Southern California 3rd Edition

SPINAL CORD INJURY FIRST 90 DAYS

by Sam Maddox

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SPINAL CORD INJURIES | MEDICAL MALPRACTICE

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Dear Friend,

It's likely that you never imagined what life would be like with a spinal cord injury (SCI). The shock and uncertainty of this moment can be overwhelming, and it's natural to feel terrified about what life will be like in this new reality. When I was injured in 2004, I had no idea what questions to ask, what services I would need, or how I would ever be able to move forward dealing with paralysis. It all boiled down to one question for me, "What's next?"

This question is asked by every person who has experienced an SCI, whether for themselves or a family member or friend. I can uniquely understand the fear, anger, and pain that come with this life-altering event because I've been there. I won't sugarcoat it - the first 90 days after a spinal cord injury are some of the most challenging moments you'll ever face. But I also know that you won't feel this way forever.

And that's why we want you to have this book. "Spinal Cord Injury - First 90 Days," was written specifically for you by my friend and fellow SCI advocate, Sam Maddox.

We believe in your ability to triumph over your injury and that your future is brighter than you could ever imagine. This book is packed with info that's easy to understand, including valuable information and practical advice to help you navigate the first 90 days of your spinal cord injury.

It will guide you through the basics of your personal, medical, legal and emotional care, both now and in the future. It'll share our own experiences and insights, as well as tips and tools from medical experts and others who have overcome similar challenges. So, if you're ready to overcome your limitations and triumph over your injury, keep reading.

The journey won't be easy, but with the right mindset, resources, and support, you can get through it and emerge stronger on the other side.

Keep moving forward,

Andrew Skinner
Founder
Triumph-Foundation.org

Spinal Cord Injury: First 90 Days/SoCal
Third Edition

by **Sam Maddox**

Book Design: **George Kenton**

Disclaimer: The material contained in this book is presented for the purpose of educating and informing readers about spinal cord injury. Nothing contained herein should be construed as medical diagnosis or treatment advice. Information in this book should not be used in place of the advice of a physician or qualified health care provider. Users should never disregard professional medical advice or delay in seeking it because of something presented in this book.

This book does not recommend or endorse any specific tests, drugs, products, or procedures mentioned in the text.

For additional copies of this book:
Download at scifirst90days.com
Contact: sammaddox@scifirst90days.com

ACKNOWLEDGMENTS

Spinal cord injury is an equal opportunity adversary. Doesn't care what kind of car you wrecked, or whether you jumped or got pushed. Young or old, hip or square, mean or nice, welcome to the least exclusive club nobody ever thought about joining. It's a long way from your comfort zone, yes? Untethered, and totally unprepared for all this drama? How could you not be. There's too much happening, too fast: life and death medicine, therapies, uncertain recovery, prepping to get back home, scrambling to pay for it, figuring out how you're supposed to live with it.

This book won't make the anxiety disappear but it can help you process it. ***SCI: First 90 Days*** offers resources and connections to sort through the madness so you can make informed choices for the long-run. It will take time but you will get your bearings. It will take even more time, but you will also find ways to calm the turbulence in your head.

For newbies in the club, there's no denying that you have hit the reset button. Yes, SCI sucks and life's a bitch. But then you live. What choice do you have but to go forward? You will. Your inner warrior has more grit than you dreamed was possible. From the archives of advice:

- Don't go into this alone. There is a vibrant and caring SCI community in SoCal. If you don't find these folks, don't worry, they'll find you.
- Stay active. Be part of something. Get out, play, travel, explore.
- Stay aggressive about staying healthy.
- Stay hopeful. An army of researchers has its eye on new therapies.
- Read. Learn. Interact. Connect. Information is the coin of this realm.
- Know your rights and be ready to advocate for yourself.

Dr. Steve Heimberg

DOCTOR & LAWYER

Focused on Spinal Cord Injuries

> Steve Heimberg... a great friend of the spinal cord injury community for years.
>
> -Andrew Skinner, Founder, Triumph Foundation

TRIUMPH FOUNDATION

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SPECIAL THANKS

SCI: First 90 Days would not have been possible without the help of many people, or without the support of many sponsors. Please patronize these businesses and services, listed on page 196.

First, I want to sincerely thank the following doctor specialists who helped me understand trauma medicine, the world of specialized rehabilitation, and the necessity of good care across the life-span.

Yaga Szlachcic, Chief of Medicine at the busiest rehab in the SoCal area, Rancho Los Amigos National Rehabilitation Center, in Downey.

Suzy Kim, board-certified in spinal cord injury medicine, practices at St. Jude Rehab in Orange County. Suzy's expertise and attention to detail are informed by her own experience with spinal cord injury.

Ann Vasile, also board certified in SCI medicine, practices at Tustin Rehab, Care Meridian, and has a private practice based in Long Beach.

Christopher Boudakian is a doctor of physical medicine and chief of staff at California Rehabilitation Institute in West LA.

David Patterson leads the SCI medical team at Casa Colina Hospital in Pomona. He is a board-certified physiatrist.

Lawrence Vogel is chief of pediatrics and SCI at Shriners Hospitals for Children, Chicago. Larry and I sat for several years on the steering committee for the Consortium for Spinal Cord Medicine, which develops authoritative clinical practice guidelines for SCI (to which I often refer).

Thanks to my key SCI community assets: **Andrew Skinner**, who founded the Triumph Foundation; **Janette Knudson**, who works with Triumph and with the housing resource Freedom to Live Foundation; **Rick Hayden**, head of the United Spinal chapter (Spinal Network) in Murrieta; **Candace Cable**, Paralympic champion and disability advocate; **Mark Willits**, attorney and activist; and **Bob Yant**, SCI research champion.

Thank you also to **Steve Heimberg**, a trial attorney who is also a medical doctor. He has been active in the Los Angeles spinal cord injury community for many years.

Sam Maddox
Los Angeles, California
June 2023

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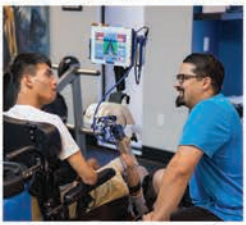

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SCI: FIRST 90 DAYS

YOU ARE NOT ALONE

- WELCOME TO PLANET SCI
- PEER-TO-PEER RESOURCES

SCI DISCHARGE CHECKLIST

These are some of the basic things that need to be sorted out before leaving rehab and heading home. The best chance for a successful reentry to an independent life is to be knowledgeable, and resourceful.

- ☐ Do you have long-term outpatient medical care lined up, with doctors who understand spinal cord medicine?
- ☐ Medications: do you understand your prescriptions and dosages, how best to source your meds, and how to store them?
- ☐ Medical supplies: Where you are going to source your urological supplies, durable medical equipment, etc.?
- ☐ Are you eligible for Social Security benefits? Workers Comp? VA? These systems are complicated. You might need expert help.
- ☐ Insurance: As best you can, understand your coverage. For many Medicaid will come into play (varies by state). Ask about your state's SCI Medicaid waivers. For some, Medicare will apply. Benefit management can be complex so reach out to your SCI community for help.
- ☐ Home care: Are you going to need a personal care attendant, or nurse? Got home cleaning covered? Food prep? If you need caregivers, you need to know how to train them for your hygiene, eating, grooming, etc.
- ☐ Home accessibility: Can you get in the house, and into the bathroom? Need ramps or other mods?
- ☐ Body care: You better know how to manage the bowel and bladder. Remember what your PTs tell you about range of motion. Skin will always be a concern. Eat a healthy diet. Smoking is bad for you.
- ☐ Transportation: Do you have an accessible vehicle? You may need to figure out public transportation or disability ride services.
- ☐ Financial issues: To protect your assets you may need expert help to set up trusts. There are fundraising options available, too.
- ☐ Legal affairs: You should have a will, healthcare directive, someone with power of care, and power of attorney. If you think you have a civil lawsuit, look for someone with experience, be aware of deadlines.
- ☐ Home emergency or disaster: Have you prepared a response or evacuation plan for various scenarios?
- ☐ Recreation or fitness: Know what's out there. And get active!
- ☐ Community: Find your local SCI groups or peer networks. Hook yourself up with a support network beyond your family.

List provided by Get Up Stand Up to Cure Paralysis (see GUSU.org)

WELCOME TO PLANET SCI

You wouldn't be looking at a book like this unless you or someone you know just entered the parallel universe of spinal cord injury. Welcome to a strange new world. It really is like being on another planet. Your sense of time is way off: You may feel cut off from your past, but also your future.

You can't go back and undo what's been done; but what's ahead is rushing at you faster than you can imagine. So let's get you ready.

SCI: First 90 Days attempts to slow things down a bit, to take inventory of the new situation, perhaps to make some sense of the chaos, especially that of the very early days post-injury. The book is based on resources and connections in Southern California. A great deal of this information applies to any geographic region; some of it will become useful sooner, some will make more sense later.

First, a few important things to keep in mind:

DON'T GO ALONE

Plenty of people ahead of you went from walking to paralyzed, in the same blink of an eye you know all about. If you take away one message, it is to get connected to folks who have been where you are, and who have found ways to reinvent themselves. They're not the same as they were before, but they have come to terms with the way things are, and they are OK. They can help you.

IT'S NOT JUST YOU

Spinal cord injury affects more than the injured party, or the person suddenly paralyzed by a disease. Friends, families and loved ones get swept up in it too. Everybody hurts, everybody needs a little help.

IT GETS BETTER

Seriously, keep breathing. OK, it sucks. There is pain, there is fear, and anxiety, and depression. And probably anger and regret. Go ahead, hide out in denial for a while. But you have a resilience you never knew was there. And as long as you still have a pulse, you

YOU ARE NOT ALONE

still get to choose: get busy living, or get busy not living.

MIRACLES HAPPEN

Doctors have very good imaging tools to assess the damage to your spinal cord. Some will flat-out tell you somewhat brutally what your outcome will be. Know this: doctors don't always get it right. Diagnosis is not destiny. Sometimes people with paralysis get better, sometimes quite a lot better.

MIRACLES DON'T HAPPEN OFTEN

This is how it goes: You see these sorts of resources about life with paralysis and it doesn't apply to you because whenever you've been hurt in the past, you got better. You're not that person doing wheelies in a cool titanium wheelchair, you're not the one playing wheelchair basketball. You're the one who's going to walk out of rehab. Unless you don't. So just in case, we've got some things to share with you.

IS THE CURE OUT THERE? NO DOUBT, BUT NOT YET

Treatments are being developed to restore function after paralysis. Will this mean walking again? No. They're not that close, certainly not enough to put life on hold waiting for it. There is no treatment or therapy now or on the immediate horizon – including stem cells in a sketchy overseas clinic – that you can have done and assure yourself a better outcome. The best bet: stay as active as possible, stay healthy, stay ready.

THIS THING IS EXPENSIVE

Money. Best bring a lot of it. You could try a crowdfund campaign, or maybe better, you could set up a fund that allows donors to get a tax write-off. There are some local funds that can help, too. Tip: get Social Security Disability Insurance going ASAP.

"It sucks. There is pain, there is fear, and there is depression. And probably anger and regret. But you have a resilience that you never knew about."

ADVOCATE FOR YOURSELF

Resist being a spectator when it comes to your medical or personal care, equipment needs, housing accommodations, legal rights, etc. This isn't easy in the early days, when everyone is too freaked out by trauma to pay attention. You will meet plenty of gatekeepers. Remember, it's OK to question, appeal, or flat-out disagree with their decisions.

SEX, LOVE, BABIES

Yes. You can still do it but new rules apply. You can still have babies. (Old rules apply, with perhaps some high-tech assistance.)

KNOW YOUR RIGHTS!

The first weeks post-SCI are all about medical care and rehab,

YOU ARE NOT ALONE

getting you ready for home. But outside the womb of rehab, out in the modern world, paralysis is challenging. This is true on many levels, including social and political. You just joined America's largest minority: the disability community. There are laws to protect you from discrimination. Moreover, if you are injured and think it might be the fault of someone else, you may have legal recourse.

THIS BOOK

This resource guide is not a daybook or a calendar. The timing and sequences are quite general. Your sixth week may not be like someone else's. No two spinal cord injuries are exactly alike, and no two people should expect the same pathway to recovery.

