensuring Reserve component soldiers receive the care they require prior to and after deployment to remain mission ready. [https://www.army.mil/article/229469/army\\_warrior\\_care\\_and\\_transition\\_program\\_restructures](https://www.army.mil/article/229469/army_warrior_care_and_transition_program_restructures)

**Marine Corps Wounded Warrior Regiment** provides leadership and ensures compliance with laws and Department of Defense (DOD) regulations related to the support, recovery, and non-medical care of combat and non-combat wounded, ill, and injured (WII) Marines, Sailors attached to Marine units, and their family members in order to maximize their recovery as they return to duty or transition to civilian life. [www.woundedwarrior.marines.mil](http://www.woundedwarrior.marines.mil)

**Navy Safe Harbor Foundation** aims to ensure that every seriously wounded, ill and injured Navy and Coast Guard Sailor is given every opportunity for a full recovery by providing non-medical care and support to them and their families. The Navy Safe Harbor Foundation provides financial assistance and support to Navy and Coast Guard Sailors and their families enrolled in the Navy Wounded Warrior Program. <https://safeharborfoundation.org>

**Navy Wounded Warrior (NWW)** is the Navy’s sole organization for coordinating the non-medical care of seriously wounded, ill and injured Sailors and Coast Guardsmen, and providing resources and support to their families. Through proactive leadership, the program provides individually-tailored assistance designed to optimize the success of the wounded warriors’ recovery, rehabilitation and reintegration. [www.navywoundedwarrior.com](http://www.navywoundedwarrior.com)

**U.S. Special Operations Command (SOCOM) Warrior Care Program (Care Coalition)** was established to provide Special Operations Forces (SOF) wounded, ill, or injured service members and their families, advocacy after life changing events in order to navigate through recovery, rehabilitation, and reintegration as quickly as possible, strengthening SOF readiness. Whether you are returning operational status, moving into a different field or transitioning into veteran status, the USSOCOM Warrior Care Program (Care Coalition) will help you get there. [www.socom.mil/care-coalition](http://www.socom.mil/care-coalition)



**Yellow Ribbon Reintegration Program (YRRP)** is a Department of Defense-wide effort to promote the well-being of National Guard and Reserve members, their families and communities, by connecting them with resources throughout the deployment cycle. Through Yellow Ribbon events, service members and loved ones connect with local resources before, during, and after deployments.

[www.yellowribbon.mil](http://www.yellowribbon.mil)

## FOR LOVED ONES:

### Being an Active Member of the Recovery Team

You are very important to your service member's recovery. But it can take a while to fully understand your active role. These suggestions can help:

- *Know who is providing care. Learn names and specialties and write this information down.*
- *Learn everything you can about your service member's condition. Talk with doctors, nurses, case managers, social workers and other care providers.*
- *Be sure to read any written medical information your team provides. Knowledge will help alleviate fear of the unknown and help you make better decisions.*
- *Contact your Casualty Liaison, Recovery Care Coordinators (RCC) and Advocates.*
- *Learn the hospital's schedule and routines. Be aware of shift changes and times when staff is less available.*
- *Write your questions down ahead of time. It can be easy to forget things if*

you don't write them down.

- Ask for explanations of procedures and medications. If you don't understand something, ask questions until you do understand.
- Remember that the diagnosis and treatment plan may change.
- Be flexible and try to stay positive.
- Learn patient and caregiver rights and responsibilities. Ask for a copy of your medical treatment facility's description of patient and caregiver rights and responsibilities.
- Pay attention to moods and feelings. The healing process involves both physical and emotional aspects. It's important to talk with care providers about any behavior changes you might notice.
- Remember that your observations are unique and valuable. You will spend more time with your service member than any other member of his or her medical team.
- You don't have to go it alone; connect to other caregivers.

### Communicating with the Recovery Team

Sometimes it will feel as though doctors and military people are speaking another language and you're the only one who doesn't understand. You will be expected to learn new words and acronyms when your mind is full of emotion and your life is in upheaval. Sometimes you will have to make important decisions after hearing unpleasant news. It can make anyone feel overwhelmed.

In circumstances like these, it can be hard to communicate well, but you will get better results if you try. Begin now to practice effective communication in order to build relationships of trust with the members of the recovery team. Here are some suggestions from other people who have been in situations similar to yours:

- Be assertive in a friendly way. Don't say, "Yes, I understand," if you don't understand. Ask for clarification, again and again if necessary. There are no dumb questions and you can't afford to be shy. You need to understand as much as possible.
- Remember that the medical team takes care of many patients, but that you take care of one. Speak up to make sure that your service member's needs are met, but try to be patient when members of the medical team are doing their best to help many people.

- Keep in mind that all these people are on your side. You are on the same team, rooting for your service member's recovery. Try to trust and support each other.
- Recognize that when you are stressed, scared, or confused you may need to step back from your emotions to communicate effectively. If you feel rushed to make a decision but can't think clearly, ask for a few minutes to clear your head. Count to ten or step outside and take some time to calm down.
- Be friendly with the people around you. You will find that they can help you in many ways. Remembering to say "please" and "thank you," even when you feel stressed, seems like a small gesture, but in the end, civilities like these can make a big difference in how you, your service member, and the rest of the recovery team feel. From Military OneSource, Keeping It All Together.

### Department of Defense Resources

**Defense Manpower Data Center (DMDC)** serves under the Office of the Secretary of Defense (OUSD) to collate personnel, manpower, training, financial, and other data for the DOD. The DMDC website provides sponsors, spouses, and children 18 years and older with access to personal information, healthcare eligibility, personnel records, and other information from the Defense Enrollment Eligibility Reporting System that contains information for each uniformed service member.

For Benefits Support, call the DMDC/DEERS Support Office (DSO): 800-538-9552. For assistance with technical support, call the DMDC Support Center: 800-477-8227; <https://milconnect.dmdc.osd.mil/milconnect>

Service members and their support networks can access a guide to compensation and benefits titled **DOD's Wounded, Ill and/or Injured**

**Compensation and Benefits Handbook** [https://warriorcare.dodlive.mil/files/2019/06/DoD\\_Compensation\\_and\\_Benefits\\_Handbook.pdf](https://warriorcare.dodlive.mil/files/2019/06/DoD_Compensation_and_Benefits_Handbook.pdf)

Military caregivers can access information about national-level resources and programs in a booklet titled **DOD's Caregiver Resource Directory** <https://warriorcare.dodlive.mil/files/2019/08/Caregiver-Directory-2019-Edition.pdf>

The **National Resource Directory** is a searchable database of resources vetted for service members, veterans, family members and caregivers and provides access to resources to support recovery, rehabilitation and reintegration.

<https://nrd.gov>

### VETERANS SERVICE ORGANIZATIONS (VSO)



**American Legion** is a Congressionally chartered mutual-aid veterans organization founded in 1919 by veterans returning from Europe after World War I. Today the group has nearly 2 million members in more than 13,000 posts worldwide. The Legion supports the interests of veterans and service members, including veterans' benefits and the VA hospital system. 317-630-1200, toll-free 1-800-433-3318; [www.legion.org](http://www.legion.org)

**AMVETS (or American Veterans):** In one recent year, AMVETS national service officers processed more than 24,000 claims that resulted in veterans receiving \$400 million in compensation. Toll-free 1-877-726-8387; [www.amvets.org](http://www.amvets.org)

**AMVETS HEAL Program** ensures veterans with medical needs receive the help they have earned to access the best quality healthcare, including mental health and specialized services (traumatic brain injury, polytrauma, post-traumatic stress) and live longer, healthier lives. These services are free. HEAL, which stands for healthcare, evaluation, advocacy, legislation, encompasses all necessary steps the team will take to intervene directly on behalf of veterans, service members, families, and caregivers to reduce veteran suicide, unemployment, homelessness, and hopelessness as it relates to mental and physical wellness. <https://amvets.org/vet-heal>

**Disabled American Veterans (DAV)** was founded in 1920 to represent disabled veterans returning from World War I. DAV provides free assistance to veterans and their families in obtaining benefits and services earned through military service. Toll-free 1-877-426-2838; [www.dav.org](http://www.dav.org)

**Paralyzed Veterans of America (PVA)** was founded by a band of service members who came home from World War II with spinal cord injuries. A core strength of PVA is its network of National Service Officers, highly trained in VA law, benefits, and healthcare. Toll-free 1-800-424-8200; [www.pva.org](http://www.pva.org)

**Veterans of Foreign Wars (VFW)** traces its roots to 1899. VFW maintains a nationwide network to assist veterans with their VA disability claims. A VFW program called Unmet Needs assists military service members and their families who run into unexpected financial difficulties; assistance grants of up to \$1,500 do not need to be repaid. 816-756-3390; [www.vfw.org](http://www.vfw.org)



## MEDICAL EVALUATION PROCESS

Service members who suffer serious injury or develop any sort of debilitating condition that impacts typical mental or bodily function may be preliminarily deemed unfit for service. A unit commander or designee will be responsible for ensuring these service members are given the opportunity to undergo a review of their disqualifying condition and circumstances around its incurrence, overall health and fitness, and character of service. Prior to the implementation of the Integrated Disability Evaluation System (IDES), the Defense Department would provide separation exams to service members, and those same service members had to undergo another exam pursuant to a VA claim of entitlement to disability compensation and other benefits.

DOD and the Department of Veterans Affairs (VA) work together to make disability evaluation seamless and transparent with the IDES. The IDES integrates DOD and VA's disability processes and uses a single set of medical examinations to determine fitness for duty as well as a single set of disability ratings to determine the level of DOD and VA disability benefits. The IDES improves the accuracy and consistency of disability determinations and the timeliness of providing both DOD and VA disability benefits to eligible service members. It is the primary disability evaluation system used by the military departments.

A service member is referred into the IDES when their doctor determines the member, within 12 months of the onset of their condition, is not likely to return to duty. Once the examination results are received, the Physical Evaluation Board Liaison Officer will coordinate with administrative staff at the Military Treatment Facility to convene a Medical Evaluation Board (MEB).

**Medical Evaluation Board (MEB)** - The MEB is the medical portion of the disability evaluation process. The results determine whether the service member meets the service-specific medical retention standards. The MEB does not determine the service member's fitness for duty or level of disability.

**Physical Evaluation Board (PEB)** - The PEB is the personnel portion of the disability evaluation process that determines whether the service member is fit for continued military service. For members determined unfit because of duty-related impairments, it determines their eligibility for disability benefits. The board looks at many factors, including the service member's medical information, letters from their chain of command, as well as their rate or military occupational specialty to determine how their medical condition(s)



impact their ability to perform required military duties.

Read more about the military evaluation process through the DoD's Warrior Care webpage: <https://warriorcare.dodlive.mil/disability-evaluation/integrate-ddes/#MedicalEvaluationBoard>

## DEPARTMENT OF VETERANS AFFAIRS (VA)

If you are serving on active duty in the United States uniformed services, including active National Guard and Reserve with federal pay, you may be eligible for VA benefits both during service and after separation or retirement. If you're a traditional or technical member of the National Guard and Reserve, you may also be eligible for some VA benefits. Find out which benefits you may qualify for—and when to apply. You can also learn about these benefits in your required Transition Assistance Program (TAP) briefing through this link: <https://www.va.gov/service-member-benefits>

### VA Benefits to Consider while on Active Duty

**Pre-discharge disability claim** - If you have an illness or injury that you believe was caused—or made worse—by your service, learn how to file a disability

claim through the Benefits Delivery at Discharge program. This may help speed up your claim so you can get your benefits sooner. You'll need to file 90 to 180 days before separation. Open to active-duty service members, Guard members, and Reservists.

**GI Bill and other education benefits** - Find out if you qualify for VA education benefits to help pay for school or training. If you qualify for the Post-9/11 GI Bill, learn how to transfer your unused benefits to your spouse or dependent children. Open to service members and veterans (active duty, Guard, and Reserve).

**Home Loan Guaranty** - used for a VA-backed home loan to buy, build, improve, or refinance a home. Open to service members and veterans (active duty, Guard, and Reserve).

### **Time-sensitive VA benefits to consider when separating or retiring**

**Converting your life insurance after separation** - There is a limited window of time (usually 180 days) to determine coverage options for you and your family after separation or retirement.

Find out how to convert your SGLI coverage to a Veterans' Group Life Insurance (VGLI) or commercial policy. Learn about other options for coverage if you have service-connected disabilities. In some cases, you must act within 120 days of separation to ensure no lapse in coverage. Open to service members and veterans (active duty, Guard, and Reserve) who have a Servicemembers' Group Life Insurance policy.

**Educational and career counseling** - Get support transitioning to a civilian career with free educational and career counseling (also called Chapter 36). You'll need to apply between six months before and one year after separation. Open to active-duty service members and veterans only.

**Active-duty service members and VA health care** - Learn about your health care options after separation or retirement and how to apply for VA health care when you receive your separation or retirement orders. If you're a combat veteran, apply right away to take advantage of five years of enhanced eligibility. Open to active-duty service members and veterans only.

**Vocational Rehabilitation and Employment** - If you have a service-connected disability that limits your ability to work or prevents you from working, find out how to apply for vocational rehab. You can apply up to 12 years from when you receive your notice of separation or your first VA disability rating. Open to

service members and veterans (active duty, Guard, and Reserve).

### **REMEMBER**

*It is important to note that once the window of opportunity closes on these decisions, there's no recourse even if the service member was not advised of the options.*

### **Other VA benefits to consider as a veteran**

**Disability compensation** - File a claim for disability compensation for conditions related to your military service, and manage your benefits over time. Open to veterans (active duty, Guard, and Reserve).

**Support for veteran-owned small businesses** - If you served on active duty, register to do business with the VA and get support for your veteran-owned small business. If you have a service-connected disability related to active-duty service or training, you may qualify to register as a service-disabled veteran-owned small business. Open to veterans (active duty, Guard, and Reserve).