This book provides a snapshot of what happens to you in emergency management, in acute trauma care in the emergency room, and in the first days of hospitalization. Granted, the injured party isn't likely to read this part while experiencing it; chances are you beat up more than just your spinal cord. You may be medicated and less than fully coherent.

Actually, patients or loved ones almost never get to decide about emergency management. Typically, you get taken by ambulance or air transport to a designated trauma center. You should expect that you are admitted to a so-called Level I center, or at the very least a Level II unit. Research has shown that people who wind up in designated trauma centers emerge with better outcomes. You may have broken bones, lacerations, burns, other issues. Those, of course, are taken care of here. Early on there may be spine surgery to remove bone fragments or to fortify the spinal column. You may be asked to be in a clinical trial. We'll run down what that entails.

There is a new language in your new world, and we will learn some medical terminology and some basic anatomy. It's confusing when you hear C5 and T6, and complete or incomplete, AIS score, FIM and FAM. Don't worry, it will make enough sense soon.

INPATIENT REHAB CHOICE

The first major choice for the injured and his or her family is finding the most appropriate rehabilitation setting. There are a number of hospitals in Southern California that provide care for people with new spinal cord injuries. A top tier inpatient rehab is specialized in SCI, and accredited – that means the facility has been certified by independent outside experts to have the skills to manage all the complexities of SCI.

In the era of managed care, choosing a rehab depends in large part on your insurance. We will look at the basics of private insurance, Medicare, Medi-Cal, Affordable Care Act, and options for military veterans.

It is very important to know that if coverage is denied you have the right to appeal; we'll show you how.

What if you don't have any health insurance, or don't even have documentation of citizenship? You won't be abandoned.

YOU ARE NOT ALONE

You can still get taken care of by a team of specialists at a spinal cord injury center.

DOING REHAB

Once you land in rehab, work hard to use this time well. You will meet a lot of people looking after you, including doctors and nurses, but also therapists. You will probably be assigned to a case manager; sometimes this person is called a social worker. He or she helps with insurance stuff and helps plan for your exit.

Rehab goes by pretty fast these days – sometimes two or three weeks for some lower level injuries, a month or two for cervical SCI. That's not enough time to get you ready to go home, honestly, but you're going to be discharged anyway, ready or not. We'll look at things you need to know to get you closer to ready *(See Discharge Checklist p.2)*.

SCI messes with the body in many ways. Early on, you need to learn to take care of skin, avoid infections, manage bladder and bowel functions, etc. We'll look at a list of ailments that come with SCI, including chronic pain and spasticity. We'll also have a look at the topics of sex and intimacy.

For injuries in the upper part of the spinal cord, issues with breathing can be critical. Autonomic dysreflexia is a blood pressure issue that becomes a dangerous complication – all the more so because most doctors outside of the physical medicine area don't know about it. It's potentially lethal, so learn about this early, and save yourself a lot of aggravation.

SCI messes with the mind, too. Depression is often a major part of this, but to a large degree, it is treatable. There are no magic words to replace the loss, to make this go away, or to make sense of it. Counseling is a good thing, if you can find it. Reclaiming yourself and your self-worth is a work in progress.

ALSO AHEAD IN THE BOOK:

GEAR

We will cover things that are important as you head home and go about figuring out what may soon seem like normal. This includes equipment and supplies. There are many, many choices, and you'll be guided by what you see your peers rolling around in, and by what your insurance will reimburse. Remember the words "medical necessity." Your doctor can often help you get something paid for as long as it's considered necessary.

HOME MODS

Maybe you never noticed all those narrow doorways before, but now you can't get in the bathroom at home. Some home modifications are fairly easy, like ramps, and some more complex, such as door widening, or putting in a lift.

DRIVING

Want to get on the road again? Of course you do. Even those with limited hand function are able to drive with proper gear and training.

YOU ARE NOT ALONE

GETTING ACTIVE

We like to say that exercise is medicine. And not just for the body but for the mind. Competitive sports are well-organized, if you are so inclined, and there are programs in nearly every town that offer recreation, on land or water or snow. There are endless options for being active; you don't need a formal program, just get out and bike, ski, sled, shoot, dance, bowl, sail or soar. Maybe all in the same day!

SCI RESEARCH

This section offers an overview of how the spinal cord is damaged and some of the ways scientists are hoping to restore its function. They're getting closer. They are not there yet. But there's no reason not to stay hopeful.

LAWYER UP?

A person's paralysis might be due to someone else's wrongdoing. If that's the case there may be remedies by way of a civil lawsuit to compensate for one's losses. If you think you have a case, you need a strong, experienced legal advocate. You might also seek legal counsel if you think your insurance company is acting in "bad faith."

FUNDING

We will look at some options for finding money. A lot of people use crowd-funding, but there are other options, including tax-advantage programs, and grants.

RESOURCES

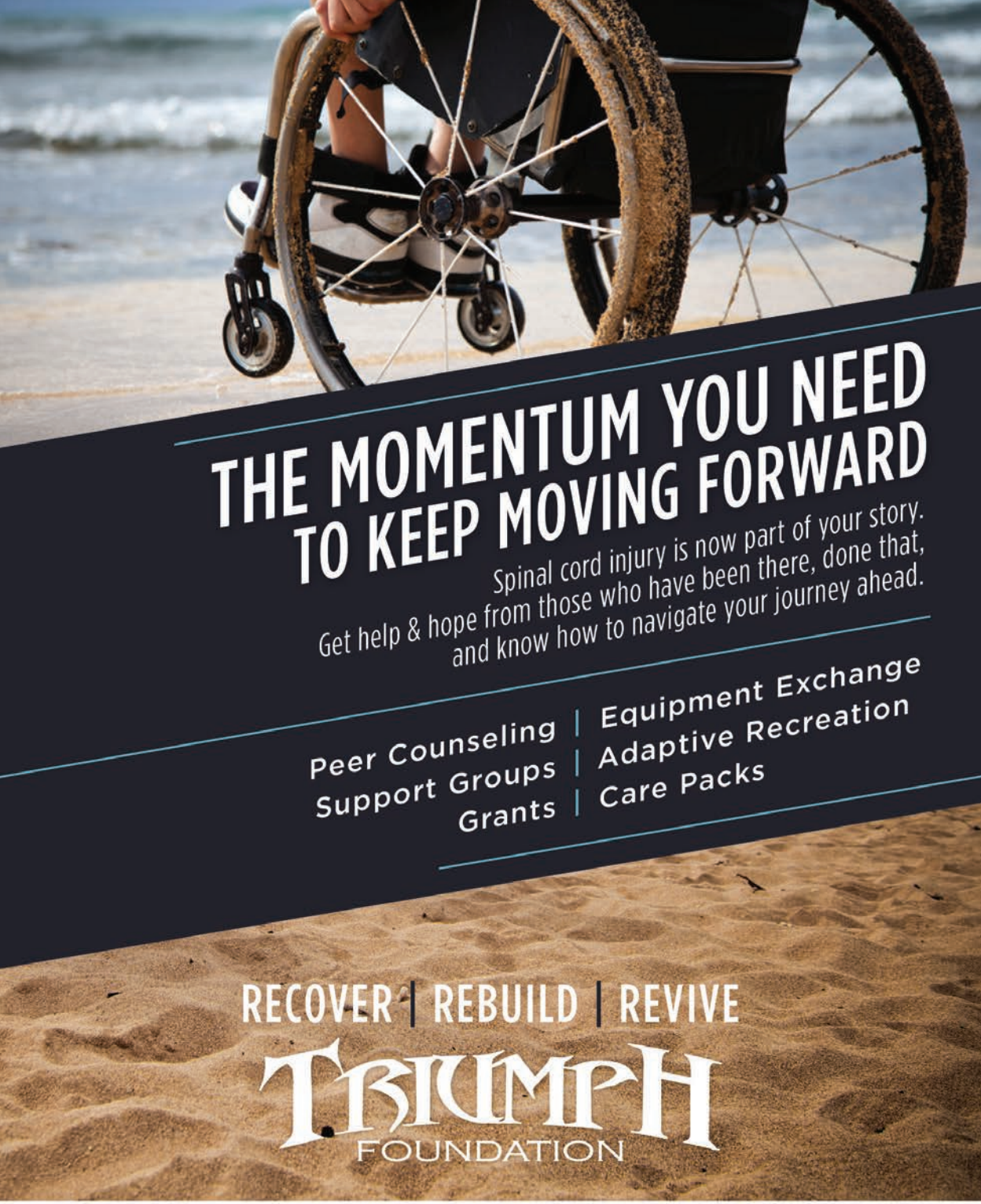
This guide is full of practical resources for living with SCI. Dialing in your exact connections may take some calling around.

CAREGIVING

Paralysis is a family issue. In the pages ahead we'll look at the role of family caregivers, who are so often swept into the chaos, and handed a job they never asked for. Families do the valuable work of caring for a loved one. They persevere, tirelessly, sometimes thanklessly, and at the risk of their own isolation and even health. There are tools and resources that might help, especially by connecting to a community of caregivers.

DISABILITY RIGHTS

The Americans with Disabilities Act (ADA) sets forth rules that guarantee full participation in society for people with physical or mental impairments, both in the workplace, and in the community. It's good to know you have these civil rights; especially if your think your rights have been infringed.



THE MOMENTUM YOU NEED TO KEEP MOVING FORWARD

Spinal cord injury is now part of your story.
Get help & hope from those who have been there, done that,
and know how to navigate your journey ahead.

Peer Counseling | Equipment Exchange
Support Groups | Adaptive Recreation
Grants | Care Packs

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PEER SUPPORT: YOU ARE NOT ALONE

The surest way to move forward after spinal cord trauma is to connect with people who share your circumstances first-hand. Clearly, those living with paralysis are the real experts. There is power in community – and that's why it's so important to connect with your SCI peers. See the next four pages for national support organizations, and also the best sources of local support.

If you ask people living with paralysis if there was one thing they know now that they wish they had known when they were first injured, you often hear that they wish they had been in touch sooner with other people who had been down the SCI road. At first, people with new injuries describe feeling alone, isolated, and scared. But contact with fellow SCI survivors helps turn things around; it's the most helpful and honest way to come to terms with the physical and psychological challenges of spinal cord injury.

Fortunately, there are many ways to connect with the SCI community, especially within the network.

Here are several ways to connect with the community of people living with spinal cord injury in Southern CA.

TRIUMPH FOUNDATION

Triumph Foundation is a full-service organization for people living with spinal cord injury. Their goal is to increase your independence, encourage self-efficacy, and reintegrate you back into the community.

Triumph offers numerous support programs providing education, assists with grants and equipment, and hosts many recreation and social activities across the Southland.

Triumph has peer-mentor Ambassadors that visit hospitals to deliver CarePacks full of resources to people with new injuries, as well as offering companionship, advice, and referrals. Triumph organizes over 20 SCI peer-support groups from Santa Barbara to the Inland Empire, all across the LA metro area, and including Orange County and San Diego.

In some cases, Triumph can provide assistance for home modifi-

YOU ARE NOT ALONE

cations, items & services, and has a robust equipment repurposing exchange program. 661-803-3700; *see triumph-foundation.org*

CASA COLINA SCI SUPPORT GROUP

Casa Colina SCI Support Group offers free education, resources, and socialization for individuals with SCI. Meets every Friday at 10:30am. 909-596-7733, ext. 4143; *casacolina.org*

KNOWBARRIERS

KnowBarriers is a peer-to-peer mentoring program developed by Rancho Los Amigos, the largest SCI rehab hospital in the area. They offer life-coaching and skill-building to help clients develop the confidence and skills to move forward and achieve their life goals. 562-401-8175; *knowbarriers.org*

PUSHRIM

Pushrim is a social network, support resource, and media platform for friends, family, and survivors of spinal cord injury in the greater LA area; *pushrim.org*

POSSABILITIES

PossAbilities is a robust community outreach program from Loma Linda University Health in San Bernardino County. Offers physical, social, and educational interaction with peers. 909-558-6384; *teampossabilities.org*

SPINAL NETWORK - UNITED SPINAL

Spinal Network is a resource hub for individuals, families and friends with SCI or related diseases. This chapter of United Spinal Association is led by Rick Hayden, a seasoned SCI survivor with wisdom and resources to share. 951-775-2561; *scchapter.org*

PVA - CALIFORNIA CHAPTERS

There are two chapters of the Paralyzed Veterans of America in Southern California. They offer advocacy, support and resource programs for folks living with SCI. 800-423-2778; *see caldiegopva.org*, *pvacc.org*

BANKERS HILL CLUB

Bankers Hill Club is a social and service club for PWD in San Diego. "We are a strong community bonded by circumstance and empowered by opportunity. We aim to help every person living with a disability live a full and well rounded life." 3030 Front St., San Diego CA, 619-574-9151; visit *bankershillclub.com*

NATIONAL RESOURCES

CHRISTOPHER & DANA REEVE FOUNDATION

Named for the late Superman actor paralyzed in a 1995 riding accident, CDRF offers a ton of information, a staff of resource specialists on-call who answer any question related to SCI, and an active Internet forum area called Reeve Connect. The Foundation offers a number of free publications, and has a national peer-to-peer program to pair you with someone who knows the ropes. CDRF houses the largest library of disability related books in the U.S., available free via interlibrary loan. Get a free copy of Don't Call it A Miracle, a spinal cord cure primer by Kate Willette, or the Paralysis

YOU ARE NOT ALONE

Resource Guide, by Sam Maddox; call for printed copies or download online for free. 800-539-7309; *see christopherreeve.org*

FACING DISABILITY

This terrific online resource features interviews and high-quality video clips of dozens of people who've been through a spinal cord injury, or who are experts in SCI care and support. Says FD, "Our video library has 2,000 high-quality HD videos of people who are living with spinal cord injury. They give honest answers to straightforward questions about how they cope. Their personal experiences are powerful evidence that successful, fulfilling lives are still possible." Sponsors and monitors a Facebook group, You Are Not Alone, "a closed community where you're surrounded by others who are living in your world....It's all spinal cord injury, all the time." *facingdisability.com*

MORE THAN WALKING

More Than Walking promotes independent living after spinal cord injury by sharing the experiences of active peer-mentors and rehab professionals. *Visit morethanwalking.com*

UNITED SPINAL ASSOCIATION

United Spinal Association incorporates the 70-year old National Spinal Cord Injury Association, and offers a national chapter network (including Triumph Foundation and Spinal Network), and a vast amount of resources. If you join (free) you get a subscription to New Mobility, the very cool and handy monthly national magazine for active people who use wheelchairs. USA has a strong policy advocacy program. Also offers lots of useful online connections and information; *visit spinalcord.org*, be sure to check out *newmobility.com*

PARALYZED VETERANS OF AMERICA

Paralyzed Veterans of America is a venerable organization formed in 1947 to empower service members with spinal cord injuries. Invaluable resources and advocacy for service-connected injuries. Today PVA is attuned to the needs of all persons with SCI, not just vets. Lots of resources and support, with chapters and service offices all over the U.S. Publishes SCI clinical practice guidelines *(See p.116)*, PN and Sports 'N Spokes magazines. *pva.org*

BACKBONES

Backbones is an online SCI community, "a place to connect with others with the purpose of learning, teaching, and sharing ... helps bridge that connection by finding and pairing people with similar injuries, backgrounds, experiences and hobbies. Jumpstart a friendship with someone who is uniquely familiar with your experiences." *backbonesonline.com*

NORTH AMERICAN SPINAL CORD INJURY CONSORTIUM

North American Spinal Cord Injury Consortium is a coalition that works to unify achievements in research, care, cure, and policy by supporting collaboration across the SCI community. Meets annually. You are welcome to

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join and participate. Recently launched a search tool to find clinical trials related to a person's specific spinal cord injury. *See SCITrials.org*; 905-508-4000; main site: *nasciconsortium.org*

WHEEL:LIFE

Wheel:Life offers peer support and information via Facebook and Twitter. Free online books on travel, relationships, fundraising, more.
4252 NW 120th Ave.,
Coral Springs, FL 33065
wheel-life.org

SPINALPEDIA

The motto here is "everything spinal cord." This is a place where people living with paralysis find strength and support in the power of the shared experience. Search through thousands of profiles to meet people of interest. Find lots of rolling role models here, including founder Josh Basile and hostess/editor Tiffiny Carlson. Basile, injured (C4-5) in 2004 at the age of 18, started the Determined2heal Foundation, which supports SPINALpedia; he is a trial attorney in Washington, D.C. Carlson, C6, from Minnesota, has written about her disability experience since 1999. *spinalpedia.com*

CARE CURE COMMUNITY

Care Cure Community features numerous and active message boards, including ones on "cure" research, equipment, medical issues, financial topics and caregiving. A message area called "Care" features certified nurse administrators who offer reliable clinical expertise on SCI health. The CareCure boards, hosted at Rutgers University by research scientist Wise Young, have been archived for nearly 20 years. This offers tremendous depth and a unique historical perspective on SCI life and the quest for recovery. *carecure.net*

LIVE TO ROLL

Live To Roll is a YouTube channel created by Shawn Fluke (C6) that features instructional videos on how to perform normal activities of daily living. The channel also features live streamed talk shows featuring Shawn and fellow hosts Tom Conway (C5) and Bobby Rohan (C6) weekly, and monthly shows Women with Disability featuring Brianna Wheeler (T12) and Rolling Over The Hill with hosts Robert Soto (T12) and Bobby. They feature guests, special topics, Q&A, and keep it fun and real. *livetoroll.org*

YOU ARE NOT ALONE

FACEBOOK COMMUNITIES

These forums can be noisy and unfiltered but very real; the SCI community tries its best to handle every sort of issue, from medical to lifestyle. Use FB search to locate the various groups. Note: these are closed FB sections; they usually require approval to join.

- **MobileWomen**
- **Spinal Cord Injury Support**
- **Spinal Cord Injury Peer Support/USA**
- **Peers for Paras**
- **You Are Not Alone/SCI**
- **Spinal Cord Injury Walkers**
- **Wives & Girlfriends**
- **CureMap**

PODCASTS

SCI related audio programs (search by name, SoundCloud or Apple).

- **QuadPodcast**: Hosted by Bob Ness, C6 injury.
- **PushLiving**: Hosted by Deborah Davis, C6/7, PushLiving.
- **United On Wheels**, hosted by Ian Ruder, editor, New Mobility.
- **SCI Life Uncovered**, with Tiffiny Carlson from SPINALpedia.
- **SCI CureCast**, the "voice of the cure," talks with SCI scientists, hosted by Matthew Rodreick, Executive Director, Unite 2 Fight Paralysis.

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FacingDisability.com was specifically created to connect families who suddenly have to deal with a spinal cord injury to people like them who have already been there.

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Our video library has 2,000 high-quality HD videos of people who are living with spinal cord injury. Their personal experiences are powerful evidence that successful, fulfilling lives are still possible.

What the Experts Say

Video interviews with medical experts give you easy-to-understand answers to the most important questions.

Resources

Our Resources center is a gateway to over 500 of the best spinal cord injury information sources on the web. It's designed to help you find what you need quickly.

Who Knows the Most about Coping with Spinal Cord Injury?

We interviewed more than 100 people with paraplegia and quadriplegia and their parents, children, spouses and siblings to create our video library. We asked about their early days in the hospital, transitioning to home, rehabilitation, employment, education, changing relationships, their fears and feelings, their plans for the future and the best advice they have for others in their situation. They are the voices of experience.

Join our Private Facebook Group

We created this special place for you to discuss everything and anything about living with paralysis. Membership is limited to people with spinal cord injuries and their families. Join now and get connected:

www.facebook.com/groups/FacingDisability

SCI: FIRST 90 DAYS

EMERGENCY MANAGEMENT

- AT THE SCENE
- AT THE TRAUMA CENTER
- CLINICAL TRIALS

FIRST HOUR: AT THE SCENE

A person who sustains a spinal cord injury in Southern California will almost always be transported by ambulance or helicopter to a top tier trauma center. The complexity of SCI and other possible life-threatening injuries that often come with the injury must be treated by the most experienced specialists at the elite trauma centers.

Before you are moved from the scene, though, EMTs and paramedics will keep you alive and get you ready for transport. They are much more careful these days: it's been reported that a generation ago up to 25 percent of cervical spinal injuries occurred after the initial insult due to mishandling and poor technique. Better pre-hospital care makes a huge difference in patient outcome: Until the 1980s most spinal cord injuries were considered "complete." Now, the overwhelming majority are "incomplete." See page 34 for more on complete/incomplete.

Things at the scene unfold pretty fast: There's a saying among those who treat strokes that "time is brain." The faster to treatment, the more brain tissue is saved, the better the outcome. Same goes for the sensitive nerve tissue in the spinal cord, where the line goes, "time is spine." Being near city centers is an advantage: mortality rates for motor vehicle accidents are four to five times greater in rural areas than those in urban areas.

Keep in mind, at this stage of the SCI experience, you really have no input. You don't get to make any decisions for a while. Truth is, you may not be fully aware of what's going on in the immediate aftermath of a spinal cord injury.

You may have acquired a head injury along with a back or neck injury; the percentage of those with a primary SCI who also have a traumatic brain injury (TBI) is reported to be between 24 and 74 percent – depending on how TBI is defined. Certainly because the spinal cord is an extension of the brain, it makes sense that injury to the brain could very well affect the spinal cord, and vice versa. SCI + TBI complicates medical

and rehab care (for example, TBI can be associated with agitation, seizures or sleep disturbances, and also higher levels of depression. Moreover, a second diagnosis of TBI may alter an SCI patient's cognitive skills – not the ideal scenario heading into the demanding world of rehab).

It's also possible people don't know what's happening at the accident scene because they're impaired; studies show that at the time of injury, as many as half of those with SCI were intoxicated, one in three were high on drugs, and one in four were affected by drugs and alcohol. But believe me, there is very little judgment in emergency medicine; the first responders will do everything they can to speed you to the hospital, regardless of toxicology.

"There is very little judgment in emergency medicine; the first responders will do everything they can to speed you to the hospital, regardless of your toxicology."

WHAT HAPPENS AFTER 911

This is how this goes: someone calls 911, the ambulance crew arrives at the crash, the fall, the sports injury, the shooting. They may have to cut you out of the wreckage; they may need to compress the leakiest of your wounds. The paramedics make sure your airways are open, that you're drawing breath and that circulation is working. A spinal cord injury may not be obvious but if there's any doubt, you'll be handled as if there is one. An unconscious or unresponsive patient is assumed to have a spinal cord injury.

The situation is widely variable but some features of SCI require immediate attention. Stabilization is a priority; the emergency techs quickly secure the spine, using a backboard with head restraints. The first providers often use a rigid cervical collar along with supportive blocks, strapping down the entire spine. Some things have to wait. If a foreign object has penetrated the body, for example, the ambulance crew will leave it be, for fear of uncontrolled bleeding.

Higher level injuries affect breathing, which of course can lead to hypoxia (lack of oxygen in the body), which can trigger cardiac arrest – and a much more critical emergency situation. Many with acute SCI will likely require supplemental oxygen, and perhaps intubation. Sometimes patients are scared, agitated or combative. Skilled paramedics may need to employ an anesthetic and perhaps a short-acting muscle relaxant to keep you from gagging and thrashing around too much as they quickly insert a tube down your windpipe without further aggravating the cervical spine.

Acute SCI typically causes your blood pressure to drop, due to the shock of trauma, and because of something called spinal shock, a temporary loss of spinal reflexes which comes and goes in the first days after spinal cord injury. Low blood pressure, or hypotension, may require treatment at the scene with intravenous fluid, or with drugs. Research has shown that maintaining adequate blood pressure can reduce secondary damage in the spinal cord, thus

improving neurologic outcome. *(See page 31 for more about the dangerous second wave of damage that happens in the hours and days after the initial trauma.)*

Where the ambulance takes you: In California, emergency services are managed mainly at the county level, accredited by the state Emergency Medical Services Authority. This agency sets standards for EMT and paramedic training and establishes the basics of trauma center triage – sorting out at the emergency scene the urgency of the injuries, and deciding whether special hospital expertise is required. In spinal cord injury, such expertise is indeed critical: protocols have been established so that any suspected paralysis will be transported to a Level I or Level II trauma center, the highest level of emergency care possible.