**Veterans Pension program** - If you served on active duty during wartime, are at least 65 years old or have a service-connected disability, and have limited or no income, find out if you qualify for Veterans Pension benefits. Open to active-duty veterans only.

**Aid and attendance or housebound allowance** - If you need help with your daily activities or you're housebound, check whether you're eligible to have increased aid added to your monthly veteran's pension payments. Open to active-duty veterans only.

**VA Automobile Allowance and Adaptive Equipment** - Run by the Veterans Benefits Administration. These allowances are solely for service connected veterans with qualifying conditions.

<https://www.benefits.va.gov/compensation/claims-special-auto-allowance.asp>

**Disability housing grants** - If you have a service-connected disability, find out how to apply for a housing grant to make changes to your home so you can live more independently. Open to veterans (active duty, Guard, and Reserve).

Read more about these benefits and more through this link:

<https://www.va.gov/service-member-benefits/#va-benefits-you-can-use-during-and-after-service>

## About VA/DOD eBenefits

The eBenefits web portal provides service members, veterans, their families, and authorized caregivers with a single sign-on, central access point to clinical and benefits information. To gain access to most eBenefits resources and services, you need an account. There are two types of accounts that are free and require a [DS logon](#) to register:

- A Basic account that gives you limited access to various features.

### VA BENEFITS FOR NON-SERVICE CONNECTED SPINAL CORD INJURY/ DISORDERS



Sherman Gillums

**Q.** My spinal cord was injured in a motor vehicle accident after I returned from active duty. Do I still get VA medical benefits?

**A.** Yes, you are eligible for VA healthcare based on your service, which basically means you earned an honorable discharge and have a DD214. The VA will assign you to a Priority Group based on whether you have service-connected conditions. Depending on the Priority Group in which you're placed, you may have co-pays for inpatient care, outpatient care, and prescriptions. If you have private insurance, the insurance company may get billed as well. In your case of a non-service-connected catastrophic injury, you will be assigned to Priority Group 4, following what's called a Catastrophic Disability Evaluation conducted by a VA physician. Once deemed catastrophic, a veteran's income will determine whether he or she will be responsible for co-pays. There are other benefits available to veterans who are non-service-connected and have a spinal cord injury. Based on being enrolled in the VA system and having loss of use of lower extremities, a veteran is entitled to two customized wheelchairs, a grant to have a vehicle modified for wheelchair ingress/egress, and a small grant for home modifications. These don't cost the veteran anything as they are administered as an extension of VA healthcare. If the veteran has a need for bowel/bladder services, the VA can pay for this contracted care in the home through a fee basis. In many instances, the spouse is the veteran's caretaker and, once trained by VA, can perform and get paid for these contracted services.

Thanks to Sherman Gillums, Jr., Chief Advocacy Officer, AMVETS National

### NON-ACTIVE DUTY VETERANS PROCESS CHECKLIST AFTER SPINAL CORD INJURY/ DISORDERS

Non-active duty veterans who incur a spinal cord injury/disorder should try to do the following:

Acute Care

1. **Admission** to nearest trauma center for surgery and stabilization (VA does not provide trauma care)

2. **Locate DD214**

- If already receiving VA care, request transfer to VA SCI/D unit
- If not receiving VA services, apply for category 4 status through VA
- Transfer to either civilian or VA SCI rehabilitation center
- If at civilian SCI rehabilitation center, upon qualification transfer to VA SCI/D unit
- If receiving care at civilian facility, apply for outpatient VA SCI/D care

3. **Contact a VSO** (PVA or AMVETS) to assess benefits eligibility and conduct an evaluation to determine whether spinal cord injury can be directly or secondarily connected to military service

4. **Establish your "center"** for SCI care

Pay attention to the following resources and sections in this chapter for key areas of assistance: eBenefits web portal, Crisis and VA Helplines, Suicide and Crisis Prevention, Military Relief Organizations, VA Benefits for Non-Service Injuries.

- A Premium account that gives you unlimited access.

Read more about eBenefits through this link:

<https://www.ebenefits.va.gov/ebenefits/about>

## VA Health Benefits

**VA Health Care Enrollment and Eligibility** - If you served in the active military, naval or air service and are separated under any condition other than dishonorable, you may qualify for VA health care benefits. Current and former members of the Reserves or National Guard who were called to active duty



(other than for training only) by a federal order and completed the full period for which they were called or ordered to active duty also may be eligible for VA health care. Most veterans who enlisted after September 7, 1980, or entered active duty after October 16, 1981, must have served 24 continuous months or the full period for which they were called to active duty to be eligible. This minimum duty requirement may not apply to veterans who were discharged for a disability incurred or aggravated in the line of duty, were discharged for a hardship or received an “early out.” Since there are a number of other exceptions to the minimum duty requirements, VA encourages all veterans to apply to determine their enrollment eligibility.

**Returning Service Members (OEF/OIF/OND)** - Every VA medical center has a team ready to welcome OEF/OIF/OND service members and help coordinate their health care and other services. For more information about the various programs available for recently returned service members, log on to the Returning Service Members website at [www.oefoif.va.gov](http://www.oefoif.va.gov)

Veterans who served in a theater of operations after November 11, 1998, are eligible for an extended period of eligibility for health care for five years after their discharge. In the case of multiple call-ups, the five-year enrollment period begins on the most recent discharge date. This special eligibility includes cost-free health care services and nursing home care for conditions possibly related to military service and enrollment for five years from their date of discharge or release from active duty, unless they are eligible for enrollment in a higher priority group.

Combat veterans who enroll with VA under this enhanced Combat Veteran authority will continue to be enrolled even after their enhanced eligibility period ends,

although they may be shifted to a lower priority group, depending on their income level, and be required to make applicable copayments. Additionally, for care not related to combat service,



copayments may be required, depending on their financial assessment and other special eligibility factors.

This guide is not intended to provide information on all of the health benefits and services offered by VA. Additional information is available at the following resources: Toll-Free: 1-877-222-VETS (8387)

[www.va.gov/healthbenefits](http://www.va.gov/healthbenefits)

**MyHealtheVet** - this is a web-based customizable management application that offers tips and tools to help you partner with your health care team, so together you may work to manage your health. Here you may find useful

### **SOCIAL SECURITY & MEDICARE**

*Military service members can receive expedited processing of disability claims from Social Security. These benefits are different than those from the VA and require a separate application. Social Security pays disability benefits through two programs: the Social Security Disability Insurance (SSDI) program, which pays if you worked long enough and paid Social Security taxes; and the Supplemental Security Income (SSI) program, which pays benefits based on financial need. File an application for disability benefits as soon as possible. Full details at [www.ssa.gov/people/veterans](http://www.ssa.gov/people/veterans)*

**Medicare:** *Coverage begins automatically after you have received disability benefits for twenty-four months. For service members who are entitled to Medicare Part A (hospital insurance) and Part B (medical insurance), TRICARE provides Medicare “wrap-around” coverage. Medicare is the primary payer for these beneficiaries, and TRICARE serves as a supplement, paying the Medicare deductible and patient cost share. For more about TRICARE, visit <https://tricare.mil>. For information about Medicare, see [www.medicare.gov](http://www.medicare.gov)*

*Please see Chapter 6, Navigating the System for more information on Social Security and Medicare.*

resources when you need them. The support tools on this page are designed to enrich your experience with My HealtheVet and help you make informed decisions. Read more about MyHealtheVet and how to register for an account through this link:

<https://www.myhealth.va.gov/mhv-portal-web/web/myhealthvet/about-mhv>



### Post-Traumatic Stress Disorder (PTSD)

The **National Center for PTSD** does not provide direct clinical care or individual referrals. The center provides information to help you find local mental health services and information on trauma and PTSD. No matter where you live, PTSD treatment in the Department of Veterans Affairs is available. Each medical center within VA has PTSD specialists who provide treatment for veterans with PTSD and there are nearly 200 specialized PTSD treatment programs throughout the country. [www.ptsd.va.gov/gethelp/tx\\_programs.asp](http://www.ptsd.va.gov/gethelp/tx_programs.asp)

Some large Community Based Outpatient Clinics (CBOCs) also offer PTSD care. When there are no nearby facilities, smaller CBOCs provide needed treatment services by telemental health (counseling or mental health services delivered via technology) or by referral to veteran centers or community clinicians. You can find specialized PTSD programs and other options within the VA for getting PTSD treatment using this VA PTSD Program Locator to see if there is a specialized program near you: [www.va.gov/directory/guide/PTSD.asp](http://www.va.gov/directory/guide/PTSD.asp)

### Polytrauma System of Care

VA's Polytrauma System of Care (PSC) is an integrated network of specialized rehabilitation programs dedicated to serving veterans and service members with both combat and civilian related traumatic brain injury (TBI) and polytrauma. Services available through PCS include: interdisciplinary evaluation and treatment, development of a comprehensive plan of care, case management, patient and family education and training, psychosocial support, and application of advanced rehabilitation treatments and prosthetic

technologies. Learn more about the Polytrauma System of Care through this link: <https://www.polytrauma.va.gov/system-of-care/index.asp>

### Spinal Cord Injuries and Disorders System of Care

VA's Spinal Cord Injuries and Disorders (SCI/D) System of Care provides a coordinated life-long continuum of services for veterans with a spinal cord injury or disorder. VA serves veterans in a convenient and connected network that delivers care for each phase of life. VA's Spinal Cord Injuries and Disorders System of Care is designed around a system of "hub and spokes." The 25 SCI/D centers are the hubs. Each center has highly trained and experienced providers including doctors, nurses, social workers, therapists, psychologists, and others who can deal with the unique problems that can affect people with a spinal cord injury or disorder.

SCI/D centers work closely with other designated medical facilities that do not have SCI/D Centers (called spokes) to provide excellent care as close to home as possible. SCI/D spokes teams are located around the country. At SCI/D spokes, health care providers work closely with the centers to ensure that comprehensive primary and specialized care needs are addressed. It is important to get primary care from providers that have SCI/D training so that they can check for the development of problems unique to SCI/D. There are 25 Spinal Cord Injuries and Disorders Centers (SCI/D Centers) located around the country. See the list of them on the next page.

### Rehabilitation and Prosthetic Services (includes assistive technology, sports, and other support services)

**Prosthetic & Sensory Aids Service (PSAS)** provides comprehensive support to optimize health and independence of the veterans with severely disabling conditions through prosthetic and orthotic services, sensory aids, medical equipment, and support services.

Veterans who are rated for a service-connected disability for which he or she uses prosthetic or orthopedic appliances may receive an annual clothing allowance. The allowance is also available to veterans whose service-connected skin condition requires prescribed skin medication that irreparably damages the veteran's outer garments. Learn more through this link:

[https://www.prosthetics.va.gov/psas/Clothing\\_Allowance.asp](https://www.prosthetics.va.gov/psas/Clothing_Allowance.asp)

The **Automobile Adaptive Equipment (AAE)** program permits physically challenged persons to enter, exit, and/or operate a motor vehicle or other

### **VA SCI/D CENTERS**

- Long Beach SCI/D Center, Long Beach, CA 90822, 562-826-5701
- Palo Alto SCI/D Center, Palo Alto, CA 94304; 650-493-5000
- San Diego SCI/D Center, San Diego, CA 92161, 858-642-3117
- Denver SCI/D Center, Aurora, CO 80045, 720-723-3300
- Miami SCI/D Center, Miami, FL 33125, 305-575-3174
- Tampa SCI/D Center, Tampa, FL 33612, 813-972-2000, ext 7517
- Augusta SCI/D Center, Augusta, GA 30904, 706-733-0188
- Hines VA SCI/D Center, Hines, IL 60141, 708-202-2241
- Boston SCI/D Center, West Roxbury, MA 02132, 857-203-5128
- Minneapolis SCI/D Center, Minneapolis, MN 55417, 612-629-7005
- St. Louis SCI/D Center, St Louis, MO 63125, 314-894-6677
- East Orange SCI/D Center, East Orange, NJ 07018, 973-676-1000
- Albuquerque SCI/D Center, Albuquerque, NM 87108, 505-256-2849
- Bronx SCI/D Center, Bronx, NY 10468, 718-584-9000
- Syracuse SCI/D Center, Syracuse, NY, 315-425-2682
- Cleveland SCI/D Center, Cleveland, Ohio 44106, 216-791-3800
- Memphis SCI/D Center, Memphis, TN 38104, 901-577-7373
- Dallas SCI/D Center, Dallas, TX 75216, 214-857-1757
- Houston SCI/D Center, Houston, TX 77030, 713-794-7057
- San Antonio SCI/D Center, San Antonio, TX 78229, 210-617-6414
- Hampton SCI/D Center, Hampton, VA 23667, 757-722-9961
- Richmond SCI/D Center, Richmond, VA 23249, 804-675-5000, ext. 5128
- Seattle SCI/D Center, Seattle, WA 98108, 206-764-2332
- Milwaukee SCI/D Center, Milwaukee, WI 53295, 414-384-2000, ext. 41230
- San Juan SCI/D Center, San Juan, PR 00921, 787-641-7582

Source: [www.sci.va.gov/VAs\\_SCID\\_System\\_of\\_Care.asp](http://www.sci.va.gov/VAs_SCID_System_of_Care.asp)

conveyance. Veterans are trained, through the VA Driver's Rehabilitation Program, how to safely operate their vehicle on our nation's roadways. The VA also provides necessary equipment such as platform wheelchair lifts, UVLs (under vehicle lifts), power door openers, lowered floors/raised roofs, raised doors, hand controls, left foot gas pedals, reduced effort and zero effort steering and braking, and digital driving systems. Additionally, VA's program provides reimbursements for standard equipment including, but not limited to, power steering, power brakes, power windows, power seats, and other special equipment necessary for the safe operation of an approved vehicle.