Level II centers offer similar coverage as a Level I but typically deal with less volume, and are usually not part of teaching hospitals.

"There is very little judgment in emergency medicine; the first responders will do everything they can to speed you to the hospital, regardless of your toxicology."

More tubes at the accident scene: you may get a nasogastric tube to remove stomach secretions, and an indwelling catheter to drain the bladder.

Most SoCal injuries happen not far from a major trauma center. Still, the emergency team has to be very careful during transport to avoid pressures that can damage skin. You can get a dangerous pressure sore in less than an hour of immobility. If transfer to the trauma ER is going to take longer than an hour, you should be turned for pressure relief at least every 30 minutes. (Skin care will forever be a top priority for people living with SCI; *see page 114 for more.*)

EMERGENCY MANAGEMENT

SOCAL LEVEL I TRAUMA CENTERS

- Cedars Sinai Medical Center, Los Angeles
- Harbor-UCLA Medical Center, Torrance
- LA County/USC Medical Center
- Loma Linda University Medical Center, Redlands
- Ronald Reagan UCLA Medical Center, Los Angeles
- Scripps Mercy Hospital, San Diego
- UC San Diego Health System
- UC Irvine Medical Center, Irvine

SOCAL LEVEL II TRAUMA CENTERS

- Arrowhead Regional Medical Center, Colton
- California Hospital Medical Center, Downtown Los Angeles
- Desert Hospital, Palm Springs
- Henry Mayo Newhall Memorial Hospital, Santa Clarita
- Huntington Hospital, Pasadena
- Kern Medical Center, Bakersfield
- Long Beach Memorial
- Los Robles Hospital & Medical Center, Thousand Oaks
- Mission Hospital, Mission Viejo
- Northridge Hospital
- Orange County Global Medical Center, Anaheim
- Palomar Medical Center, Escondido
- Providence Holy Cross Medical Center, Mission Hills (Valley)
- Riverside Community Hospital
- Riverside County Regional Medical Center, Moreno Valley
- Santa Barbara Cottage Hospital
- Scripps Memorial Hospital, La Jolla
- Sharp Memorial Hospital, San Diego
- St. Francis Medical Center, Lynnwood
- St. Mary Medical Center, Long Beach
- Ventura County Medical Center, Ventura


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AT THE TRAUMA CENTER

Good News: You made it to the emergency room, and if the trauma triage system is efficient, you are being cared for at a high-volume, high level unit. The first 24 hours of trauma care are said to be the deadliest, so getting top level care is essential.

As you know from all the medical dramas you've seen on TV, the trauma team swarms around you as the ambulance arrives. First priority of their workup, same as at the accident scene, is making sure the airways are clear and that breathing is functional. If the airway is injured or obstructed, an endotracheal tube may be inserted. This can be tricky with any suspected injuries to the neck or cervical spine; they don't want to disturb the cord any further.

Sometimes an emergency breathing passage is necessary, especially in those with high cervical injuries. The ER doctors may not yet know the full extent of injury (especially if the patient is incoherent or unconscious) but if you're having trouble breathing unassisted they won't hesitate to open the neck and trachea to mechanically ventilate.

Respiratory complications are common in acute SCI. Muscle weakness reduces the ability to cough, so secretions in the lungs have to be managed manually, or with a cough assist machine. Pneumonia is always a threat, and mechanical ventilation increases the risk of infection.

Circulation must be secured. Any external wounds are treated and if there are indications of internal bleeding, surgery may be required. In high-impact injuries, there is a strong possibility of an injury to the aorta, the main artery of the body, passing over the heart and running down in front of the spinal column.

Blood pressure is closely watched, with a goal of 85 to 90 mm Hg for the first week following an acute spinal cord injury. Low blood pressure (hypotension) can be treated with drugs that tighten blood vessels (vasopressors, such as dopamine or norepinephrine), and by way of intravenous fluid resuscitation.

Early on, mental and motor func-

tion tests are performed, including checking for movement of the extremities, which of course isn't easy if the patient is unconscious. The Glasgow Coma Scale measures responsiveness. Examination of the pupils may reveal loss of reflex; this and other signs might indicate dangerous pressure due to swelling of brain tissue (as noted previously, there is a high correlation between brain injury and spinal cord injury). If SCI is suspected, full immobilization is continued. This may include fitting of what's called a halo vest – a tight-fitting, rigid vest affixed with titanium fittings to the skull. The advantage of a halo is that it is relatively comfortable and permits mobility; it might remain in use for a few weeks for some patients, including use while in rehab.

The situation in the ER is widely variable, of course, and we risk over-simplifying it, but once you are more or less patched up and your vital signs are secure, assessments are made to determine the extent of neurological damage. The doctors need to know what's going on, and what to expect clinically in coming days and weeks. And of course so do you, your family and loved ones.

Doctors typically start with a baseline AIS score (short for ASIA Impairment Scale), carried out as soon as possible and almost always in the first 72 hours. If SCI is confirmed, the next step is to determine the level of neurological injury *(See p.33-35 for more on levels of injury)* and completeness of injury. AIS detects neurological deterioration, or improvement, by measuring motor and sensory function below the injury; the score is derived by testing ten muscle groups in the elbow, wrist, fingers, hips, knees, ankles and toes. Sensation is measured using light touch or pinprick measures of sensation across 28 sensory zones in the body. A key part of the exam involves rectal sensation and voluntary contraction.

Motor and sensory assessments are not 100 percent predictive of outcome *(See p.37 for more on outcome prediction)* but they are very useful to the treating team; ASIA scores will be taken several times over the course of the first days of injury, as scores can change, for better or worse.

As soon as possible, a patient is brought to the radiology area to image the damaged cord. There, technicians will do a CT scan, and in some cases, an MRI. (Normal x-ray scans are not ruled out, but are less sensitive than CT; x-rays alone have been reported to miss more than half of fractures of the cervical spine, which would be a big problem if not immobilized). CT (same as CAT scan) is best for viewing injuries to bone. It has the advantage of speed – it takes just a few minutes. MRI is considered best for examining soft tissue and ligament injuries – useful in diagnosing spinal cord damage – but can take up to 30 minutes. Advanced imaging such as diffusion tensor magnetic resonance imaging, which can identify intact nerve tracts, are becoming more common and offer doctors finer detail, and may therefore be a

better tool to predict outcome.

BRUISED, NOT SEVERED

The popular terminology you read in the news media is that a person has a "severed" spinal cord. That is almost never the case, except for bullet or knife wounds. Typically, the cord is fully intact but bruised (contusion) by the impact of the accident. The initial trauma may knock out some primary nerves, which brings about loss of function. But there's more damage to come. The immediate injury to the cord also produces a cascade of other destructive events, including bleeding, swelling and biochemical chaos at the injury site. This contributes to further nerve death and loss of body functions, and may continue for hours, days, and even weeks, after injury. While nothing can be done to reverse the initial crushing impact that caused the injury, many experiments have shown that so-called secondary damage can be minimized, thus reducing the degree of disability.

There have been numerous experiments with drugs, cell therapies and with procedures such as cooling of the spinal cord, yet no drug or procedure has ever been approved by the FDA to treat acute spinal cord injury. Some emergency room doctors prescribe a high-dose steroid called methylprednisolone (MP) very soon after SCI. Twenty years ago most newly injured patients got MP, administered within eight hours of injury; it was believed to reduce inflammation, preserve blood flow and therefore rescue sensitive spinal cord tissue. In recent years, however, research has suggested that a major side effect of MP – the susceptibility to infection – outweighs any benefits.

If the bones of the spine are damaged or dislocated, the ER doctors may recommend realignment by nonsurgical means – using tongs on the skull and traction, for example, to gently pull and reposition the neck bones. Surgery may be required to take pressure off spinal cord tissue, especially removing bone fragments that may be pressing on the cord. If the bony vertebrae are damaged, or if damage extends along several vertebrae, the surgeon may fortify the spine, often using bone from the patient's hip bones (iliac crest) to rebuild the vertebral bone. Other options include use of metal hardware such as plates, screws and rods to secure the backbone, and to eliminate pressure on the cord.

If surgery is recommended, the trauma center neurosurgeon decides when to begin, either soon after injury, within the first 12 to 24 hours, or to wait for the cord to heal for a few days. There is evidence in the medical literature that early surgery and decompression after SCI is safe and is associated with improved neurologic outcome; there are surgeons who prefer to wait, operating only when swelling of the damaged cord calms down.

OTHER COMPLICATIONS

Other medical issues are carefully monitored early on after SCI. Deep vein thrombosis is common, the result of poor circulation and blood clotting in the lower extremities. The greatest risk is for a clot to move through the bloodstream and into the lungs, resulting in a life-threatening pulmonary embolism. The blood-thinning drug heparin addresses this complication. Many patients may also be fitted with compression socks. In some, a tiny filter is inserted in a major artery so a loose clot won't reach the lungs.

Skin care, we will say it again, is a critical issue for people with SCI. It is carefully monitored in the acute care setting. A pressure sore, a skin infection that can occur if pressure on skin is not relieved often, can begin even after a short time of immobility. Hospitals may consider using a specialized bed for patients with an unstable spinal column if a long immobilization is expected.

Do not take chances with your skin! Pressure wounds occur in as many as half of patients with new SCI during the first month post-injury – this often begins in acute trauma care and is entirely preventable.

Bladder and bowel management begin as soon as vital signs are stabilized. *(For more on B & B, See p.109, 111)*. SCI commonly causes urinary retention, even in those with incomplete injuries. In the ER setting an indwelling catheter is often used to prevent an overfull bladder.

Nutrition is important in trauma care to prevent complications and promote healing. Difficulty swallowing (dysphagia) is common in acute cervical SCI, and can cause choking. Food or liquid that goes down the windpipe is not good, as it may lead to pneumonia. This often requires food to be fed by tube.

Pain accompanies SCI in most cases. The source may be from external injuries or from nerve pain, felt at the level of injury or below. Neuropathic pain can be difficult to measure, and is more difficult to treat than musculoskeletal pain. The sense of touch can become hypersensitive (allodynia). Doctors try to balance sedation with the need for further assessments of nerve function. Sometimes they prescribe short-acting medications to allow periodic neurologic testing. *(See more on pain, p.111.)*

Injuries above the T6 level are often accompanied by autonomic dysreflexia (AD), which can be a serious, life-threatening complication and must be closely watched. *(For more about AD, See p.108.)*

Patients with the most severe injuries remain in the ER before transfer to the trauma center's medical/surgical area. You'll stay in med/surg until medically cleared for rehab – depending on your complications. It could only be a day or two. The national average for staying in the ER is 11 days (it used to be 24 days in the 1970s).

CLINICAL TRIALS

People with acute spinal cord injury may be asked to participate in a clinical trial, an experimental research study to test new therapies or devices. Some of these studies must begin within the first few hours or days after injury, an urgency that may complicate the decision to participate.

Here we will look at what a clinical trial is, how trials work, and trials that are currently looking for participants in Southern California.

The best resource for information on clinical trials comes from the U.S. National Institutes of Health, c/o *ClinicalTrials.gov*, which sponsors an up-to-date, searchable database for all publicly and privately sponsored clinical trials, for all conditions, in all locations around the world. Look up spinal cord injury, for example. There are over 300 clinical trials in the U.S. now recruiting patients, with about 60 open trials recruiting patients with acute, or brand new, spinal cord injuries. If you narrow the search to just California, there are about 20 current clinical trials for SCI. An industry-academic collaboration called Spinal Cord Outcomes Partnership Endeavor (SCOPE) maintains a very handy chart of all clinical trials specific to SCI *(see scope-sci.org/trials)*. *See also SCITrials.org*.

Important consideration for any patient considering participation in a trial: A trial is *not* a treatment. Those running the trial cannot ethically make any presumptions or promises about the effect of the drug, device or therapy. These are experiments, not treatments. The drug, device or intervention might demonstrate a clear benefit in some participants but that cannot be used to persuade you to join the trial.

A clinical trial is a research project that uses human volunteers (participants). The goal is to learn about disease, injuries and therapies, and thus to add to medical know-how. Clinical trials are sponsored or funded by drug or medical device companies, university medical centers, or non-profits (for example, Wings for Life). Federal agencies including the National Institutes of Health, the

Department of Defense, and the Department of Veterans Affairs also sponsor research. Clinical trials involve no cost to participants.

HOW FEDERAL REGULATORS DESCRIBE THE TRIALS PROCESS:

"Clinical trials may compare a new medical approach to a standard one that is already available, to a placebo [a dummy drug, e.g., a sugar pill] that contains no active ingredients, or to no intervention. Some clinical trials compare interventions that are already available to each other. When a new product or approach is being studied, it is not usually known whether it will be helpful, harmful, or no different than available alternatives (including no intervention). The investigators try to determine the safety and efficacy of the intervention by measuring certain outcomes in the participants. For example, investigators may give a drug or treatment to participants who have high blood pressure to see whether their blood pressure decreases."

Many trials are "blinded," that is, neither the patient nor the research team knows if a particular dose or intervention was the active drug or the placebo.

There are several phases to a clinical trial; the first two are mainly focused on safety.

PHASE I: tests an experimental drug or treatment in a small group of people to study safety and identify side effects. No efficacy (benefit) is planned for.

PHASE II: a drug or therapy is administered to a larger group of people to further evaluate effectiveness and safety.

PHASE III: an experimental drug or treatment is administered to large numbers of people (1,000+) to confirm safety and effectiveness, and to look for side effects.

PHASE IV: After a drug is approved by the FDA and marketed to the public, researchers must track its effectiveness, safety, and side effects.

IF YOU PARTICIPATE IN A STUDY

A clinical trial is conducted within a specific protocol, designed to answer research questions and safeguard the well-being of participants. The protocol must be spelled out; it contains the following information:

- The primary reason for doing the study.
- Who and how many are eligible to participate. In SCI, a trial may be restricted to injuries less than year a old, for example, or to injuries of the cervical spinal cord only.
- How long will it take, what tests, procedures, or drugs are involved.

Informed consent is an important part of any clinical trial. This is the way in which researchers protect participants by giving them critical details about a study, including its risks. This helps people decide whether they want to enroll, or continue, in a study. Generally, one must sign an informed consent document before beginning a study to validate that information was provided and understood on risks, potential benefits, and alternatives. Participants can quit a trial at any time, even before the study is over.

QUESTIONS TO ASK

Those thinking about participating in a clinical trial should know as much as possible about the study.

- What exactly is being studied, how long will the trial last, and what is the basis for thinking the intervention might work?
- Has it been tested before?
- Who will know if I get a drug or a placebo during the trial?
- What tests and procedures are involved?
- Will I need to be hospitalized, and how often do I have to visit the clinic?
- Will I be reimbursed for any expenses?
- Is there long-term follow-up care as part of the trial?
- Who supervises my medical care while I'm in the trial?
- What if I am injured or adversely affected during the study?

SOCAL SCI CLINICAL TRIALS

(Subject to change; all human trials on hold at press time; see clinicaltrials.gov for the most up-to-date information.)

Neuralstem is testing the safety of human spinal cord-derived neural stem cell transplantation for the treatment of chronic spinal cord injury. Candidates must live within 500 miles of San Diego and must be at least 1 year but no more than 2 years from time of injury. Early data suggests the procedure is safe and may bridge the gap in spinal cord circuitry. Contact 844-317-7836; email *alphastemcellclinic@ucsd.edu*

Exoskeleton Research: Casa Colina rehab near LA is evaluating the overall safety profile of the ReWalk Personal Device exoskeleton outside of the institutional setting. Subjects have injuries at levels T7 to L5. Contact: Emily Rosario, 909-596-7733, ext 3036, *erosario@casacolina.org*

UCLA is recruiting in the LA area for several neuromodulation trials, one for bladder (at least one year post injury; SCI at C2-T8, motor complete AIS A or B); another for hand function (at least one year post injury, AIS C, C7 or higher cervical injury); and one using transcutaneous (surface) stimulation of the legs (AIS A, B, or C, one year post injury, cervical or thoracic injuries). Daniel C Lu, MD PhD, 310-825-4321, *dclu@mednet.ucla.edu*

Rancho Los Amigos Rehabilitation Hospital, in collaboration with USC and CalTech, is recruiting high level quadriplegics for a study of closed loop brain-machine interface technology, reanimating the paralyzed body transmitting signals from the patient's brain to a computer to facilitate hand function. In Los Angeles. Contact Dr. Charles Liu, *chasliu@cheme.caltech.edu*

Keck Medicine, USC is enrolling people with chronic cervical spinal cord injuries to test a molecular cocktail called Nogo Trap, being developed by ReNetX *(renetx.com)*, a biotech startup. Each participant will be given a dose of Nogo Trap, called AXER-204. The drug is given via lumbar puncture. The trial will evaluate the safety, tolerability, and pharmacokinetics (how the drug acts in the body). Sandra Oviedo, *sandra.oviedo@med.usc.edu*

Keck/USC is also recruiting people with SCI for non-invasive bladder stimulation studies. Contact Keck urologist Egeniy Kreydin, 818-790-1278

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1. Barbosa et al.2012, 2. Wyndaele JJ Spinal Cord 2002

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SCI: FIRST 90 DAYS

SCI BASICS

- WHAT GOT DAMAGED
- PREDICTING OUTCOMES
- NON-TRAUMATIC SCI

THE BASICS OF SPINAL CORD INJURY

Spinal cord injury is usually the result of forceful trauma related to motor vehicle accidents, sports injuries, falls, or acts of violence. SCI is sudden and dramatic, and happens to an estimated 17,000 people a year in the United States, or about 1,200 in the SoCal region. Most injuries occur to men (about 80 percent) and mostly to young people. In recent years higher numbers of people 60 and older are becoming spinal cord injured, the result, apparently, of more active and therefore riskier lifestyles across the lifespan.

More than half of spinal cord injuries occur in the cervical area (neck), a third occur in the thoracic area (mid-chest), and the remainder occur mostly in the lumbar area (the lower back).

The spinal cord is an extension of the brain; it's a thin bundle of nerve fibers that extends from the base of the brain down to the tailbone. It is made up of long nerve fibers, some extending the length of the back, plus numerous nerve networks up and down the cord. The spinal cord coordinates movement and activity of arms and legs and torso; the cord also transmits messages for sensation, such as touch, heat, or pain. Researchers have found that the spinal cord is itself "smart" – it is capable of processing sensory information to control movements of the extremities, without input from the brain; studies have shown it may be possible to "awaken" dormant spinal cord function *(See p.151)*.

Until the 1940s, long-term survival after SCI was very poor. People often died of infections to the urinary tract, lungs, or skin. The era of antibiotic drugs, beginning around World War II, made it possible for people living with spinal cord injury to stay healthy and to closely match life expectancy with the general public.

The most common cause of SCI is blunt force trauma, although damage also occurs from diseases at birth or acquired later in life, from tumors, electric shock, poisoning or loss of oxygen related to surgical mistakes or scuba diving mishaps.

The cord is well-protected by the

bones of the backbone, called vertebrae. In the case of trauma, however, the force of impact can exceed the strength of the bone. Except in cases of gunshot or knife wound, the spinal cord is not usually cut, it is pinched, compressed, or bruised.

LEVELS OF INJURY

The backbone is made up of 33 vertebral segments. The spinal cord is labeled by its position on the vertebrae (if you map this, it's called a dermatome, see illustration next page). These segments are important in SCI: basically, the lower the segment, the higher the function, and vice versa.

In the neck, or cervical region, the segments are labeled C1 through C8, and correspond to nerves that control function in the neck, arms, hands, and diaphragm. Injuries to this area result in tetraplegia (the medical term) or quadriplegia (as it is more commonly called).

C1 – C3: A high cervical injury, such as that of the late actor Christopher Reeve (C2) affects breathing and requires mechanical ventilation. Reeve was unable to move or feel any part of his body except his head. He required assistance for eating, dressing, bathing, hygiene, everything except for piloting his power wheelchair with a sip and puff controller. If he had been injured just a few vertebrae lower on his spinal column – a matter of an inch or two – Reeve would have had some ability to move his arms, and perhaps fingers, thus retaining some ability for self-care and a larger degree of independence.

C4 generally means loss of movement and sensation in all four extremities; C5 injuries usually spare the shoulders and biceps, but not so much the wrists or hands. C5s can handle many activities of daily living on their own, including feeding. C6 injuries have sufficient wrist control to drive an adaptive vehicle, but not much power in the hands. C7 and T1 injuries can handle most of their own self-care but hands and fingers still are not 100 percent.

"The spinal cord is itself 'smart'. It is capable of processing sensory information to control movements of the extremities."

In the thoracic, or upper back region, T1 to T8 segments affect control of the upper torso and trunk. This is the result of abdominal muscle loss but arms and fingers are OK. Lower thoracic injuries (T9 to T12) allow better trunk control.

Lumbar, or lower-back region segments (L1 through L5) affect hips and legs. A person with an L4 injury can often extend the knees. The sacral segments (S1 through S5) in the lower back affect groin, toes, and legs

It's important to note that no two spinal cord injuries are exactly alike. Other than level of injury,

the major factor that determines level of function and potential for recovery is how badly the spinal cord was bruised.

Just about all segments of spinal cord injury affect the legs and feet, as well as bladder, bowel and sexual function. A number of other complications may accompany SCI: low blood pressure, autonomic dysreflexia (for injuries above T6), spasticity, and chronic pain. Then there are the secondary issues related to paralysis: pressure ulcers, respiratory issues, urinary tract infections, pain, and depression.

TWO OTHER TYPES OF INJURY

- **Brown-Séquard Syndrome** is an injury that causes damage to half of the spinal cord (hemisection), resulting in paralysis on the same side as the injury, and loss of pain and temperature sensation on the opposite side.
- **Central Cord Syndrome** is a cervical spinal cord injury with more impairment in the arms and hands than in the legs; this is sometimes called "walking tetraplegia."

COMPLETE VS INCOMPLETE INJURY

There are several tests doctors use to measure level of injury and degree of paralysis. The most common is American Spinal Injury Association (ASIA) Impairment Score (AIS), which assigns a letter grade to general levels.

- **AIS A** means no motor (muscle) or sensory function is detected below the level of injury.
- **AIS B** means there is some sensory function, no motor function.
- **AIS C** indicates some motor function and some sensory function have been preserved.
- **AIS D** means more than half of muscle and sensory function remains. Many Ds can walk.
- **AIS E** is normal.

One of the key aspects of the AIS metric is completeness vs. incompleteness. In simple terms, a person with an incomplete injury has some ability to move muscles, or to feel touch or pinprick below the level of injury. That means there is spared sensory or motor function below the level of injury.

Another assessment you might get is the Functional Independence Measure (FIM), an 18-item score of physical, psychological and social function. Almost everybody's FIM goes up after even a little therapy.