<https://www.prosthetics.va.gov/psas/AAE.asp>

**Home Improvements and Structural Alterations (HISA)** grants provide medically necessary improvements and structural alterations to veterans and service members' primary residence. Some excluded HISA structural alterations are exterior decking; purchase or installation of spa/hot tubs/Jacuzzi type tubs; home security systems; removable equipment or appliances such as portable ramps; porch lifts, and stair glides; and routine repairs. Learn more through this link: <https://www.prosthetics.va.gov/psas/HISA2.asp>

**Service dogs** are guide or service dogs prescribed for a disabled veteran diagnosed as having a visual, hearing, or substantial mobility impairment. Eligible veterans may receive assistance from VA with maintaining the health and viability of a qualifying service animal.

<https://www.prosthetics.va.gov/ServiceAndGuideDogs.asp>

**VA's Office of National Veterans Sports Programs and Special Events** provides veterans with opportunities for health and healing







through adaptive sports and therapeutic art programs. These specialized rehabilitation events aim to optimize veterans' independence, community engagement, well-being, and quality of life. The programs are built on clinical expertise within VA, with essential support from Veteran Service Organizations, corporate sponsors, individual donors and community partners. [sports4vets@va.gov](mailto:sports4vets@va.gov)

### Community Care Overview

VA provides healthcare for veterans from providers in your local community outside of VA. Veterans may be eligible to receive care from a community provider when VA cannot provide the care needed. This care is provided on behalf of and paid for by VA. Community care is available to veterans based on certain conditions and eligibility requirements, and in consideration of a veteran's specific needs and circumstances. Community care must be first authorized by VA before a veteran can receive care from a community provider. As with care provided directly by VA, veterans are charged a copayment for non-service-connected care. Learn how to pay your bill and alternative payment options. In addition, VA may bill veterans' health insurance for medical care, supplies, and prescriptions related to treatment of

non-service-connected conditions. Learn more through this link:

<https://www.va.gov/COMMUNITYCARE/programs/veterans/index.asp>

### Information for Dependents

**Benefits for Dependents** - VA offers health care and services for a veteran's family members and dependents (beneficiaries) based on certain conditions and eligibility requirements. VA serves more than 360,000 beneficiaries through its family member and dependent health care benefit programs. In general, these programs reimburse the costs of specific types of covered services provided. Information about specific programs is provided below.

#### Civilian Health and Medical Program of the Department of Veterans Affairs (CHAMPVA)

is a comprehensive health care program in which the VA shares the cost of covered health care services and supplies with eligible beneficiaries. The program is administered by the Veterans Health Administration Office of Community Care (VHA OCC) in Denver, Colorado.

Due to the similarity between CHAMPVA and the Department of Defense (DOD) **TRICARE program** (sometimes referred to by its old name, CHAMPUS), the two are often mistaken for each other. CHAMPVA is a Department of Veterans Affairs program while TRICARE is a regionally managed health care program for active duty and retired members of the uniformed services, their families, and survivors. In some cases, a veteran may appear to be eligible for both or either program on paper; however, if you are a military retiree, or the spouse of a veteran who was killed in action, you are and will always be a TRICARE beneficiary and cannot choose between the two programs.

[www.va.gov/COMMUNITYCARE/programs/dependents/champva/index.asp](https://www.va.gov/COMMUNITYCARE/programs/dependents/champva/index.asp)

**Camp Lejeune Family Member Program (CLFMP)** is for family members of veterans that lived or served at U.S. Marine Corps Base Camp Lejeune, North Carolina, between August 1, 1953, and December 31, 1987, and were potentially exposed to drinking water contaminated with industrial solvents, benzene, and other chemicals. On August 6, 2012, the Honoring America's Veterans and Caring for Camp Lejeune Families Act of 2012 was signed into law. This law (H.R. 1627, now Public Law 112-154) requires the Department of Veterans Affairs (VA) to provide health care to veterans who served on active duty at Camp Lejeune and to reimburse eligible Camp Lejeune family members for health care costs related to one or more of 15 specified illnesses or medical conditions listed in the law.

<https://www.va.gov/COMMUNITYCARE/programs/dependents/CLFMP.asp>

## CAREGIVER RESOURCES

**VA Caregiver Support** The VA provides benefits and services specifically to support family caregivers, both in and out of the home. Contact the VA's Caregiver Support Line, toll-free 1-855-260-3274, or connect with a Caregiver Support Coordinator at a VA Medical Center. A Caregiver Support Coordinator is a licensed professional who can match you with services and offer resources that can help you stay smart, strong, and organized. Services may include adult day care centers, home-based primary care, skilled home care, home telehealth resources, respite care, and home hospice care. Family caregivers of veterans injured post-9/11 may be eligible for additional VA services, including a stipend, travel expenses, respite care, comprehensive training, and medical coverage through the VA if you are not already covered by a plan. Call the support line listed above or visit [www.caregiver.va.gov](http://www.caregiver.va.gov)

**Elizabeth Dole Foundation: Caring for Military Families** has created a Military and Veteran Caregiver journey map, that addresses all aspects of the caregiver's role and participation from time of injury forward.

<https://caregiverjourney.elizabethdolefoundation.org>,  
[www.elizabethdolefoundation.org](http://www.elizabethdolefoundation.org)

**Resources and Education for Stroke Caregivers' Understanding and Empowerment (RESCUE)** is an online VA resource providing stroke caregivers—applicable also to caregivers of loved ones with other sudden

disabilities—with information and resources to help better care for a loved one. The website also offers information to help caregivers take care of themselves. The site features over forty easy-to-read fact sheets about stroke and stroke caregiving (also available in Spanish). [www.cidrr8.research.va.gov/rescue](http://www.cidrr8.research.va.gov/rescue)



### Special Compensation for Assistance with Activities of Daily Living

**(SCAADL)** was authorized by the Fiscal Year 2010 National Defense Authorization Act. This special monthly compensation is for service members who incur a permanent catastrophic injury or illness. SCAADL helps offset the loss of income by a primary caregiver who provides non-medical care, support and assistance for the service member thus keeping the service member out of institutional care.

<https://warriorcare.dodlive.mil/benefits/scaadl>

**Tragedy Assistance Program for Survivors (TAPS)** offers compassionate care to all those grieving the death of a loved one serving in the Armed Forces. Since 1994, TAPS has provided comfort and hope 24 hours a day, seven days a week through a national peer support network and connection to grief resources, all at no cost to surviving families and loved ones. [www.taps.org](http://www.taps.org)

*For more on the topic of caregiving, see Chapter 10.*

## BRAIN INJURY RESOURCES

The VA offers rehabilitation for service members with brain injuries so they receive coordinated, comprehensive care. Specialized services are available at four traumatic brain injury (TBI) centers (Palo Alto, CA; Tampa, FL; Minneapolis, MN; and Richmond, VA). The goal is to return the brain injury survivor to the highest quality of life and level of functioning and to educate family members and caregivers on the patient's long-term needs. Contact your local VA medical center for more information about TBI services available.

**Bob Woodruff Foundation** works to support injured service members with a special emphasis on the hidden injuries of war—traumatic brain injury and combat stress. <https://bobwoodrufffoundation.org>

**Brain Injury Association of America (BIAA)** works toward brain injury prevention, research, treatment and education and to improve quality of life for all people affected by brain injury. 703-761-0750; [www.biausa.org](http://www.biausa.org). BIAA's **National Brain Injury Information Center**: Toll-free 1-800-444-6443.

**Defense Centers of Excellence for Psychological Health and Traumatic Brain Injury (DCoE)** evaluates and disseminates evidence-based practices and standards for the treatment of psychological health and TBI within the Defense Department. DCoE is part of the Military Health System's continuum of care—from initial accession to deployment to discharge. *DCoE's centers include:*



- **Deployment Health Clinical Center (DHCC):** improves deployment-related health by providing assistance and medical advocacy to military personnel and families, including assessment of post-deployment physical symptoms, specialized care programs, education and clinical and health services research. 301-295-7692; [www.pdhealth.mil](http://www.pdhealth.mil)
- **Defense and Veterans Brain Injury Center** ensures expert care, coordination, and individualized, evidence-based treatment to maximize function and minimize disability. DVBIC provides services to enable return to duty, work, or community. Any service member or veteran with TBI covered by TRICARE or VA benefits may be referred to DVBIC; toll-free 1-800-870-9244; [www.dvbic.org](http://www.dvbic.org)
- **Connected Health:** designs, builds, tests and evaluates technologies in support of psychological health and traumatic brain injury recovery. 253-968-1914; <https://health.mil/About-MHS/OASDHA/Defense-Health-Agency/Operations/Clinical-Support-Division/Connected-Health>

## NO WRONG DOOR PROGRAMS (NWD)

The current long-term services and supports (LTSS) access system involves multiple funding streams with often duplicative eligibility and enrollment processes, leaving many individuals feeling bewildered and overwhelmed. The NWD System vision is developed and supported through a partnership between the Administration for Community Living, the Centers for Medicare and Medicaid Services and the Veterans Health Administration.

The NWD System makes it easier for people of all ages, disabilities and income levels to learn about and access the services and supports they need. This includes veterans and their caregivers. The foundation of a No Wrong Door System is built on key initiatives designed to help states effectively transform their access systems for veterans, families, and caregivers. To learn more, log onto <https://nwd.acl.gov/serving-veterans.html#Services>

**NWD's Veteran Directed Care Program** provides veterans greater choice and control over the long-term services and supports that help veterans live at home. <https://nwd.acl.gov/vdc.html>

**NWD's Connecting Older Veterans (Especially Rural) to Community or Veteran Eligible Resources (COVER to COVER) Program** helps veterans in

rural areas gain information and access to benefits within their communities. <https://nwd.acl.gov/cover-to-cover.html>

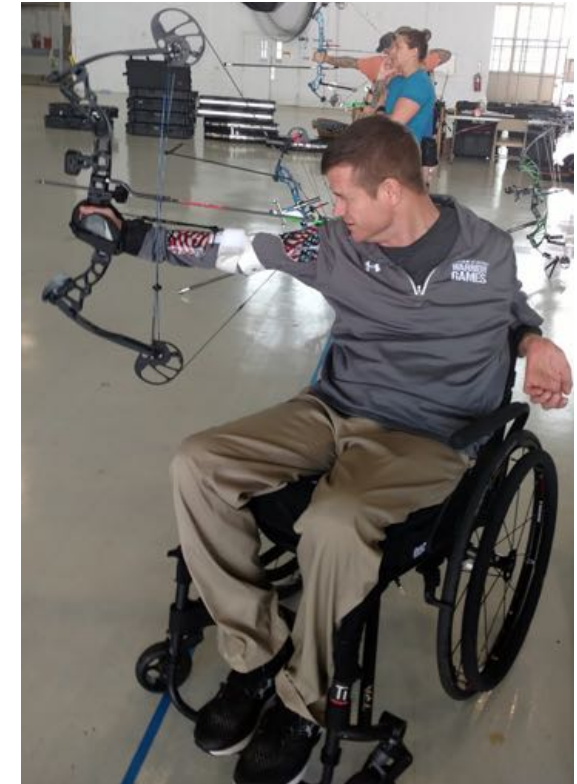
**NWD's Ask the Question Initiative** improves access to and quality of services for veterans and their families. <https://nwd.acl.gov/ask-the-question.html>

## ADAPTIVE SPORTS

For many veterans with spinal cord injuries, the transition from physical, occupational, and recreational therapy culminates in adaptive sports. While the competitive aspects of wheelchair sports, such as quad rugby, basketball, motorized soccer, air guns, and others are part of the experience, these recreational activities mimic the mental and physical challenges of everyday living and movement that ultimately promote problem solving and independence. It is for this reason that adaptive sports are encouraged as an extension of rehabilitation and as part of a lifestyle of wellness and activity in individuals who have limited opportunities to exercise.

Investment in adaptive sports and recreation opportunities will vary depending on several factors, including location, concentration of persons with disabilities, funding, staffing, and awareness of the need.

**Challenged Athletes Foundation** offers "Operation Rebound" which is designed specifically for veterans by offering grants for adaptive sports equipment. [www.challengedathletes.org](http://www.challengedathletes.org)





**Independence Fund** empowers severely wounded veterans and their caregivers to take control of their lives. (Through adaptive sports, all terrain mobility devices as well as networking opportunities for caregivers.) [www.independencefund.org](http://www.independencefund.org)

**National Veterans Golden Age Games** is the premier senior adaptive rehabilitation program in the United States.

<https://www.blogs.va.gov/nvspse/national-veterans-golden-age-games>

**National Veterans Summer Sports Clinic** promotes the value of rehabilitation through sports therapy.

<https://www.blogs.va.gov/nvspse/national-veterans-summer-sports-clinic>

**National Veterans Wheelchair Games** is the world's largest annual wheelchair sports event solely for military veterans. <https://www.wheelchairgames.org>

**National Veterans Winter Sports Clinic** involves disabled veterans with profound injuries and medical concerns the opportunity to engage in therapeutic outdoor experiences and education.

<https://www.wintersportsclinic.org>

**Oscar Mike Foundation** strives to be a leading provider of funding for injured veterans to participate in life-changing adaptive sports. The organization utilizes 100% of donations to its foundation and proceeds from its Oscar Mike apparel sales to provide support to injured veterans looking for an opportunity to stay active. By focusing on the arena of adaptive sports, the Oscar Mike Foundation assists in offering an outlet for an ongoing competitive lifestyle to thousands of American veterans who have sacrificed for the defense of our country. <https://www.oscarmike.org/pages/foundation>

**Wounded Warrior Independence Program** is designed to help warriors living with moderate to severe brain injuries, traumatic brain injury, spinal cord injury, or neurological conditions, take positive steps towards independent living through various services including recreation.