You might also hear about the IRF PAI (Inpatient Rehabilitation Facility Patient Assessment Instrument), developed by the Medicare program to standardize measures

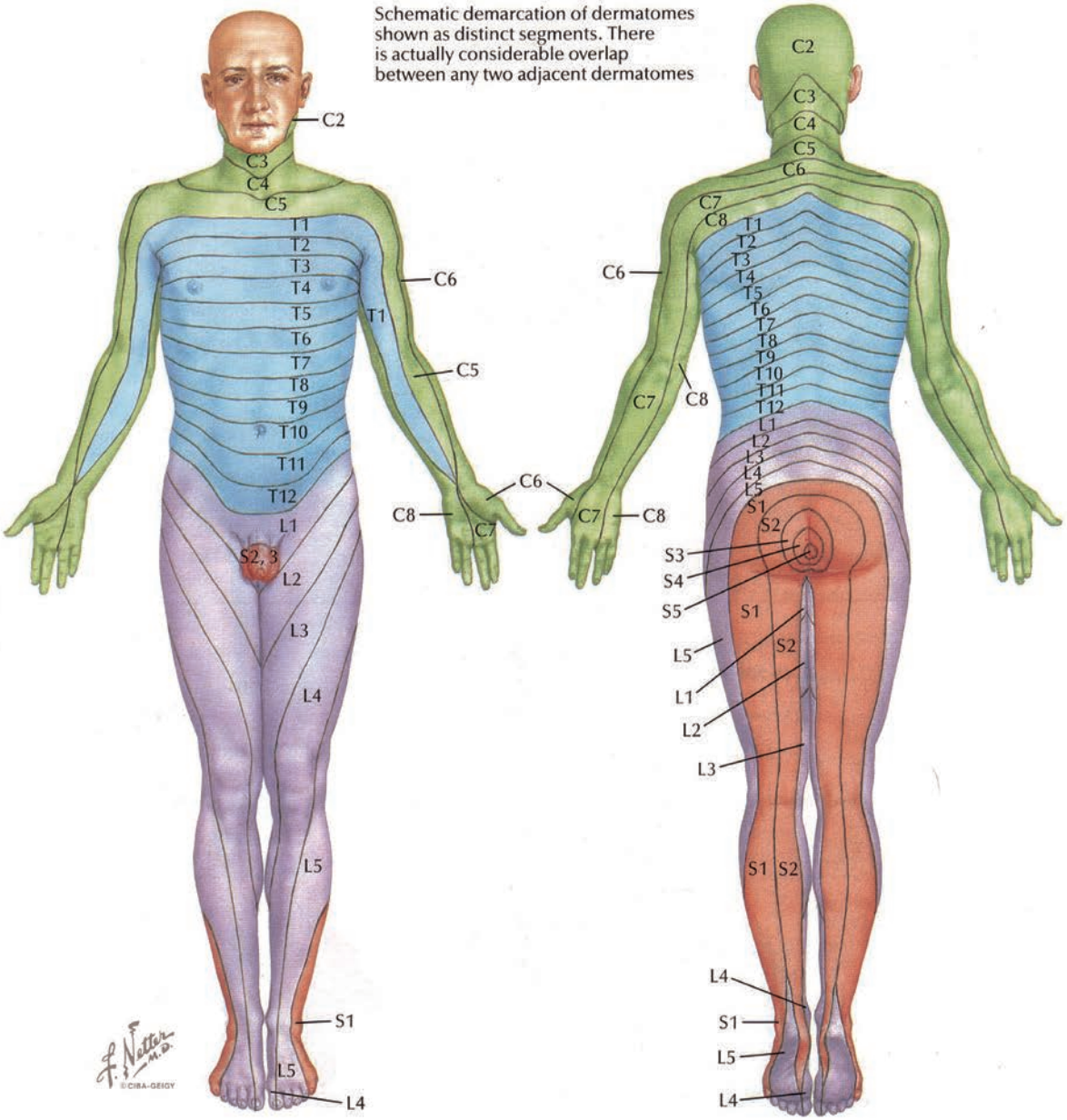
of physical, cognitive and functional skills at admission and at discharge. This tool, nicknamed FAM, is beginning to replace the widely-used FIM.

In most cases of SCI people improve beyond their initial diagnosis. Many people get quite a bit better over the first few months but generally, improvement plateaus after six months to a year. Historically, incomplete patients stand a better chance of recovering some function than those labeled complete.

BEWARE OF INFECTION

Infection has always been a deadly issue in SCI: Pneumonia is still the leading gateway to doom post-SCI. Now we learn that getting any infection early after SCI doubles your long term risk. Don't get one!

Alas, hospital-acquired pneumonia is common in acute SCI care; generally, patients who get pneumonia will have worse long-term outcomes than those who don't. Those who acquire an infection during acute care or inpatient rehab have significantly lower FIM scores at five years post-injury. That means those who get early infections are less able to take care of themselves, and more likely to die within 10 years of injury. Reminder infections are almost entirely preventable.


Schematic demarcation of dermatomes shown as distinct segments. There is actually considerable overlap between any two adjacent dermatomes
C2
C3
C4
C5
C6
C7
C8
T1
T2
T3
T4
T5
T6
T7
T8
T9
T10
T11
T12
L1
L2
L3
L4
L5
S1
S2
S3
S4
S5
S2, 3
F. Netter M.D.
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PREDICTING OUTCOME

So, what's going to happen to you? When will you get better? How much recovery can you expect? What are you going to be able to do on your own? How much help will you need? What sort of equipment will you need?

You and your family need to make plans and manage expectations. Doctors and therapists also need to know how to tailor treatments and rehab for your specific injury. You are about to get an outcome prediction.

In the trauma center, as soon as you're medically stable, doctors will measure your function with several diagnostic tools. They can also use x-ray, MRI or other devices to visualize the damage to your spinal cord. They can compare your injury to many others they have seen. They'll tell you what they think will happen, and what might not happen. While doctors are not always certain what your outcome will be, they should be able to give you a good idea what you are facing.

IMPORTANT TO KNOW

Prediction is not destiny. Keep in mind that your situation is unique and may not fit the usual pattern. You could recover much more than expected. There is also a chance your recovery might not meet your doctors' outcome expectations.

A **"complete injury"** may not be so complete. The medical field has always defined complete spinal cord injury as lacking motor or sensory function below the level of injury. That's not the whole story. Recent experiments with spinal cord stimulation have shown that a group of paraplegics considered ASIA A – full motor and sensory complete injuries – were able to initiate voluntary movement in paralyzed limbs, and were also able to control bladder and bowel function. Stimulation appears to awaken intact but dormant nerve circuits in the spinal cord. These circuits then reactivate movement patterns programmed into the cord. There's more vitality in the injured spinal cord than previously thought.

The nervous system has potential for recovery. The spinal cord is "plastic." Some nerve messages can be rerouted and, perhaps, restored. This hasn't been fully figured out yet, but be hopeful, and be wary of the word "never." *(See SCI research, p.151.)*

The following information is based on what usually occurs for people with various levels of injury, gathered over many years at U.S. rehab centers. It's important to know that no two spinal cord injuries are exactly alike, and many variables come into play that affect recovery – your age, other injuries or health conditions you may have, even your state of mind.

THE FUTURE IS UNWRITTEN

There is usually hope for at least a little improvement after spinal cord injury, but even with the most sophisticated tools, no one can predict your future. Even measured on the first day or two post-injury, outcome predictions are fairly reliable, though not infallible.

- Generally, those with a complete injury (no muscle power or sensation below the level of injury) regain one or two levels of function.
- About 80 to 90 percent of those with complete injuries will usually remain complete.
- The majority of those with motor incomplete injuries recover some ability to walk.
- If improvement continues, such as increasing muscle movement, chances for more improvement are usually better.
- The longer you go without improvement, chances for improvement are lower.
- Those with an incomplete injury (some muscle or sensory function below level of injury) are more likely than those with a complete injury to regain movement.
- There is no sure way to know how much will return.
- Younger people generally recover more than older people.

Doctors have seen recovery after two years; some people injured longer than that continue to recover. Generally, though, most functional recovery takes place in the first 12 months after injury.

EXPECTATION BY LEVEL OF INJURY

Here are summaries of outcome expectations (remember, these are general outcomes, based on a large number of patients. They are not immutable facts regarding your injury). People with incomplete injuries are especially variable, and therefore hard to categorize across all measures of function. This data comes from the Consortium for Spinal Cord Medicine, which publishes authoritative, peer-reviewed clinical practice guidelines for spinal cord injury. (Obtain full reports at *pva.org*, search "publications.")

LEVEL C1-3

This is the highest level of spinal cord injury; it involves total paralysis of the trunk and arms and legs. Most likely these injuries will require mechanical ventilation and typically need 24-hour care for daily activities, including help with bowel, bladder, bed mobility, transfers, eating, dressing, grooming, bathing and transportation. Caregivers may need to use a mechanical lift with a sling. People with high level injuries are still mobile; they can power an electric wheelchair by way of sip-and-puff devices, and can handle independent communication, with the right equipment. They can manage their caregivers as long as they are able to explain everything.

LEVEL C4

This level of injury involves full body paralysis with some neck and shoulder movement. People with these injuries are usually able to breathe without a ventilator. The functional profile is similar to that for a C1-3 person (some neck flexion, no hand function, no cough). A C4 will require a wheelchair with power recline and/or tilt. A tilt or standing table might be used. Total assistance is generally needed for all tasks of daily living, except power wheelchair use.

LEVEL C5

This is the most common level of spinal cord injury. People at this level usually retain shoulder and elbow flexion, but have weak hands and wrists. Many C5s use hand splints. A hydraulic standing frame might be used. Some at this level can push a manual wheelchair with adaptive rims. Breathing endurance is reduced, limiting ability to cough; assistance may be needed for secretions. A person with a C5 injury can eat independently if meals are properly set up. Personal care assistance is needed daily, especially for grooming, bed transfers, and dressing. Some C5s can drive a vehicle with the right specialized gear and training.

LEVEL C6

This level involves total paralysis of trunk and legs. People with this injury are generally able to do more on their own than those with higher injuries. There is usually some compromised vital capacity (air volume). Some help may be needed for bowel management, transfers, and bathing. Wrist flexion and hand movement are impaired; adaptive gear may be helpful. A C6 can usually push a manual chair and do weight shifts. Personal care is required for getting up in the morning, grooming, going to bed. Driving is not complicated.

LEVEL C7/8

This level of injury involves paralysis of the trunk and legs but with greater arm and hand dexterity, including elbow, wrist and thumb extension. People with this level of injury are mostly independent for bladder and bowel self-care, bed-to-chair transfers, eating, grooming, etc. A personal care attendant is typically needed for some daily activities.

SCI BASICS

LEVEL T1-9

This level of injury involves lower trunk paralysis, somewhat limited trunk stability, but full arm and hand function. Paraplegics with this injury may have impaired vital capacity but are mainly independent for activities of daily living, including wheelchair loading and unloading into a car, work, school, and homemaking.

LEVEL T10-L1

This level of injury indicates paralysis of the legs but with good trunk stability and an intact respiratory system. People with this injury are mainly independent in most functional activities; some paras at this level are able to stand and ambulate with forearm crutches or a walker.

LEVEL L2-S5

This very low injury involves partial paralysis of legs, hips, knees, ankles and feet. People with an injury to the sacral spinal cord have good trunk support and are mainly independent for the wheelchair lifestyle. Bladder, bowel, and pain issues are possible. Some people with this injury are able to stand and ambulate with braces, crutches, or a cane.

NON-TRAUMATIC SPINAL CORD INJURY

This book concerns the first weeks after trauma – the sudden onset of paralysis due to impact on the spinal column. There are other pathways to spinal cord dysfunction that do not involve trauma, including conditions present at birth and those acquired later via disease or medical error.

Acute care and medical management are not directly comparable between traumatic and non-traumatic SCI. The rehabilitation therapy processes can overlap in many ways, though, as will certain psychosocial parameters, technology options, legal rights, community and lifestyle connections, and so on.

Here are some of the ways non-traumatic SCI happens:

CONGENITAL

Cerebral Palsy is not so much an issue with the spinal cord; CP affects a part of the brain that controls movement, and in more severe cases can involve paralysis. Most CP occurs in children at birth but can occur in the first few years of life due to brain infections or head injury.

Friedreich's Ataxia is a degenerative spinal cord disease that usually begins between ages five and 15. The spinal cord becomes thin and loses some of its myelin, the insulation on nerve fibers. FA is rare, one case in 50,000. There is no cure, but many symptoms can be managed.

Spina Bifida is a rare birth condition wherein the spinal column does not fully form a protective covering of the cord. Children born with spina bifida often undergo surgery soon after birth to close the spinal column; in recent years doctors have even operated on babies in utero, before they are born. While SB babies do grow and live long lives, there are sometimes unique issues, including

accumulation of spinal fluid in the brain (hydrocephalus).

Many aspects of SB parallel spinal cord trauma, such as bowel and bladder incontinence, and lower limb paralysis. About 1 in 1000 newborns are affected by spina bifida, a number that is declining due to improved maternal nutrition, especially the addition of folic acid to the diet.

Spinal Muscular Atrophy (SMA) is an inherited disease that affects the nerves in the brain and spinal cord that control voluntary movement. SMA usually affects children but there is an adult-onset form too. Symptoms vary between weakness and greater loss of mobility. Two new medications have recently been approved to modify the genes that cause SMA, leading to significant functional improvement for some patients. They drugs are shockingly expensive: Spinraza is $750,000 the first year and $375,000 annually after that; Zolgensma is $2.1 million for a single dose.

ACQUIRED AND DISEASE RELATED

Lyme Disease is a bacterial infection transmitted by a tick bite. Severe cases can involve loss of function or paralysis in arms and legs.

Multiple Sclerosis is a disease believed to be caused by one's immune system attacking the nervous system. MS can progress to weakness, incontinence, fatigue and paralysis. There are many medications for MS, designed to dampen the immune response.

Acute Flaccid Myelitis: there is no more polio in the United States but there is a mysterious new scourge that affects children in much the same way as polio did. The Centers for Disease Control and Prevention began tracking acute flaccid myelitis in 2014. Several hundred children have gotten it, causing sudden loss of muscle control in limbs and other parts of the body. Some cases involve the muscles that control breathing, this requiring mechanical ventilation to survive. There is no treatment yet.

Spinal Cord Infarction is a stroke within the spinal cord or the arteries that supply the oxygen-sensitive spinal cord. Chances for recovery are good but symptoms can include pain, weakness in the legs, loss of reflexes, loss of temperature sensation, incontinence, and paralysis.

Spinal Tumors: overgrowth of tissue, e.g., cancer, can form tumors that impinge upon the spinal cord, causing motor and balance problems, weakness, spasticity and paralysis. Advances in chemotherapy and microsurgery may be able to help.

Stroke: blood to the brain is blocked by a blood vessel burst or by a clot of some kind. The result usually affects one side of the body, and may include cognitive issues (memory, judgment, learning), weakness, and paralysis. Clinical trials have shown promise for stem cells to treat stroke.

Transverse Myelitis is caused by an inflamed spinal cord, and leads, often quite suddenly, to loss of body function below the level of damage. About one in three cases recover fully, about one in three

join the world of paralysis. No therapies are available but symptoms are for the most part manageable.

MEDICAL ERROR

According to reports published in the medical literature, doctor error is now the third leading cause of death in the United States, behind heart disease and cancer. The numbers are shocking: it has been reported that more than 250,000 deaths a year are due to preventable doctor error.

Doctors who perform medical procedures on or near the spine can cause injury. There is an inherent risk in many procedures, but it is often the case that a treatment falls short of the standard of care, and thus into the realm of medical negligence, for which a doctor and/or hospital may be liable and owe you compensation.

(Note: If you suspect that you have been harmed by a medical treatment, consult with an attorney who has experience with medical error.)

Here are several types of medical error that can lead to paralysis:

Birth Injury: infants can suffer from lack of oxygen during birth, leading to brain damage, mental retardation, motor deficits, or cerebral palsy.

Anesthesia: too much or too little anesthesia can lead to brain injury or even death.

Surgical Error: neurological or orthopedic surgery carries a risk of causing paralysis if blood flow to the cord is restricted for too long a time. There are monitors for this but they are not fail-safe.

Sometimes doctors operate on the wrong body part, or leave surgical tools inside the body. Preventable infection is often acquired in a hospital. Failure to recognize or diagnose conditions, including spinal cord disease or stroke, can result in permanent loss of function.

SCI: FIRST 90 DAYS

CHOOSING A LAWYER

HOW TO SELECT AN ATTORNEY

By Steven Heimberg, M.D., J.D.

If you are reading this, either you or your loved one has recently suffered a serious spinal cord injury. And, of course, you are dealing with enormously difficult life issues that must be addressed:

- How will I work and support myself and my family?
- How will I pay my medical bills?
- If I need help in the future, where will the money come from?
- If I am in a chair, or worse, is my current housing situation suitable?
- And so on.

If your injury occurred as a result of the wrongdoing of others, two things are true: 1) those wrongdoers are legally responsible; 2) you may be entitled to "compensation" – that is, repayment for what has been taken from you. This includes money to pay for your new care needs.

A lawsuit is not a lottery ticket. It is a means to compensate you for some of what has been lost. It is your right. There is nothing wrong with holding another accountable for his or her wrongdoing. And there is nothing wrong with seeking money that you and your family need to get by because of what has been wrongfully taken from you.

In practice, however, it is not easy to get repayment for what you've lost. It's rare that people (and particularly companies) admit to their wrongdoing in injuries as severe as yours. Insurance companies, employers or others pressure even honest people to deny or avoid responsibility, or at the very least, to keep key information hidden.

In addition to denying their own fault, the wrongdoers also might try to argue that you are responsible for what you have been through. They will then say that your portion of fault means you are entitled to less or no compensation.

The wrongdoers will often have insurance companies, corporate lawyers and enormous resources

to fight you and prevent you from getting what you deserve. Prevailing in court against those possessing much greater resources than you possess is difficult with an attorney, but almost impossible without one. This truth is compounded by the reality of how much you already have on your plate dealing with your injury.

Moreover, the laws regarding where, when and how you can bring your lawsuit are complex. For example, there are severe and strict limits on the time in which you are allowed to bring your lawsuit. There are also many other technical requirements with which you must comply in bringing and pursuing your case.

Next, your case will depend on the evidence your side can present at trial. But the rules for preserving, gathering and using evidence at trial also are complex and require legal assistance.

Even if you could correctly gather and synthesize all the evidence in your case, it will be almost impossible to settle for fair value if the other side knows you are without an attorney. That is because these experienced companies know well how little chance you have to prevail at trial if you do not have someone experienced to skillfully present the evidence and to do so in compliance with the many rules of court.

Finally, the seriousness of your injury is potentially very expensive for the wrongdoer. They are at risk of having to pay you for a lifetime of care, lost work and lost enjoyment of life. Because of their great exposure, these companies will throw large amounts of money and other resources to defeat, or at least minimize, your case.

Therefore, if you decide you want to pursue a case against those who harmed you, you will likely need to hire an attorney. And you should do so as soon as possible.

HOW TO CHOOSE A LAWYER

If you decide you need a lawyer, finding one is easy. However, selecting the right attorney for your case can be difficult. Yet, your success with your case often will depend on how well you make this difficult choice.

If you decide to seek compensation for your injuries, you'll want to find a lawyer who is well qualified, who will fight for your rights, and who will care about you and your case. Find out if the lawyer you are considering meets the criteria you require and is someone you can trust. Carefully selecting your lawyer will increase your chances of receiving just compensation for your injuries.

All lawyers who take on cases like yours are not alike. It is crucial that the attorney you select is well qualified and extremely capable. But how do you determine his or her level of talent and expertise? Essentially, you need to ask the right questions.

CHOOSING A LAWYER

QUESTIONS TO ASK INCLUDE: KNOWLEDGE

- Does the lawyer have expertise in the type of incident that led to your injury: surgery mishaps, intraoperative monitoring, industrial accidents, auto accidents, road design cases, defective products, etc.?
- Does the lawyer have sufficient medical expertise to fully understand your specific injuries, analyze the facts, and effectively oppose the many experts that the wrongdoer's insurance companies will hire?
- Is the attorney and firm involved in consumer organizations or charities supporting others in your circumstances?
- Does he or she have sufficient experience to evaluate and hire experts to support your case?
- How many cases like yours has the lawyer handled? How many has he or she tried?

QUALITY OF WORK AND TRACK RECORD

In addition to having the proper experience, has your prospective attorney demonstrated skill in trial work and in obtaining settlements for his clients?

- What is the attorney's track record? What are his or her accomplishments?
- How much money did other clients similar to you receive?
- Does the firm hold any records for settlements or verdicts in your type of case?
- Do the firms' attorneys handle as many cases as possible, or limit themselves to a smaller number of cases on which they can concentrate their efforts?
- Who exactly (assistants, paralegals, junior or senior attorneys) will be working on your file?

CHOOSING A LAWYER

RECOGNITION AND REPUTATION

There are many organizations that provide lawyer ratings and rankings, indicating the top lawyers in a particular field. For example, the Consumer Attorney Association of Los Angeles selects its Trial Lawyer of the Year; Best Lawyers (in conjunction with US News & World Report) selects the very best lawyers in a given region, in each specialty area, and also selects the top firms in each specialty area, including personal injury and medical malpractice (the two most relevant to spinal cord injury); *SuperLawyers* (in conjunction with LA Magazine) selects the top 5 percent of attorneys in Southern California from all legal fields combined, and then further picks out the 100 superstars from Southern California; the American Trial Lawyers Association selects the Top 100 Trial Lawyers in California; and LawDragon has a list of the Top 500 Litigators and Top 500 Plaintiff (victim) attorneys in America.

So, you can inquire as to attorneys you are considering:

Are the attorney's accomplishments sufficiently substantiated to attain recognition from his or her peers as being a superior attorney?

What such special recognition has the attorney received from his or her colleagues (ask for lists of specific awards and honors)?

How has the lawyer been assessed by former clients (ask for references from previous clients)?

EXPERIENCE

Does the attorney you are considering have substantial trial experience? If not, he or she will not be able to deal effectively with the complex procedures of the courtroom. Moreover, a less experienced lawyer is unlikely to get the respect of opposing lawyers and the judge. Like sports rookies, new lawyers rarely get favorable calls from the referees (judges) or understand the fine points of the competition.

If the attorney has trial experience, does that experience include your specific type of case? For example, if you were injured while getting medical care, does the lawyer have experience with medical malpractice cases and dealing with the medical system? Even if the lawyer handles medical malpractice cases, has he or she pursued and tried cases specifically like yours? This is true for whatever accident, drug or device, or other incident that led to your spinal cord injury.

If your attorney is insufficiently experienced, he or she likely will either: 1) do an inadequate job and drastically reduce your chances of winning; 2) settle your case to avoid trial; 3) use you as the guinea pig to gain experience; or 4) try the case to an unfavorable outcome, either losing a case that should have been won, or obtaining a verdict that is insufficient.

Many inexperienced lawyers also seek cases only to send them to more experienced attorneys, and then claim a piece of the pie as a "referral fee." Unfortunately, by the time the case is sent to the suffi-

ciently skilled and experienced attorney, the case often already has been mishandled. This seriously undermines both your chance of winning and the amount you eventually will receive.

Does your potential attorney have the background and skills to deal with the complexities of your particular case? In spinal cord injury cases, there are technical medical issues related to the severity of harm, physical deficits and mechanism of injury.

In many cases, there are complex arguments between opposing medical experts on how the injury occurred, when it occurred, whether it was avoidable, and whether proper steps were followed. In spinal cord injury cases it is always useful, and often essential, that your attorney have substantial medical expertise in additional to legal expertise.

SERVICE

Of course the quality of service you receive is also important. While many lawyers will give you a one-time free consultation, not all lawyers are accessible, professional, courteous, and client-oriented, and neither are their offices. It has been said: "Nobody cares how much you know until they know how much you care." Will your potential lawyer care about you and your case?

Finally, ask your network, professionals, other people who have been injured, and even other lawyers if the lawyer you're considering seems like the best fit for you.

Steven Heimberg is a medical doctor and personal injury attorney in Los Angeles; *heimbergbarr.com*

Dr. Steve Heimberg

DOCTOR & LAWYER

Focused on Spinal Cord Injuries

> Steve Heimberg... a great friend of the spinal cord injury community for years.
>
> -Andrew Skinner, Founder, Triumph Foundation

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THE MOMENTUM YOU NEED TO KEEP MOVING FORWARD

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and know how to navigate your journey ahead.

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YOUR CIVIL RIGHTS

Back in 1990, a report from the U.S. Congress noted that "individuals with disabilities continually encounter various forms of discrimination, including outright intentional exclusion, the discriminatory effects of architectural, transportation, and communication barriers, overprotective rules and policies, failure to make modifications to existing facilities and practices, exclusionary qualification standards and criteria, segregation, and relegation to lesser services, programs, activities, benefits, jobs, or other opportunities."

So they passed a law.