<https://www.woundedwarriorproject.org/programs/independence-program>



ZACK WEINSTEIN BY CHRISTOPHER VOELKER

# 9

## KIDS' ZONE

The most important tools for parents are other parents. There is no substitute for the advice and counsel of those who have been in similar circumstances.



GAYLA ELIZABETH

Maile, 3, who has spina bifida and uses a wheelchair, rides the Malibu surf with Life Rolls On.

Spinal cord injury or disease in children is marked by many of the complications and secondary effects of paralysis in adults, including sensory loss, bowel and bladder loss, etc. SCI in kids is complicated by growth and development. Children are skeletally immature; they have an increased risk of developing secondary skeletal conditions such as scoliosis and hip dysplasia. Their injuries may not be seen with standard x-rays so a CT scan or MRI may be needed to properly diagnose the injury. Crying may mask respiratory failure. Irritability may disguise autonomic dysreflexia, an over-activity of the autonomic nervous system that can cause an abrupt onset of extremely high blood pressure, leading to seizures, stroke and, in the most severe cases, death (see page 90 for more on this medical emergency).

A primary difference in treating younger patients is that care becomes family centered. The parents are involved in nearly every aspect of physical care and must also nurture the child's psychological growth. It is important to foster expectations that the child will grow into an independently functioning adult.

### READY FOR REHAB

When a child is injured, a parent must first understand the injury and begin planning for the rehabilitation phase. An Information Specialist at the Reeve Foundation can provide many resources; call toll-free 1-800-539-7309. It is never too early to begin researching rehabilitation centers. Acute hospital stays are short and your child will be moving on to a rehabilitation center very soon. Make a well-informed choice based on your child's level of injury, your family's needs and your insurance guidelines. You may find that many rehabilitation centers have a minimum age requirement for admission because they are not equipped to meet the special needs of young children and their families.

Parents play a critical role in determining what is best for both child and family. Parents have a right to participate in the selection of a rehabilitation facility. Be proactive, do your research and advocate for what best meets your child's and family's needs. Remember that rehabilitation is short term—your child might be home in as few as 30 days.

A starting point in locating pediatric centers is the Commission on Accreditation of Rehabilitation Facilities (CARF). Look for a special designation of Spinal Cord Injury (SCI) as well as having the facility be an accredited rehabilitation center. There are very few programs that are

specifically CARF accredited for children with spinal cord injury or disease. However, many of the major children's hospitals have rehabilitation programs and can meet your child's special needs. Additionally, many adult rehabilitation centers accept teens.

*Some questions to ask a pediatric rehabilitation center:*

- Do you have a specialized program for pediatric SCI patients?
- How many children with SCI does your facility admit each year?
- Do you have a specialized program for adolescents?
- How many adolescents with SCI do you admit each year?
- Do you have a program so my child can continue school work?
- Are siblings and friends allowed to visit?
- What level of involvement do you expect from parents?
- Do you provide training in care issues for the parents?
- Do you provide family housing near the hospital?
- Do you offer services to school districts that will ease my child's transition back home?
- Are there therapeutic recreation programs, as well as an opportunity to go off the hospital grounds?
- How many ventilator dependent children do you treat each year?
- What is your success rate for weaning from a ventilator?
- May I tour the facility?
- Do you have a list of former patients' families I can talk to?

Because pediatric spinal cord trauma is rare, expertise may not readily be available. Parents are advised to contact Shriners Hospitals. Shriners has taken the lead in developing clinical practice standards for children with SCI and has three comprehensive SCI rehabilitation centers designed specifically for children (Chicago, Philadelphia and Northern California). Care is often provided at no cost for children up to age 18 who have no insurance. Toll-free 1-800-237-5055; see [www.shrinershospitalsforchildren.org](http://www.shrinershospitalsforchildren.org)

Your health insurance will play a critical role in determining where your child can go for rehabilitation. In the early days post injury, it is important to contact your insurance carrier and ask for a case manager based on your child's injury and future healthcare needs. The insurance case manager, in collaboration with the acute care hospital case manager, can assist you in selecting a

rehabilitation program that meets your child's and family's needs and is covered by your insurance. If you disagree with the decision of your insurance company, you can file an appeal.

If you do not have insurance or are underinsured, it is important to apply for Medicaid as well as Social Security for your child. Each state has financial guidelines as well as eligibility criteria that take into consideration the severity of the disability. If you do not qualify for Medicaid, the Children's Health Insurance Program (CHIP) was designed to assist families who can not afford a private health insurance policy but who make too much money to qualify for Medicaid. CHIP was created by the federal government but individual states operate their own program. Visit Medicaid and CHIP for more details; see pages 251-257.



*All-access playground from Shane's Inspiration*



## CHILDREN'S RESOURCES

**The Arc** is devoted to promoting and improving supports and services for people with intellectual and developmental disabilities; 800-433-5255 [www.thearc.org](http://www.thearc.org)

**Ability Online** is a social network for children and youth with disabilities or chronic illnesses to connect to each other as well as to friends, family members, caregivers and supporters. 866-650-6207 [www.abilityonline.org](http://www.abilityonline.org)

**Council for Exceptional Children** is dedicated to improving the educational success of individuals with disabilities. Toll-free 888-232-7733; [www.cec.sped.org](http://www.cec.sped.org)

**Camp Ronald McDonald** is an accessible residential camp for kids with special needs, in Southern California. 310-268-8488; [www.campronaldmcdonald.org](http://www.campronaldmcdonald.org)

**Easter Seals** provides services, education, outreach, and advocacy so people with disabilities can live, learn, work and play in their communities. 800-221-6827, [www.easterseals.com](http://www.easterseals.com)

**Education Resources Information Center (ERIC)** is a digital library of education research and information. It is sponsored by the Institute of Education Sciences (IES) of the U.S. Department of Education. [www.eric.ed.gov](http://www.eric.ed.gov)

**Family Voices** supports family-centered care for all children and youth with special healthcare needs or disabilities. Toll-free 1-888-835-5669; [www.familyvoices.org](http://www.familyvoices.org)

**Island Dolphin Care**, Key Largo, Fla., allows children to swim and play, and perhaps heal, with dolphins. [www.islanddolphinscare.org](http://www.islanddolphinscare.org).

**Family Center on Technology and Disability** offers a range of information and services related to assistive technologies for children with disabilities. [www.ctdinstitute.org](http://www.ctdinstitute.org)

**Early Childhood Technical Assistance Center (ECTAC)** works to ensure that children with disabilities (birth through 5 years) and their families receive and benefit from high quality, culturally appropriate and family-centered supports and services. 919-962-2001, <http://ectacenter.org>

**National Organization for Rare Disorders (NORD)** is a federation of voluntary health organizations dedicated to helping people with rare "orphan" diseases; <http://rarediseases.org>

**Parents Helping Parents (PHP)** provides lifetime guidance, supports and services to families of children with any special need and the professionals who serve them. 855-727-5775, [www.php.com](http://www.php.com)

**Parent Advocacy Coalition for Educational Rights (PACER)** Center works to expand opportunities and enhance the quality of life of children and young adults with disabilities and their families, based on the concept of parents helping parents. 800-537-2237, [www.pacer.org](http://www.pacer.org)

**Sibling Support Project** is dedicated to the concerns of brothers and sisters of people who have special health or developmental concerns. [www.siblingsupport.org](http://www.siblingsupport.org)

**Starlight Children's Foundation** develops multi-media and technology projects that empower seriously ill children to deal with the medical and emotional challenges they face. [www.starlight.org](http://www.starlight.org)

**Through the Looking Glass** is a nationally recognized center that pioneers research, training, and services for families in which a child, parent or grandparent has a disability or medical challenge. [www.lookingglass.org](http://www.lookingglass.org)

## EDUCATION

Whether your child is a toddler or graduating soon from high school, it is important to be aware of available educational programs and services. There are a variety of educational programs to assist children with disabilities; most fall under the Individuals with Disabilities Education Act (IDEA), the federal law that addresses the needs of children with disabilities.





*Giant Steps therapeutic riding program, Petaluma, CA*

SAM MADDOX

There are time frames that school systems must follow. In order to ensure that your child is ready to return to school and receive services immediately, it is important to make the referral in the early days of recovery or diagnosis. Notify your school's principal of your child's disability and to convene an Individualized Education Program (IEP) team meeting for evaluation for services. Some schools may want you to wait until your child has been discharged from the hospital. Ask if the school system will accept the hospital's assessments and recommendations—if they will, ask that communication begin between the school and hospital. Document all communication and, if necessary, put your requests in writing.

Many families feel pressure to keep their child caught up in school to continue on with classmates the following school year. While a child is in the hospital or in a rehab center, school can come directly to them. A child can be assigned

a teacher and class work can be sent from school. Many rehab programs have set hours for classroom instruction.

The Individuals with Disabilities Education Act was created to ensure that all children with disabilities, regardless of the severity of their disability, have available a “free appropriate public education,” including special education and related services. IDEA makes funds available for states and cities to assist in the education of infants, toddlers, preschoolers, children and youth with disabilities. As much as possible, all children with disabilities are to be educated in the regular education environment. In order to remain eligible for federal funds, states must ensure that children with disabilities receive a complete individual evaluation and assessment of their specific needs.

An Individualized Education Program (IEP) will be drawn up for every child or youth found eligible for special education or early intervention services. An IEP is the contract between the school district and the student that lists the type and amount of services it will provide to the student.

Those receiving special education have the right to receive the related services, which may include transportation, speech pathology and audiology, psychological services, physical and occupational therapy, recreation (including therapeutic recreation), rehabilitation counseling, and medical services for diagnostic or evaluation purposes. Parents have the right to participate in all decisions related to identification, evaluation and placement of their child with a disability. Parents may appeal any decision concerning the education of their child.

### **Early Intervention: Birth to 3rd birthday**

Services for very young children, from birth through age two, are called Early Intervention or Part C services (named for its designation in IDEA). Early intervention is an effective way to help children with disabilities and those who are experiencing developmental delays catch up or address specific developmental concerns as soon as possible in their lives.

If you believe your infant or toddler can benefit from early intervention services, you can make a referral yourself or have your hospital or doctor refer your young child. The state is responsible for implementing early intervention programs for infants and toddlers. Call your state agency and explain that you want to find out about early intervention services for your child. Ask for the name of the office, a contact person, and the phone number in your area where you can find out more about the program and have your child screened for a

disability or delay. Even though you know that your child has paralysis, he or she will still need to be screened so that necessary services will be identified.

As with all areas of your child's health and education, keep a log of who you talked with, the date, time and any notes you may have taken.

### Services for Preschoolers with Disabilities: Ages 3 through 5

Services for preschool children (ages 3 through 5) are provided free of charge through the public school system. If your child was receiving Early Intervention services and is still eligible, he or she will transition over to services for preschool, ages 3-5. Another way for very young children to become identified is through the local Child Find office; each state must have comprehensive systems to identify, locate, and evaluate children with disabilities residing in the state and who are in need of special education and related services. Your pediatrician or rehabilitation hospital may suggest that you contact the appropriate agency to have your child screened and/or evaluated to determine if he or she qualifies for services.

You don't have to wait until someone suggests that your child be screened, though. If you are concerned about your child's development, contact the local Child Find office (through your local school system) and arrange to have your child screened. These screenings are free of charge.

### IDEA, Kindergarten through age 22

Before your child can receive any special education and related services (occupational therapy, physical therapy, nursing, assistive technology) he or she must be referred and evaluated. The school system has 60 days to complete the assessments—the quicker you make a referral, the faster your child can return to school. If your child qualifies for services, an Individualized Education Program will be drafted and the specific services, goals, objectives and accommodations will be outlined. For many students with disabilities, the key to success in the classroom lies in having appropriate adaptations, accommodations, and modifications made to the instruction and other classroom activities. This is particularly true for students with paralysis. Examples of related services are: physical and occupational therapy, school health services, and rehabilitation counseling. Supplementary aids and services might include an aide, a note taker, or other assistive technology.

### Transition to Adulthood

If your child is 16 or older, the IEP will include transition services intended to help



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them move from the world of school to adulthood. As part of transition planning, the IEP team will consider post-secondary education, vocational training or employment. Often, a school's IEP team is joined by a vocational rehabilitation counselor from the state. By planning the transition process, your teen will be prepared to move onto the next phase of their life with supports in place.

Section 504 of the Rehabilitation Act of 1973 and Title II of the Americans with Disabilities Act of 1990 prohibit discrimination on the basis of disability. Practically every

school district and postsecondary school in the United States is subject to one or both of these laws. Section 504 and Title II protect elementary, secondary, and postsecondary students from discrimination. Some of the requirements that apply through high school are different from those that apply beyond high school. Section 504 requires a school district to provide a free, appropriate public education to each child with a disability in the district's jurisdiction. Unlike high school, however, a postsecondary school is not required to provide free services. Rather, a postsecondary school is required to provide appropriate academic adjustments as necessary to ensure that it does not discriminate on the basis of disability. If a postsecondary school provides housing to nondisabled students, it must provide comparable, convenient, and accessible housing to students with disabilities at the same cost.

If you want a postsecondary school to provide an academic adjustment, you must identify yourself as having a disability; your postsecondary school is not required to identify you as having a disability or to assess your needs. Academic adjustments may include auxiliary aids and services, as well as modifications to academic requirements as necessary to ensure equal



educational opportunity. Examples of adjustments are: arranging for priority registration, reducing a course load, substituting one course for another, providing note takers, recording devices, sign language interpreters, extended time for testing, and equipping school computers with screen reading, voice recognition, or other adaptive software or hardware. A postsecondary school does not have to provide personal attendants, individually prescribed devices, readers for personal use or study, or other devices or services of a personal nature, such as tutoring and typing.

Practically every postsecondary school must have a person—frequently called the Section 504 Coordinator, ADA Coordinator, or Disability Services Coordinator—who coordinates the school's compliance with Section 504, Title II, or both laws. You may contact that person for information about how to address any concerns about discrimination. To learn more about the complaint process, call toll-free 1-800-421-3481 or see <https://www2.ed.gov/about/offices/list/ocr/docs/howto.html>

## **EDUCATION RESOURCES**

**Association of University Centers on Disabilities (AUCD)** is a resource for local, state, national, and international policy makers concerned about people living with developmental and other disabilities and their families.

[www.aucd.org](http://www.aucd.org)

**Financial aid:** Resources for students with disabilities; see [www.finaid.org/otheraid/disabled.phtml](http://www.finaid.org/otheraid/disabled.phtml); scholarships for undocumented students. [www.finaid.org/otheraid/undocumented.phtml](http://www.finaid.org/otheraid/undocumented.phtml)

**Going to College** is about college life with a disability; aimed at high school students. <http://going-to-college.org>

**HEATH** is a national clearinghouse on postsecondary education for people with disabilities. It develops and disseminates fact sheets, website directories, newsletters, and resource materials. [www.heath.gwu.edu](http://www.heath.gwu.edu)

**IDEA Partnership** is a collaboration of more than 50 national organizations, technical assistance providers, state and local organizations and agencies working to improve educational results for children and youth with disabilities. [www.ideapartnership.org](http://www.ideapartnership.org)

**Kids' Chance** provides scholarships for children of workers seriously injured or killed on the job. [www.kidschance.org](http://www.kidschance.org)

**National Center on Disability and Access to Education** addresses issues of Internet access and technology to enhance the lives of people with disabilities and their families. [www.ncdae.org](http://www.ncdae.org)

**Office of Special Education and Rehabilitative Services (OSERS)**, from the U.S. Dept. of Education, works to improve outcomes for people with disabilities with supports to parents and individuals, school districts and states. [www.ed.gov/about/offices/list/osers/index.html](http://www.ed.gov/about/offices/list/osers/index.html)

**U.S. Dept. of Education's Tool Kit** on Teaching and Assessing Students with Disabilities focuses on improving instruction, assessment, and accountability. <https://osepideasthatwork.org/federal-resources-stakeholders/tool-kits/tool-kit-teaching-and-assessing-students-disabilities>



Christiaan Bailey and Ocean Healing campers in Mexico.

# 10

## CAREGIVING

Caregiving duties cannot be skirted and cannot always be delegated. But the job does not have to be performed in isolation. Connect to others with similar situations.



MARY ELLEN MARK

*Dear Caregiver,*

*After my husband Christopher was injured, it became obvious that paralysis is a family issue. Taking care of our families' physical, emotional, social and economic needs can be fulfilling and rewarding. But providing care to a person who is paralyzed is a job we don't always expect to get. We mourn our loved one's loss of mobility and independence. We also mourn our own losses: We feel isolated; we have no personal time; we feel exhausted, overwhelmed. And we feel no one else understands the demands placed upon us.*

*A caregiver must deal with medical concerns, hygiene, transportation, financial planning, advocacy, and end-of-life issues. Being an effective caregiver means gaining some sense of control over the situation. One way this is done is through information, and by sharing experiences or solving problems with other caregivers.*

*Please know that you are not alone, that you are extremely valuable, and that you and your family can lead active, fulfilling lives despite the challenges of paralysis. Don't ever be embarrassed to ask our Paralysis Resource Center for assistance. Just call toll-free 1-800-539-7309.*

*Best Wishes,*

**Dana Reeve**

*(written in 2005, a year before her death)*

### THE CAREGIVER ROLE

Helping someone you care for to continue living independently in the home is valuable work. Caregiving can be a satisfying experience; it demonstrates fulfillment of a commitment to a loved one. True enough, though, caregiving is not a role anyone really chooses. It seems to choose us, emerging from events and circumstances outside our expectations, beyond our control.

Family members provide the vast majority of care for people who are chronically ill or disabled. According to the Caregiver Action Network, family caregivers underpin our healthcare system in a profound way. More than 50 million people provide some level of care for a loved one, which would translate into annual wages of \$375 billion—almost twice as much as is actually spent on homecare and nursing home services combined—if it weren't done for "free." As the population ages, as medical science keeps people alive longer and as healthcare policies send people home from hospitals sicker and quicker, the number of family caregivers can only grow.

Caregiving is a job that cannot be skirted and cannot always be delegated. It is frustrating. It is physically and emotionally draining. It can steal our dreams or break our hearts. It makes us sad for our loved one's loss... and for our own loss. While caring for loved ones can be enormously satisfying, there are days, to be sure, that offer little reward.

The job takes its toll. Caregivers suffer far more depression, stress and anxiety than the general population. Surveys show that up to 70 percent of caregivers report depression, 51 percent sleeplessness, and 41 percent back problems. Nearly three quarters of family caregivers do not go to the doctor as often as they should, and 55 percent say they skip doctor appointments; 63 percent of caregivers report having poor eating habits.

Caregivers feel isolated; they often report that their lives are not “normal” and that no one else can possibly understand what they are going through.

There is a financial impact, too. Families helping a person with a disability in daily living activities spend more than twice as much on out-of-pocket medical expenses than families without a disabled person. Frequently the caregiver must make sacrifices at work to attend to duties at home. But this is your family, your loved one. What are your choices? You can't just walk away. You learn to deal with the frustration while learning how to best get the job done. The lessons are often learned the hard way—for the most part, caregivers learn by trial and error how to manage daily routines for food preparation, hygiene, transportation and other activities at home.

#### **Here are a few caregiving tips compiled by Paralysis Resource Center Information Specialists:**

**Rule number one for all caregivers is to take care of yourself.** Providing care while holding down a job, running a household, or parenting can burn anyone out. A person who is exhausted or sick is more likely to make bad decisions or take out frustrations inappropriately. Stress is known to contribute to a variety of health problems. The more you keep your own well-being in balance, the more you will enhance your coping skills and stamina. By taking care of yourself, you will be better able, both physically and emotionally, to provide care for your loved one.

**Connect to the caregiving community.** Share and learn and benefit from the collective wisdom of the caregiver community. It is important that caregivers connect with one another to gain strength and to know that they are not alone. For many, the isolation that comes with the job is eased by attending

### **RELENTLESS. BUT YOU WILL FIND WAYS**

*Your partner gets hurt, and your life is changed because of something that happened to him. That is the hard truth. I remember saying to him, “Come back. Please come back.” And he would say, “I’m trying.”*



SAM MADDOX

*A caregiving spouse has to say at some point, “I freely choose this,” in the same way as before the injury happened. And, if you don't freely choose this with your whole heart, I don't see how you can make it, because there's going to be some part of you that is always mad, that always somehow resents this other person for what they've taken away from you. Being a family caregiver is relentless. You can never, ever really get away from it. It really helps to have a sense of humor; but, I think the most important thing isn't really how you*

*communicate. It's the very basic choice and knowing that no one's making you do anything. If you can accept this, you'll find ways to work it out, whatever it is.*

—Kate Willette

*Willette chronicled her experiences as a caregiver in a book, *Some Things Are Unbreakable*.*

support group meetings with others in similar situations. Support groups provide emotional support and caregiving tips, as well as information on community resources. Online support groups can be very helpful. The Reeve Foundation supports active community forums and discussions about all issues related to caregiving in their Reeve Connect Online Community. See [www.ChristopherReeve.org/Community](http://www.ChristopherReeve.org/Community)

#### **Therapy or counseling may also facilitate better problem solving.**

Counseling can help one cope with feelings of anger, frustration, guilt, loss or competing personal, work and family demands.

**Know as much as possible about your loved one's condition.** Be informed about medical issues and how the disease or disability can affect a person physically, psychologically, behaviorally, etc. You are an important member of your loved one's healthcare team. Chapter 1 provides an overview of the primary causes of paralysis. The Internet is another powerful tool for learning about the medical basis of disability. Doctors and other health professionals



### **DANA REEVE ON CAREGIVING**

*After Chris was injured, we sort of operated as if it was like landing on another planet. It can look very bleak and overwhelming. There's a tremendous amount of adjustment that needs to go on mentally. And facing the new normal, facing the adjustments, the loss...you have to grieve for the loss. Because it's true - the only way for grief to be alleviated is to grieve. You need to acknowledge the loss. But at the same time, once you do that, you're opening up a whole new area where you can have tremendous hope.*



SAM MADDOX

Dana Reeve

can help you understand how a loved one's condition might change and how that change might affect the demands on the caregiver.

**Take advantage of opportunities for respite care.** Refresh yourself and take an occasional break from daily duties. An extended vacation may not be realistic, but it is essential for caregivers to schedule some down time. This may

be a short outing, quiet time at home, a movie with a friend, etc. To get away, the caregiver may require respite care/assistance from others. See Resources at the end of this chapter for some possible connections to help you get a break.

**Be an advocate.** Keep in mind you may be the only one equipped to speak out on your loved one's behalf or to ask difficult questions. Prepare your loved one's health history and take it with you to appointments. Anticipate the future as best as you can. Financial and legal planning are important considerations. Issues such as financing long-term care, protecting assets, obtaining the authority for surrogate decision making, and other matters often need attention. Make an appointment with an attorney knowledgeable in estate planning, probate, and, if possible, public benefits planning. Other areas often requiring planning include coordination between community services and involved friends and family members. Decisions about placement in a nursing home or other care options can often be facilitated by a professional familiar with brain impairments, caregiving and community resources. In some cases, it is necessary to make end-of-life decisions regarding your loved one.

**Understand as best as you can how the system works** for insurance, Social Security and other means of public assistance. There are experts at public agencies who can help. See Chapter 6, Navigating the System, page 245.

**Ask for help.** Many caregivers are so accustomed to providing help and seeing to another person's needs that they don't know how to ask for aid themselves. Your family is your first resource. Spouses, brothers and sisters, children, and other relatives can do a lot to ease your caregiving burden. Let them know what they can and should do. Look to your place of worship for aid and counsel. Make your religious leader aware of your situation. Encourage your loved one's friends and neighbors to provide what comfort they can.

**Know everything you can about tools and adaptive equipment.** It is essential that caregivers know about the homecare products and services that might make their jobs easier. See the Tools chapter in this book, page 269, for ways to stay current and up-to-date on all that technology has to offer.

As you settle into the role of caregiver, you may find yourself making decisions for people who used to decide for you. It's sometimes tricky to balance competing needs for control. But it's important to respect the right of the

person being cared for to make choices. Choice is good; by deciding things we have a sense of control over our lives. Allow your loved one as much choice as possible, from the food on the menu to their daily wardrobe to TV programming.

**Gain confidence in your abilities and pride in your achievements.** Easier said than done—how do you stand up for yourself, take care of yourself, and find a balance between your own needs and those of your loved ones? The Caregiver Action Network offers the following principles of empowerment caregivers are urged to live.

- Choose to take charge of your life. Don't let your loved one's illness or disability always take center stage. We fall into caregiving often because of an unexpected event, but somewhere along the line you need to step back and consciously say, "I choose to take on this caregiving role." It goes a long way toward eliminating the feeling of being a victim.
- Honor, value and love yourself. You're doing a very hard job and you deserve some quality time, just for yourself. Self-care isn't a luxury. It's a necessity. It is your right as a human being. Step back and recognize just how extraordinary you are. Remember, your own good health is the very best present you can give your loved one.
- Seek, accept and, at times, demand help. Don't be ashamed to ask for help. When people offer assistance, accept it and suggest specific things that they can do. Caregiving, especially at its most intense levels, is definitely more than a one-person job. Asking for help is a sign of your strength and an acknowledgment of your abilities and limitations.
- Stand up and be counted. Stand up for your rights as a caregiver and a citizen. Recognize that caregiving comes on top of being a parent, a child, or a spouse. Honor your caregiving role and speak up for your well-deserved recognition and rights. Become your own advocate, both within your own immediate caregiving sphere and beyond.

## SOURCES

Caregiver Action Network, Family Caregiver Alliance, AARP

## CAREGIVING RESOURCES

**AARP** offers a caregiving resource center, including legal issues, long distance caregiving, end-of-life issues. Toll-free 1-888-687-2277; [www.aarp.org/home-family/caregiving](http://www.aarp.org/home-family/caregiving)

**Caregiver Action Network** educates, supports and empowers families who care for chronically ill, aged or disabled loved ones. Caregiver Helpdesk: 855-227-3640; [www.caregiveraction.org](http://www.caregiveraction.org)

**Caregiver Media Group** publishes Today's Caregiver magazine and offers topic-specific newsletters, online discussion lists, chat rooms and an online store. [www.caregiver.com](http://www.caregiver.com)

**CareGiving.com** is an Internet community for families and healthcare professionals who care for chronically ill or disabled family members. See [www.caregiving.com](http://www.caregiving.com)

**Family Caregiver Alliance (FCA)** is the lead agency in California's system of Caregiver Resource Centers and operates the National Center on Caregiving to develop support programs for family caregivers in every state. FCA champions the caregivers' cause through education, services, research and advocacy. 415-434-3388, toll-free 1-800-445-8106; [www.caregiver.org](http://www.caregiver.org)

**National Alliance for Caregiving** is a coalition of national groups that supports family caregivers and the professionals who help them; [www.caregiving.org](http://www.caregiving.org)

**National Caregivers Library** is large source of free information for caregivers. [www.caregiverslibrary.org](http://www.caregiverslibrary.org)

**National Respite Coalition Network** and National Respite Locator Service helps parents, caregivers and professionals get a break using respite services in their local area. <https://archrespite.org>

**Nursing Home Compare**, sponsored by Medicare, offers information about the past performance of most nursing homes in the U.S. Also features "A Guide to Choosing a Nursing Home" and a nursing home checklist. [www.medicare.gov/nursinghomecompare](http://www.medicare.gov/nursinghomecompare)

**Personal Care Assistants: How to Find, Hire & Keep** Information from Craig Hospital <https://craighospital.org/resources/personal-care-assistants-how-to-find-hire-keep>

**Reeve Connect**, a resource of the Christopher & Dana Reeve Foundation, is a safe and secure online social networking site with a robust discussion area on many areas of paralysis, including caregiving; please see [www.ChristopherReeve.org/Community](http://www.ChristopherReeve.org/Community)

**Rosalynn Carter Institute for Caregiving** establishes local, state and national partnerships committed to promoting caregiver health, skills and resilience; [www.rosalynncarter.org](http://www.rosalynncarter.org)

**Shepherd's Centers of America (SCA)** is an interfaith organization that



coordinates nearly 100 independent Shepherd's Centers across the United States to help older adults remain independent. [www.shepherdcenters.org](http://www.shepherdcenters.org)

**Spinal Cord Injury Caregivers** is a Yahoo Internet forum, a place to share information and to support other caregivers who are caring for people with SCI. Visit <http://groups.yahoo.com/neo/groups/scic/info>

**Well Spouse Association** is a national organization that gives support to wives, husbands, and partners of the chronically ill and/or disabled. Addresses issues common to family caregivers: anger, guilt, fear, isolation, grief, and financial threat; [www.wellspouse.org](http://www.wellspouse.org)



Lyena Strelkoff by Christopher Voelker





## RESOURCES

### Useful Resources for the Paralysis Community

#### ADVOCACY

**ADAPT** started as American Disabled for Accessible Public Transit, blocking buses in cities across the nation to demonstrate the need for access to public transit. The organization played a major role in gaining passage of the Americans with Disabilities Act and continues to take its message to the streets so people with disabilities can live in the community with real supports instead of being locked away in nursing homes or other institutions; [www.adapt.org](http://www.adapt.org)

**American Association of People with Disabilities (AAPD)** is the largest national cross-disability member organization in the United States, dedicated to ensuring economic self-sufficiency and political empowerment for the over 60 million Americans with disabilities. 202-521-4316, toll-free 1-800-840-8844; [www.aapd.com](http://www.aapd.com)

**Association of Programs for Rural Independent Living (APRIL)** is a national grassroots, non-profit membership organization consisting of over 260 members from centers for independent living, their satellites and branch offices, state-wide independent living councils, other organizations and individuals concerned with the independent living issues of people with disabilities living in rural America. [www.april-rural.org](http://www.april-rural.org)

**Association on Higher Education And Disability (AHEAD)** is an international organization of professionals committed to full participation in higher education for people with disabilities. [www.ahead.org](http://www.ahead.org)

**Disability History Museum** is a virtual collection to chronicle the disability

experience and dispel lingering myths, assumptions, and stereotypes.

[www.disabilitymuseum.org](http://www.disabilitymuseum.org)

**Disability Social History Project** is a community history project for people with disabilities to set forth and share a rich history and culture. See

[www.disabilityhistory.org](http://www.disabilityhistory.org)

**Disabled Peoples' International** advocates for the full participation of all disabled people in the mainstream of life, particularly those in developing countries.

[www.dpi.org](http://www.dpi.org)

**Independent Living Research Utilization (ILRU)** is a national center for information, training, research, and technical assistance in independent living.

[www.ilru.org](http://www.ilru.org)

**National Council on Disability (NCD)** is an independent federal agency making recommendations to the President and Congress regarding policies and programs that empower people with disabilities to achieve economic self-sufficiency, independent living, and inclusion into all aspects of society.

[www.ncd.gov](http://www.ncd.gov)

**National Council on Independent Living** advances the independent living philosophy of self-determination and full integration and participation of people with disabilities in society. 202-207-0334; toll-free: 1-844-778-7961;

[www.ncil.org](http://www.ncil.org)

**National Organization on Disability:** Since 1982, NOD has been working to expand the participation of people with disabilities in all aspects of American life. NOD promotes voting, housing, employment, religious access, accessible urban design, statistical surveys, and marketing to the disability community.

[www.nod.org](http://www.nod.org)

**Rehabilitation International** is a worldwide network of people with disabilities, service providers and government agencies working together to improve the quality of life for disabled people and their families. [www.riglobal.org](http://www.riglobal.org)

**Society for Disability Studies** explores issues of disability and chronic illness from scholarly perspectives. SDS membership includes social scientists, health researchers, and humanities scholars, as well as those in the disability rights movement. Publishes Disability Studies Quarterly (DSQ), and hosts an annual conference. [www.disstudies.org](http://www.disstudies.org)

**United States International Council on Disabilities (USICD)** is a federation of disability-oriented agencies, associations, facilities and consumers dedicated to

furthering the full integration into society of people with disabilities.

[www.usicd.org](http://www.usicd.org)

## MEDIA

**Abilities** is Canada's cross-disability lifestyle magazine. Covers health, active living, disability rights, resources, etc. [www.abilities.ca](http://www.abilities.ca)

**Ability Magazine** crosses celebrity journalism with disability awareness.

[www.abilitymagazine.com](http://www.abilitymagazine.com)

**Exceptional Parent** is a magazine with support, ideas, encouragement and outreach for parents and families of children with every type of disability.

[www.eparent.com](http://www.eparent.com)

**Mouth** is about disability rights and empowerment that says this about itself: "This rude little magazine demands answers from the people in charge, laughs at the lying answers, and occasionally bites down, hard, somewhere near the throbbing jugular." [www.mouthmag.com](http://www.mouthmag.com)

**MSAA Motivator** is published twice per year by the Multiple Sclerosis Association of America. It covers many issues of importance to people with MS.

[www.mysaa.org/publications/motivator](http://www.mysaa.org/publications/motivator)

**New Mobility** is a monthly lifestyle magazine for the wheelchair community, created in 1988 by Sam Maddox. Essential reading for the paralysis community.

[www.newmobility.com](http://www.newmobility.com)

**PN (Paraplegia News)** is a magazine for service veterans with disabilities, and for anyone who uses a wheelchair. Covers healthcare, issues, news and events, sports and recreation. From PVA Publications. [www.pvamag.com/pn](http://www.pvamag.com/pn)

**Ragged Edge**, the online successor to The Disability Rag, covers the issues concerning disability: medical rationing, genetic discrimination, assisted suicide, long-term care, attendant services. [www.raggededgemagazine.com](http://www.raggededgemagazine.com)

**Sports 'N Spokes** is a colorful bi-monthly magazine about wheelchair athletics, competitive sports and recreation. [www.pvamag.com/sns](http://www.pvamag.com/sns)

## ONLINE COMMUNITIES

**CareCure Community** offers Internet forums with news and comments on paralysis care, caregiving, cure, funding, active living, pain treatment, sexuality, research, clinical trials and more. <http://sci.rutgers.edu>

**BrainTalk Communities** is a huge collection of Internet message boards covering nearly every known neurological problem and disability social issue.

[www.braintalkcommunities.org](http://www.braintalkcommunities.org)

**Facing Disability** provides a private Facebook group for people with spinal cord injuries. <https://facingdisability.com/join-the-conversation>

**The Stroke Network** is a community of web sites designed to help "everyone in the stroke family." Features chats, message boards, survivor profiles, resources, etc. [www.strokenetwork.org](http://www.strokenetwork.org)

**Reeve Connect:** from the Christopher & Dana Reeve Foundation Paralysis Resource Center, a safe and secure online social networking destination. Numerous discussion areas on topics related to spinal cord injury and paralysis, including active living, relationships, caregiving, cure research, and clinical care.

[www.ChristopherReeve.org/Community](http://www.ChristopherReeve.org/Community)

## RELIGION

**Episcopal Disability Network** focuses on the physical, cultural, emotional, and programmatic barriers that prevent persons with disabilities from full participation in church and society. [www.episcability.org](http://www.episcability.org)

**Joni and Friends** is a Christian ministry formed by quadriplegic Joni Eareckson Tada to evangelize people affected by disability. [www.joniandfriends.org](http://www.joniandfriends.org)

**Lift Disability Network** promotes the spiritual well-being of people with disabilities. <https://liftdisability.net>

**National Catholic Partnership on Disability (NCPD)** was established so Catholics with disabilities can fully participate in the celebrations and obligations of their faith. [www.ncpd.org](http://www.ncpd.org)

**Yachad National Jewish Council for Disabilities** insures participation in the full spectrum of Jewish life. [www.njcd.org](http://www.njcd.org)



## GLOSSARY

**Activities of daily living (ADL):** activities involved in self-care, bowel and bladder management and mobility, including bathing, dressing, eating, and other skills necessary for independent living.

**Activity-Based Therapy:** a rehabilitation modality based on the theory that activity affects neurologic recovery, that patterned activity can stimulate spinal cord plasticity and “reawaken” nerve pathways related to movement. (See Locomotor Training).

**Acute:** the early stages of an injury (as opposed to chronic, which is long-term); in spinal cord injury, better early management of acute trauma may be the reason for an increased number of “incomplete” injuries. Theoretically, early intervention with drugs or cooling will limit functional loss. If the progressive cascade of secondary effects of trauma at the cellular level (e.g., blood flow loss, swelling, calcium toxicity) can be reduced, the severity of the injury will be reduced.

**Allodynia:** condition in which pain arises from a stimulus that would not normally be experienced as painful.

**Alpha blockers:** Medications that can relax the urinary sphincter and prostate and therefore allow better bladder emptying.

**Ambulation:** “walking” with braces or crutches. Some paralyzed people have ambulated using special electrical stimulation. Many find the energy expenditure to “walk” is too much for too little function; they are more functional in their wheelchairs.

**Ankylosis:** fixation of a joint leading to immobility, due to ossification or bony deposits of calcium at joints.

**Anticholinergic:** a drug often prescribed for those with indwelling catheters

to reduce spasms of smooth muscle, including the bladder. Anticholinergics block certain receptors (acetylcholine), resulting in inhibition of certain nerve impulses (parasympathetic).

**Antidepressant:** a drug prescribed to treat depression.

**Aphasia:** change in language function due to injury to cerebral cortex of brain. Language, not understood or not formed, is often restored once swelling is reduced.

**Arachnoid membrane:** the middle of three membranes protecting the brain and spinal cord.

**Arachnoiditis:** inflammation and scarring of the membranes covering the spinal cord, sometimes caused by the dye used in a myelogram. Constant burning pain is a common symptom, as is bladder dysfunction. Some cases advance to paralysis. Arachnoiditis is often misdiagnosed as “failed back surgery syndrome,” multiple sclerosis or chronic fatigue syndrome.

**ASIA Score:** a tool to assess function after SCI, on a scale from A (complete, no motor or sensory function) through E (normal motor and sensory).

**Astrocyte:** star-shaped glial cells that provide the necessary chemical and physical environment for nerve regeneration. These cells proliferate after injury and are believed to break down toxins such as glutamate. The astrocyte also has a bad side: Reactive astrocytes contribute to the formation of glial scar, which may be a major obstacle to nerve regrowth following trauma.

**Atelectasis:** loss of breathing function characterized by collapsed lung tissue. Can be a problem for high quadriplegics who are unable to clear lung secretions. This, in turn, can lead to pneumonia.

**Augmentation cystoplasty:** A surgery that enlarges the bladder by sewing a piece of intestine onto the top of the bladder.

**Augmentative and Alternative Communication (AAC):** forms of communication that supplement or enhance speech or writing, including electronic devices, picture boards and sign language.

**Autoimmune response:** Normally, the immune system recognizes foreign substances; the system produces antibodies against the invader to eliminate it. In an autoimmune response, the body creates an antibody against itself. Multiple sclerosis is thought to be an autoimmune disease.

**Autonomic dysreflexia:** a potentially dangerous reaction that includes high blood pressure, sweating, chills, headache, which may occur in persons with



SCI above the sixth thoracic level (T6). Often caused by bladder or bowel issues. Untreated, autonomic dysreflexia can lead to stroke or even death.

**Autonomic nervous system:** the part of the nervous system that controls involuntary activities, including heart muscle, glands and smooth muscle tissue. The autonomic system is subdivided into the sympathetic and parasympathetic systems. Sympathetic activities are marked by the “flight or fight” emergency response; parasympathetic activities are marked by lowered blood pressure, pupil contraction and slowing of the heart.

**Axon:** the nerve fiber that carries an impulse from the nerve cell to a target, and also carries materials from the nerve terminals (e.g., on muscles) back to the nerve cell. When an axon is cut, proteins required for its regeneration are made available by the nerve cell body. A growth cone forms at the tip of the axon. In the spinal cord, a damaged axon is often prepared to regrow, and often has available a supply of material to do so. Scientists believe it is the toxic environment surrounding the axon, and not the genetic programming of the axon itself, that prevents regeneration.

**Biofeedback:** a process that provides sight or sound information about functions of the body, including blood pressure and muscle tension. By trial and error, one can learn to consciously control these functions. Useful in some paralyzed people to retrain certain muscles.

**BiPAP:** a type of non-invasive mechanical breathing assistance for treating sleep apnea.

**Bladder augmentation:** Another term for augmentation cystoplasty.

**Bladder outlet obstruction:** any type of blockage that restricts urine from flowing freely from the bladder. In SCI this may be related to detrusor sphincter dyssynergia, or from scar tissue.

**Botulinum Toxin:** better known as Botox, a neurotoxin used clinically to treat crossed eyes, wrinkles, and other muscle related issues, including overactive bladder and spasticity in people with paralysis.

**Bowel program:** the establishment of a “habit pattern” or a specific time to empty the bowel so that regularity can be achieved.

**Brown-Séquard Syndrome:** a partial spinal cord injury resulting in hemiplegia, affecting only one side of the body.

**Calculi:** calcium deposits form stones in either kidney or bladder. Bladder stones are easily removed; kidney stones may require lithotripsy (shock wave

shattering) or surgery.

**Carpal tunnel syndrome:** painful disorder in the hand caused by inflammation of the median nerve in the wrist bone; commonly caused by repetitive motion, including pushing a wheelchair. Splints might help; surgery is sometimes indicated to relieve pressure on the nerve. When it hurts, give it a rest.

**Catheter:** a rubber or plastic tube for withdrawing or introducing fluids into a cavity of the body, usually the bladder. Some catheters are enclosed in sterile packaging and are used but once. Some catheters remain in place in the bladder, continuously draining.

**Cauda equina:** the collection of spinal roots descending from the lower part of the spinal cord (conus medullaris, T11 to L2), occupying the vertebral canal below the spinal cord. These roots have some recovery potential.

**CAT scan:** computerized axial tomography is a cross-sectional X-ray enhancement technique that benefits diagnosis with high-resolution video images, some in three dimensions.

**Central nervous system (CNS):** the brain and spinal cord. Prevailing dogma has been that CNS cells won't repair themselves. Experiments show, however, that CNS nerves are “plastic” and thus can regrow and reconnect to appropriate targets.

**Cerebrospinal fluid (CSF):** colorless solution similar to plasma protecting the brain and spinal cord from shock. Circulates through the subarachnoid space. For diagnostic purposes, a lumbar puncture (spinal tap) is used to draw the fluid.

**Cervical:** the upper spine (neck) area of the vertebral column. Cervical injuries often result in tetraplegia.

**Clinical Trial:** a human research program usually involving both experimental and control subjects to examine the safety and effectiveness of a therapy.

**Clonus:** a deep tendon reflex characterized by rhythmic contractions of a muscle when attempting to hold it in a stretched state.

**Colostomy:** surgical procedure to allow elimination of feces from a stoma that is formed by connecting part of the large intestine to the wall of the abdomen. People with paralysis sometimes get colostomies because of bowel care issues or skin care hygiene.

**Complete Lesion:** injury with no motor or sensory function below the zone of cord destruction, at the site of primary trauma.

**Constraint-Induced Movement Therapy:** also called forced use. In hemiplegia, half the body is affected. By immobilizing the “good” limb a patient is forced to use the affected limb, leading in some cases to improved function.

**Continent urinary diversion:** A surgical procedure to bypass the bladder. This is made possible by using a section of the stomach or intestine to create an internal pouch. The ureters are sewn into the pouch, which is drained by catheter from a stoma.

**Contracture:** a body joint which has become stiffened to the point it can no longer be moved through its normal range.

**Conus medullaris:** the terminal end of the spinal cord. It occurs near the first lumbar vertebrae (L1). After the spinal cord terminates, the lumbar and sacral spinal nerves continue as a “freely moving” bundle of nerves within the vertebral canal and are called the cauda equina (literally, horse tail).

**Credé maneuver:** Pushing into the lower abdomen directly over the bladder to squeeze out urine.

**Cutaneous ileovesicostomy:** A surgical procedure in which a piece of the intestine (ileum) is attached to form a tube from the bladder to an opening in the skin (called a stoma) on the lower abdomen. Urine is thus able to drain from the bladder, avoiding the urethra.

**Cyst (post traumatic cystic myelopathy):** a collection of fluid within the spinal cord; may increase pressure and lead to increased neurological deterioration, loss of sensation, pain, dysreflexia. Cysts can form in months or years after an injury. Their cause is not known. Surgery is sometimes indicated to drain the cavity or to untether the cord. (See Syringomyelia.)

**Cystogram (CG):** X-ray taken after injecting dye into bladder; shows reflux.

**Cystometric examination:** an exam measuring pressure of forces to empty or resisting to empty the bladder. Used to evaluate catheterization program.

**Cystoscopy:** An examination of the urethra and bladder using a small, circular instrument called a cystoscope. It is used to check for inflammation, bladder stones, tumors or foreign bodies.

**Decubitus ulcer** (See Pressure injury).

**Deep vein thrombosis:** the formation of a blood clot (thrombus) in a deep vein. It commonly affects the leg veins, such as the femoral vein. The risk for DVT is greatest in the first three months after injury. The primary concern for clotting is pulmonary embolism. Most patients get an anticoagulant drug to

prevent clotting.

**Demyelination:** loss of nerve fiber “insulation” due to trauma or disease; reduces ability of nerves to conduct impulses (as in multiple sclerosis and some cases of SCI). Some intact but non-working nerve fibers might be coaxed into remyelinating, perhaps restoring function. (See Myelin.)

**Dendrite:** microscopic tree-like fibers extending from a nerve cell (neuron). Receptors of electrochemical nervous impulse transmissions. The total length of dendrites within the human brain exceeds several hundred thousand miles.

**Depression:** a mental health disorder characterized by low mood, low self esteem and loss of interest or pleasure in activities that were typically enjoyable. Causes of depression may include psychological, psychosocial, hereditary and biological factors. Patients are often treated with antidepressant medications as well as psychotherapy.

**Dermatome:** map of the body that shows typical function for various levels of spinal cord injury.

**Detrusor:** The muscle that forms the bladder.

**Detrusor sphincter dyssynergia:** A loss of coordination between the urinary sphincter and the bladder.

**Diaphragmatic pacing:** also known as phrenic nerve pacing; the rhythmic application of electrical impulses to the diaphragm, resulting in respiration for patients who would otherwise require a mechanical ventilator.

**Dorsal root:** the collection of nerves entering the dorsal section (on the back) of a spinal cord segment. These roots share central and peripheral nerve connections, and enter the spinal cord in an area called the dorsal root entry zone (DREZ).

**Double blind studies:** neither the participating trial subject nor the investigators, institutional staff or sponsoring company are aware of the treatment each subject has received during the trial.

**DREZ surgery:** dorsal root entry zone microcoagulation, a procedure used to relieve severe pain by cutting specific nerves at the point they enter the spinal cord. Less effective for pain arising from midthoracic and cervical areas; better suited for lower thoracic, upper lumbar pain in legs.

**Dura mater:** outermost of three membranes protecting the brain and spinal cord. Tough, leatherlike; from Latin, “hard mother.”

**Edema:** swelling.

**Electro-ejaculation:** a means of producing sperm from men with erectile dysfunction. Uses an electrical probe in the rectum. The sperm can be used to fertilize eggs in the uterus or in a test tube.

**Epidural stimulation:** the application of a continuous electrical current—at varying frequencies and intensities—to specific locations on the lower part of the spinal cord. It involves implanting a device or stimulator over the dura of the lumbar section of the spinal cord. The stimulator is controlled by a remote about the size of a smartphone. Epidural stimulation is being used to activate the nerve circuits in the spinal cord to provide signals that would normally come from the brain.

**Epididymitis:** an infection of the tubes that surround the testicles. If the testicle also becomes infected, the condition is called epididymo-orchitis.

**Ergometer:** exercise machine, equipped with an apparatus for measuring the work performed during exercise.

**Exacerbation:** in multiple sclerosis, a recurrence or worsening of symptoms.

**Exosome:** A nano-sized lipid vesicle that cells use to transport chemicals, lipids and proteins to other cells. Exosomes are biological carriers whose value is not in the exosomes themselves but in what they contain.

**Flaccid:** muscles are soft and limp.

**Foley:** a catheter that remains inserted in the bladder, continuously draining to a storage bag.

**Frankel Scale:** a scale for classifying severity of spinal cord injury that was modified in 1992 to create the ASIA Impairment Scale (See ASIA score).

**Functional Electric Stimulation (FES):** the application of low-level computer-controlled electric current to the neuromuscular system, including paralyzed muscles, to enhance or produce function (e.g., walking and bike exercise). FES is commercially available for exercise and for ambulation in paraplegics. Other uses include correction of scoliosis, bladder control, electro-ejaculation, phrenic nerve stimulation, stimulation of cough.

**Functional Independence Measure (FIM):** records the severity of disability based on 18 items. Thirteen items define disability in motor functions. Five items define disability in cognitive functions.

**Gait training:** instruction in walking, with or without equipment.

**Genetic engineering (recombinant DNA technology):** the manipulation of the gene codes for biologic processes. Genes are units of hereditary material located on a chromosome which, as a blueprint, determine a specific characteristic of an organism. Gene transfers have been shown to control processes of nerve regeneration.

**Gizmo:** condom catheter external device for collecting urine in males without bladder control. (Also called Texan.)

**Glial cells:** from the Greek for “glue,” supportive cells associated with neurons. Astrocytes and oligodendrocytes are central nervous system glial cells; in the peripheral nervous system, the main glial cells are called Schwann cells. Glial cells are not involved in impulses (they are not “excitable”), but play a very significant role in maintaining the proper environment for neural growth and survival.

**Glossopharyngeal breathing (GPB):** a means of forcing extra air into the lungs to expand the chest and achieve a functional cough. (Also called “frog breathing.”)

**Harrington rods:** metal braces fixed along the spinal column for support and stabilization.

**Heterotopic ossification (HO):** the formation of bone deposits in connective tissue surrounding the major joints, primarily hip and knee. Incidence of 20 percent and as high as 50 percent has been reported in SCI patients, more commonly in higher level injuries. Cause is unknown. Treatment prescribes range-of-motion exercises and weight-bearing activity, can involve surgical removal if severe loss of function occurs.

**Hydronephrosis:** a kidney distended with urine to the point that its function is impaired. Can cause uremia, the toxic retention of blood nitrogen. Long-term catheterization often prescribed.

**Hypothermia:** a technique to cool the spinal cord after injury; may reduce metabolic and oxygen requirements of the injured tissue; may reduce edema (swelling), which may reduce secondary nerve fiber damage.

**Hypoxia:** lack of blood oxygen due to impaired lung function. Important issue in emergency treatment and also for those with limited pulmonary function. Hypoxia can further damage oxygen-sensitive nerve tissue.

**Immune response:** the body’s defense function that produces antibodies to foreign antigens. Important in tissue and cell transplantation: the body is likely



to reject new tissues.

**Incomplete injury:** some sensation or motor control preserved below a spinal cord lesion.

**Incontinence:** lack of bladder or bowel control.

**Indwelling catheter:** a flexible tube retained in the bladder, used for continuous urinary drainage to a leg bag or other device. The catheter can enter the bladder via urethra or through an opening in the lower abdomen (suprapubic ostomy).

**Informed consent:** a patient's right to know the risks and benefits of a medical procedure or clinical trial.

**Intermittent catheterization:** using a catheter for emptying the bladder on a regular schedule. (See Self-catheterization).

**Intermittent positive pressure breathing:** a short-term breathing treatment where increased breathing pressures are delivered via ventilator to help treat atelectasis, clear secretions or deliver aerosolized medications.

**Intrathecal baclofen:** administration of the anti-spasm drug baclofen directly to the spinal cord by way of a surgically implanted pump. More effective than oral dosage without side effects of systemic dosage.

**Intravenous pyelogram:** A test to determine kidney anatomy and function. It involves an injection of a liquid contrast followed by an X-ray.

**Ischemia:** a reduction in blood flow; thought to be major cause of secondary injury to brain or spinal cord after trauma.

**KUB:** an X-ray of the abdomen, showing the kidneys, ureters and bladder

**Laminectomy:** an operation sometimes used to relieve pressure on the spinal cord. Also used to examine the extent of damage to the cord.

**Late anterior decompression:** surgical procedure to reduce pressure on spinal cord by removing bone fragments.

**Lesion:** an injury or wound, any pathologic or traumatic injury to the spinal cord.

**Lithotripsy:** ("litho" for stone, "tripter" for fragmentation) is a noninvasive treatment for kidney stones. Shock waves, generated under water, crumble stones into pieces that will pass with urine.

**Locomotor training:** an activity-based therapy to retrain the spinal cord to "remember" the pattern of walking. There are two versions: manual-assisted

and robotic-assisted. Both consist of supporting part of the patient's body weight with a harness suspended over a moving treadmill. Benefits include, for some, better walking, lower blood pressure and better fitness.

**Lower motor neurons:** these nerve fibers originate in the spinal cord and travel out of the central nervous system to muscles in the body. An injury to these nerve cells can destroy reflexes and may also affect bowel, bladder and sexual functions. (See Upper motor neurons).

**Lumbar:** pertaining to the lower back area immediately below the thoracic spine; the strongest part of the spine.

**Metabolic syndrome:** highly prevalent in the SCI community, characterized by risk factors including abdominal obesity, high blood pressure, insulin resistance and cholesterol issues. People with the metabolic syndrome are at increased risk of coronary heart disease, stroke and type 2 diabetes.

**Mitrofanoff procedure:** surgery to place a stoma, or alternative outlet in the abdominal area, for bladder drainage.

**Modified Ashworth Scale:** a qualitative scale for the assessment of spasticity; measures resistance to passive stretch.

**Motoneuron (motor neuron):** a nerve cell whose cell body is located in the brain or spinal cord, and whose axons leave the central nervous system by way of cranial nerves or spinal roots. Motoneurons supply information to muscle. A motor unit is the combination of the motoneuron and the set of muscle fibers it innervates.

**MRI (magnetic resonance imaging):** a diagnostic tool to display tissues unseen in X-rays or other techniques.

**Multiple sclerosis:** a chronic disease of the central nervous system wherein myelin, the insulation on nerve fibers, is lost. MS is thought to be an autoimmune dysfunction; the body turns on itself.

**Myelin:** a white, fatty insulating material for axons; produced in the peripheral nervous system by Schwann cells and in the central nervous system by oligodendrocytes. Myelin is necessary for rapid signal transmission along nerve fibers. Loss of myelin accompanies many central nervous system injuries, and is the principal cause of multiple sclerosis. The process of remyelination is an important line of research in spinal cord injury.

**Myelomeningocele:** a neural tube birth defect in which a portion of the spinal cord protrudes through the vertebral column. A form of spina bifida, usually

accompanied by paralysis of the lower extremities and by hydrocephalus.

**Nerve Growth Factor (NGF):** A protein that supports survival of embryonic neurons and regulates neurotransmitters; one of several growth factors identified in the central nervous system. These factors, including BDNF (brain-derived neurotrophic factor) and CNTF (ciliary neurotrophic factor), have important roles in regeneration.

**Neurogenic bladder:** A bladder that does not function normally due to nerve damage related to spinal cord injury, multiple sclerosis or a stroke.

**Neurogenic shock:** can be a complication of injury to the brain or spinal cord; a type of shock caused by the sudden loss of signals from the sympathetic nervous system that maintain the normal muscle tone in blood vessel walls. The blood vessels relax and become dilated, resulting in pooling of the blood in the venous system and an overall decrease in blood pressure.

**Neurolysis:** destruction of peripheral nerve by radio-frequency heat or by chemical injection. Used to treat spasticity.

**Neuromodulation:** According to the International Neuromodulation Society, neuromodulation is the alteration—or modulation—of nerve activity by delivering electrical or pharmaceutical agents directly to a target area of the body. It is most commonly used for chronic pain relief.

**Neuron:** a nerve cell that can receive and send information by way of synaptic connections.

**Neuropathic pain:** a type of pain (sometimes referred to as central pain) that cannot be traced to a simple stimulus, rather, it is a complex pathology related to spinal cord nerves that may have sprouted new, inappropriate connections, may have lost myelin, or may operate in an altered biochemical environment.

**Neuroprosthesis:** a device using electrical stimulation to facilitate such activities as standing, bladder voiding, hand grasp, etc.

**Neurotransmitter:** a chemical released from a neuron ending, at a synapse, to either excite or inhibit the adjacent neuron or muscle cell. Stored in vesicles near the synapse, released when an impulse arrives.

**Nitroglycerine:** vasodilator used in paste form for treatment of autonomic dysreflexia.

**Nogo:** is a molecule used for researching myelin-associated inhibition.

**Occupational therapist:** the member of the rehabilitation team who helps

maximize a person's independence; OTs teach daily living activities, health maintenance and self-care, and consult on equipment choices.

**Off-label:** the prescription of a drug for conditions other than what it was approved for.

**Oligodendrocyte:** a central nervous system glial cell; the site of myelin manufacture for central nervous system neurons (the job of Schwann cells in the peripheral nervous system). A myelin protein from oligodendrocytes (called Nogo) is known to be a potent inhibitor of nerve growth.

**Orthostatic hypotension:** related to pooling of blood in lower extremities in combination with lower blood pressure in people with SCI. Elastic binders and compression hosiery are often used to avoid lightheadedness.

**Osteoporosis:** loss of bone density, common in immobile bones after SCI

**Ostomy:** an opening in the skin to allow for a suprapubic catheter drainage (cystostomy), for elimination of intestinal contents (colostomy or ileostomy), or for passage of air (tracheostomy).

**Overactive bladder (detrusor):** a bladder with uninhibited (involuntary) bladder contractions. These may cause leakage (urinary incontinence). An uninhibited contraction may cause autonomic dysreflexia in a person with SCI at T6 or above.

**Oxybutynin:** an anticholinergic drug with an antispasmodic effect on smooth muscle, often used to calm overactive bladder.

**Paraplegia:** loss of function below the cervical spinal cord segments; upper body usually retains full function and sensation.

**Parasympathetic system:** one of the two divisions of the autonomic nervous system, responsible for regulation of internal organs and glands, which occurs unconsciously. (See Sympathetic nervous system).

**Passive standing:** getting on one's feet, propped up in a standing frame or other device; said to benefit bone strength, skin integrity, bowel and bladder function.

**PCA:** personal care assistant or attendant.

**Percussion:** forceful tapping on congested parts of chest to facilitate postural drainage in persons with high quadriplegia unable to cough.

**Peripheral nervous system:** nerves outside the spinal cord and brain of the central nervous system. Damaged peripheral nerves can regenerate.

**Phrenic nerve stimulation:** electrical stimulation of the nerve that fires the diaphragm muscle, facilitating breathing in high quadriplegics.

**Physiatrist:** a doctor whose specialty is physical medicine and rehabilitation.

**Physical therapist (PT):** a key member of the rehabilitation team; PTs examine, test and treat people to enhance their maximum physical ability.

**Placebo:** an inactive substance or dummy treatment, e.g., a sugar pill, that has the same appearance as an experimental treatment but does not confer a physiological benefit. The placebo effect reflects the expectations of the participant.

**Plasticity:** long-term adaptive mechanisms by which the nervous system restores or modifies itself toward normal levels of function. The peripheral nervous system is quite plastic; the central nervous system, long thought to be “wired” permanently, reorganizes or forms new synapses in response to injury.

**Pluripotency:** refers to a stem cell that has the potential to differentiate into any of the three germ layers: endoderm (interior stomach lining, gastrointestinal tract, the lungs), mesoderm (muscle, bone, blood, urogenital), or ectoderm (epidermal tissues and nervous system).

**Polytrauma:** a clinical syndrome with severe injuries involving two or more major organs or physiological systems which will initiate an amplified metabolic and physiological response.

**Post-polio syndrome:** signs of accelerated aging and decline in people who long ago had polio. Fatigue, pain and loss of function are some of the symptoms.

**Postural drainage:** using gravity to help clear lungs of mucus; head is lower than chest.

**Postural hypotension:** lowered blood pressure resulting in light-headedness. Blood pools up in legs or pelvic region. A common remedy is elastic hose. (See *also* Orthostatic hypotension).

**Pressure injury:** also known as decubitus ulcer and pressure sore; potentially dangerous skin breakdown due to pressure on skin resulting in infection, tissue death. Skin sores are preventable.

**Prosthesis:** replacement device for a body part; e.g., an artificial limb.

**PTEN:** The PTEN gene provides instructions for making an enzyme that is found in almost all tissues in the body. The enzyme acts as a tumor suppressor, which means that it helps regulate cell division by keeping cells from growing

and dividing too rapidly or in an uncontrolled way.

**Quad-coughing:** also known as assisted coughing; a caregiver assists the person with SCI to clear his or her airways by applying pressure below the ribs over the diaphragm while pushing upward.

**Quadriplegia:** loss of function of any injured or diseased cervical spinal cord segment, affecting all four body limbs. (The term “tetraplegia” is etymologically more accurate, combining “tetra” and “plegia,” both from the Greek, rather than “quadri” and “plegia,” a Latin-Greek amalgam.)

**Randomized Control Trial (RCT):** a clinical trial in which the subjects enrolled are randomly assigned to either the experimental treatment arm (group) or control study arm of the trial. It is the preferred clinical trial protocol to be used in all pivotal clinical trial phases (e.g. Phase 3 trials). Well-designed RCTs minimize the influence of variables other than the intervention that might affect trial outcomes. For this reason, they provide the best evidence of efficacy and safety. The most rigorous RCTs utilize a placebo (inactive) control group and blinding (conceal from trial examiners which participants have received active vs. control treatment) to minimize bias in interpretation of results.

**Range of motion (ROM):** the normal range of movement of any body joint; also refers to exercises designed to maintain this range and prevent contractures.

**Reciprocating Gait Orthosis (RGO):** a type of long leg brace used for ambulation by paralyzed people. Uses cables across the back to transfer energy from leg to leg to simulate a more natural gait.

**Reflex:** an involuntary response to a stimulus involving nerves not under control of the brain. In some types of paralysis, reflexes cannot be inhibited by the brain; they become exaggerated and thereby cause spasms.

**Reflux:** the backflow of urine from the bladder into the ureters and kidneys, caused by high bladder pressure (too full, or sphincter won't relax). Reflux can lead to serious kidney problems, including total kidney failure.

**Regeneration:** in brain or spinal cord injury, the regrowth of nerve fiber tissue by way of a biologic process. In the peripheral system, nerves do regenerate after damage and re-form functional connections. Central nerves can be induced to regrow, provided the proper environment is created; the challenge remains to restore connections to effectively restore function, especially in long tracts necessary for major motor recovery.



**Renal scan:** A test to determine kidney function. It involves the injection of liquid into the vein that then passes through the kidneys and down into the bladder. If the kidneys are weak or there is a lot of backpressure from the bladder, the liquid will not pass down to the bladder with its normal speed.

**Residual urine:** urine that remains in bladder after voiding; too much can lead to a bladder infection.

**Retrograde pyelogram (RP):** insertion of contrast material directly into kidney through an instrument. Used to study kidney function.

**RGMa:** stands for Repulsive Guidance Molecule A. RGMa has a role in cell adhesion, cell migration, cell polarity and cell differentiation.

**Rhizotomy:** a procedure that cuts or interrupts spinal nerve roots; sometimes used to treat spasticity.

**Sacral:** refers to fused segments of lower vertebrae or lowest spinal cord segments below lumbar level.

**Schwann cell:** responsible in the peripheral nervous system for myelinating axons; provides trophic support in injury environment. Schwann cells transplanted to the spinal cord are being studied to see if they restore function.

**Secondary injury:** the biochemical and physiological changes that occur in the injured spinal cord after the initial trauma has done its damage. Among the suspected pathologies are swelling, loss of blood flow, lipid peroxidation. Drug treatments have been used both in the lab and in clinical trials to reduce these secondary effects.

**Self-catheterization:** intermittent cathing, the goal of which is to empty the bladder as needed, on one's own, minimizing risk of infection. Some may need assistance if hand function is impaired.

**Septicemia:** local infection that spreads to affect multiple body systems.

**Shunt:** a tube to drain a cavity; in the spinal cord, used to treat a syrinx by equalizing pressures between the syrinx and the spinal fluids. In spina bifida, used to reduce pressure of hydrocephalus.

**Sleep apnea:** irregular breathing during sleep resulting in fatigue, drowsiness during the day. Higher incidence in tetraplegics. (See BiPAP).

**Spasticity:** hyperactive muscles that move or jerk involuntarily. Spasms may be triggered by bladder infections, skin ulcers and any other sensory stimulus.

Such uncontrolled muscle activity is caused by excessive reflex activity below the level of lesion.

**Sphincterotomy:** a permanent surgery that involves cutting the urinary sphincter so that urine can more easily flow out of the bladder. This surgery may be used when the sphincter does not relax at the same time the bladder is contracting (See Detrusor sphincter dyssynergia).

**Spinal shock:** similar to a concussion in the brain. After spinal cord injury, shock causes immediate flaccid paralysis, which lasts about three weeks.

**Stem cell:** a type of cell that can become any cell in the body. These cells have been found in adult animals. There are great hopes, and many great claims yet to be validated, that stem cells will treat paralysis, diabetes, heart disease, etc.

**Stoma:** a surgical opening that provides an alternative path for urine to exit the body (See Cutaneous ileovesicostomy).

**Suctioning:** removal of mucus and secretions from lungs; important for high quadriplegics who lack ability to cough.

**Suprapubic cystostomy:** a small opening made in the bladder and through the abdomen, sometimes to remove large stones, more commonly to establish a catheter urinary drain.

**Synapse:** the specialized junction between a neuron and another neuron or muscle cell for transfer of information (e.g., brain signals, sensory inputs) along the nervous system; usually involves release and reception of a chemical transmitter.

**Syringomyelia:** formation of fluid-filled cavity (a syrinx) in injured area of spinal cord, a result of nerve fiber degradation and necrosis; sometimes the result of tethered cord. The cyst often extends upwards, extending also the neurological deficit. Treatment may include surgery to insert a shunt for drainage of the cavity, or to untether the cord.

**Syringomyelocoele:** a congenital neural tube defect, a cause of spina bifida; spinal fluid fills a sac of spinal membrane.

**Syrinx:** a cyst; a cavity.

**Tenodesis (hand splint):** metal or plastic support for hand, wrist or fingers. Used to facilitate greater function by transferring wrist extension into grip and finger control.

**Tethered cord:** tendency of membranes surrounding spinal cord to scar or

stick together and thus impede flow of spinal fluid; the result is often a cyst that can, in turn, lead to functional loss. Can be treated surgically.

**Thoracic:** pertaining to the chest, vertebrae or spinal cord segments between the cervical and lumbar areas.

**Tracheostomy:** opening in neck (windpipe) to facilitate air flow.

**Transurethral resection (TUR):** a surgical procedure to reduce bladder neck resistance.

**Upper motor neurons:** long nerve cells that originate in the brain and travel in tracts through the spinal cord. Injury to these nerves cuts off contact between brain and muscle.

**Urethral diverticulum:** a small pocket in the urethra that can interfere with insertion of a catheter.

**Urethral stent:** A tubular device made of wire mesh; placed in the urethra to hold the external sphincter open.

**Urinary sphincter:** The muscles that relax when urinating and tighten to prevent leakage.

**Urinary tract infection (UTI):** Bacteria that cause symptoms (cloudy, strong smelling urine, blood in the urine or sudden increase in spasticity) in the urethra (urethritis), bladder (cystitis) or kidney (pyelonephritis). Bacteria that does not cause symptoms usually does not need treatment.

**Urodynamics:** a test that involves filling the bladder through a catheter to determine how well the bladder and sphincter are working.

**Valsalva maneuver:** Bearing down with abdominal muscles in order to push urine out of the bladder.

**Ventilator:** mechanical device to facilitate breathing in persons with impaired diaphragm function.

**Vertebrae:** the bones that make up the spinal column.

**Vesicoureteral reflux:** urine flows backward from the bladder up to the kidneys. This can cause a bladder infection to spread up to the kidneys or cause stretching of the kidneys (hydronephrosis).

**Voiding:** eliminating urine through the bladder.

**Weaning:** gradual removal of mechanical ventilation, as a person's lung strength and vital capacity increase.



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MADELINE MADDOX

**Sam Maddox** is the former Knowledge Manager for the Reeve Foundation Paralysis Resource Center. He is the author of the books *Spinal Network* and *The Quest for Cure*, and is the founder of *New Mobility* magazine.



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