The Americans with Disabilities Act (ADA) is that law; it's a major civil rights act that covers every person with any impairment that substantially limits life activities. The ADA focuses on work, school, transportation, public accommodations, and telecommunications. The concept, per Congress, is for the ADA to "provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities."

Employers, state and local governments, employment agencies and labor unions are prohibited from discriminating against qualified individuals with disabilities in job applications, hiring, firing, advancement, compensation, job training, and other aspects of employment.

Employers can't ask job applicants anything about disability, only about their ability to perform specific job functions. If a job offer is conditioned on the results of a medical examination, that same examination must be required for all entering employees in similar jobs.

An employer is required to make accommodations to an applicant or employee with a disability if it does not impose significant expense or "undue hardship" on the business. Reasonable accommodations might include making existing facilities readily accessible; job restructuring or modifying work schedules; acquiring or modifying equipment or devices; adjusting or modifying examinations, training materials, or poli-

cies; and providing qualified readers or interpreters.

The ADA prohibits banks, stores, hotels, movie theaters, health clubs, doctors' offices, etc. from discrimination on the basis of disability. Telecommunications companies must provide equivalent services for customers with disabilities, particularly those who are deaf or hard of hearing.

The ADA ensures equal access to what's called the built environment. Federal ADA standards establish design requirements for the construction and alteration of both commercial and state and local government facilities.

The U.S. Access Board develops ADA Accessibility Guidelines, used by the Department of Justice and the Department of Transportation, who make the rules the public must follow.

ADA RESOURCES

The Disability Rights Legal Center (DRLC) is a Los Angeles-based public interest advocacy organization that champions the civil rights of people with disabilities (PWD) as well as those affected by cancer and other serious illnesses; *drlcenter.org*

Disability Rights California seeks justice for people with disabilities, filing lawsuits on behalf of individuals or groups, and investigating charges of abuse and neglect; visit *disabilityrightsca.org*

Californians for Disability Rights, the oldest and largest membership organization of PWD in California, fights for independence, dignity and equality for all; *disabilityrights-cdr.org*
(To learn more about ADA visit ada.gov, or access-board.gov)

CONTACTING AN ADA ATTORNEY.

If you have questions or feel like you are being discriminated against, you may contact an attorney specializing in ADA and Civil Rights Law to advocate for you. They can ensure you have access to public spaces like restaurants, parks, schools, and stores; ensure there's proper and adequate parking; investigate employment discrimination; and make sure your housing rights are protected. They will offer free consultation, provide advice, and if necessary, litigate on your behalf to remedy the situation. Sometimes if there are proven damages, you can be awarded a settlement. While there are many lawfirms to choose from, you might start by contacting *theharrisonlawgroup.com*

BEST HOSPITALS
U.S.News & WORLD REPORT
NATIONAL REHABILITATION
2019-20

Advancing spinal cord injury care and research since 1956

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SCI: FIRST 90 DAYS

CHOOSING A REHAB

- COMPREHENSIVE
- SPECIALIZED CARE
- INSURANCE
- POST-ACUTE CARE
- LIFELONG REHAB

MOVING ON TO REHAB

Let's assume it's been a few days since the accident or incident that injured your spinal cord and sent you to the emergency room. If you are free of serious complications and don't require round the clock emergency care, it's not out of the question that you'll be shipped straight away to an inpatient rehab hospital, and if that's the case, skip ahead to p.68 for how that process is supposed to work, and what you need to know.

If you have life-endangering complications – coma, burns, internal injuries, broken bones, pneumonia, etc. – or if you had some sort of surgery the first day, you may stay in the acute hospital, moved from intensive care to a less intensive area called a step-down unit, and then on to the medical/surgical or "med-surg" area. It's also possible you'll be sent to a skilled nursing or long-term care unit until you're up for rehab.

Things slow down a bit away from the drama and urgency of the ER. Now, while the hospital staff continues to monitor your vital signs and tend to your broken body, watchful at all times for infection, they can also begin to let you and your loved ones in on the cold, hard facts about what's going on. Important: cold and hard are not the same as forever and ever. Your body took a hit; nothing works the way it used to. Some functions come back, some might not. But don't be discouraged by a prediction that sounds like a life-sentence. There are many reasons to keep hope alive. Remember: it gets better.

YOU HAVE RIGHTS

Most hospitals have a written Bill of Rights for patients. Patients and their families should know that they are indeed the directors of their own care. That doesn't mean doctors and therapists will consult with you on every detail, but it does mean you should know who your primary doctor is, as well as the names and professional relationships of other physicians and non-physicians you come in contact with.

You have a right to know what's going on. You should be provided information – privately and con-

fidentially, and in terms you can understand – about your injury and related complications, the course of treatment, and prospects for improvement. You should be allowed visitors. You have the right to refuse treatment. You can leave if you want to.

Of course, some doctors and nurses are better about explaining things than others. If you don't follow what was said, ask again. Be as annoying as you have to. This is from Loma Linda University Medical Center, one of the larger trauma and rehab units in the region: "You have the right to effective communication and to participate in the development and implementation of your plan of care. You have the right to participate in ethical questions that arise in the course of your care, including issues of conflict resolution, withholding resuscitative services, and forgoing or withdrawing life-sustaining treatment."

Regarding planning for the worst: One option is to draw up an advance directive, a legal document that designates someone to make decisions on your behalf if you become incapable of understanding a proposed treatment or become unable to communicate your wishes. (The hospital should have the advance directive forms; if not download one from the California Attorney General's office, *oag.ca.gov*). Hospital staff have to comply with these directives; all the same rights apply to the person you choose to manage your medical care as apply to you, the patient.

Read everything they ask you to sign. Are you agreeing to arbitrate disputes in a way that may cost you your day in court? Are you agreeing that the doctors who treat you are independent contractors and not employees of the hospital?

REHAB STARTS IN THE TRAUMA HOSPITAL

The process of rehabilitation may begin as soon as a day or two after injury. It won't be nearly as intensive as it will be in an actual rehab hospital, but trauma hospital therapists like to get going as soon as possible to build you up and prevent complications. Respiratory therapists will make sure the lungs are clear and hygienic. Post-SCI mortality rates have dropped tremendously since the 1970s, due in large part to better acute care of lungs and breathing.

Physical therapists won't get to know you well during your short stay in the trauma hospital, but they may provide range of motion exercises to strengthen and stretch muscles, and to keep joints from getting tight. Other staff will work with you on positioning and seating, and if needed, speech and language skills, and swallowing. The first time you try to sit up in bed you may feel extremely lightheaded; this is called orthostatic hypotension. This improves fairly soon. Once you can sit up for a longer period the nurses or therapists may get you out of bed and into a wheelchair.

Skin care will always be a top concern. The risk for breakdown is very high in the week following an acute injury, for a number of reasons. Pressure injuries usually form

on the skin over bony areas such as the hips and tailbone. These areas are vulnerable because pain sensation may be lost, due to paralysis, brain injury, or medications. It's also likely that you'll make multiple transfers for imaging and other studies during the emergency phase. This exposes skin to injury by way of shearing (stretching). If it is expected you will be immobile for a while, a special bed may be used to minimize skin breakdown. It's a shameful statistic to report but pressure injury formation is said to occur in 30 to 50 percent of patients with new spinal cord injuries during the first month post-injury. This is enormously time consuming, it delays the rehab process, and it's expensive. It doesn't have to happen.

Bladder and bowel will for the most part be managed for you in the trauma unit but you'll get the idea how this works, and perhaps you'll be able to learn some basic skills and basic hygiene to handle some care on your own.

There are lots of other things going on with the body, and the mind. This is a tough situation. There are all sorts of emotions running through your head. Depression. Anxiety. Anger. Larger trauma centers have a psychiatric staff and other counselors. Take advantage if you can. You should also be availed of all options to manage pain.

There will continue to be a lot of assessments and tests in the first days post-ER. What is the exact nature of your injury, what function was lost, what other issues are pressing? This is necessary as plans begin to form for how you will be rehabbed and eventually discharged and sent home. You probably weren't aware of it but discharge planning began the minute you were dropped off at the trauma center.

DESIGNATE AN ADVOCATE

It's obvious right away that this is a time to call in family and friends to help. No doubt your people are freaked out and lost in this new world, and no doubt they have been all over the Internet, trying to process the madness of this major traumatic event. If you're lucky enough to have this book in hand, you will know how to dig deeper and faster, without having to sort so much online noise.

Here's some advice to family and friends of a newly injured person: Check the local and national resources listed on p.11-14. These places offer a lot of material, and some have staff that can help. The Reeve Foundation, for example, has trained resource specialists on call to handle inquiries related to paralysis *(call toll free 800-539-7309)*.

Get smart fast; someone needs to come forward and be the primary advocate for the patient. Someone needs to take charge of his or her interests, to be the point person, the hub of information, and in some cases, the nag. It's not an easy time for anyone involved, but things are going to be decided in coming days that may make a big difference to the person dealing with SCI. In a perfect situation, a savvy patient advocate would suddenly emerge to handle all of

this, making sure the patient's needs are the foremost priority. You may be able to find private services that do this. You may have to take it on yourselves.

In most trauma hospital settings, a case manager or social worker comes into the picture once you're basically stable and able to pay attention to important decisions ahead. One of the first things you have to address is where you are going next. Figuring out your next move begins right away. You will need to know the details about your insurance coverage, discussed later in this chapter.

No insurance? You aren't alone; half of new cases in a large national SCI database did not have insurance at the time of injury. Don't worry, they can't kick you out of the ER if you don't have coverage, and there are ways to get help and to get high quality rehab in California. *(See p.81)*.

CHOOSING AN ACUTE INPATIENT REHABILITATION FACILITY

One of the earliest and most essential decisions a person with a new spinal cord injury has to make is where to go for rehabilitation. This is the stage of care that will prepare you for the long term – getting your body back into the best shape possible, making sure you know how to take care of your health, maximizing your independence out in the community once you get back home.

Once leaving the trauma hospital, it's very important to find a specialized center to get the most intensive, most appropriate post-acute care. Why is a specialized SCI center better? On the next page, SCI doctor Christopher Boudakian, based at California Rehab Institute in West LA, describes comprehensive multidisciplinary hospital care.

COMPREHENSIVE CARE: PICKING THE RIGHT REHAB SETTING

By Christopher Boudakian, D.O.

Where do we go from here? It is not unusual for patients and families to feel lost, rushed, and scared navigating our healthcare system following a spinal cord injury. Not only is it necessary to learn about the injury and its possible implications, but also the various options ahead for recovery.

The acute care hospital is the first step after injury and this is generally followed by a transition to inpatient rehabilitation. If all goes

to plan, this is where the majority of the initial recovery will take place.

You will meet a team consisting of the rehab physician, therapists, nurses, psychologist, and case manager and/or social worker that help guide you through this process. Before this point is reached, however, an acute rehabilitation unit must be selected.

There are several things to consider when choosing a rehab, with the hopes of achieving the best outcome. You can expect to receive great care at any facility accredited by the Commission on Accreditation of Rehabilitation Facilities (CARF), especially if the facility has also received accreditation for the spinal cord specialty program. This will signify the hospital demonstrates the commitment, capabilities, and resources to maintain itself as a specialized spinal cord program.

It is important to assess all options available for care both near and far. While choosing a facility closer to home may be more convenient for visits by family and friends, another rehab hospital may provide improved care and resources for this critical time period.

Some questions worth considering during the search include:

- Are there dedicated staff, including nurses and therapists, trained to work with the SCI population?
- What is the rate of discharge to home versus another skilled facility?
- How many patients with SCI diagnosis are treated at the facility annually?
- Is there a formalized education program for patients and family/caregivers?
- Are neuropsychology services available to help cope with injury?
- Does the hospital provide a continuum of services, including outpatient care and access to community resources?

If at all possible, visit facilities in person, as websites and online reviews alone do not always accurately depict these programs. Physicians should be board certified in spinal cord injury medicine or have extensive background in treating these injuries; there are many unique characteristics of spinal cord injury that are not prevalent in other aspects of medicine.

It is also worth mentioning that some facilities may boast about technologies such as robotics to attract patients. It is more important, however, to have a treatment team with robust experience to help the patient achieve the basic skills needed for transition to home and community. This is the fundamental role of a rehabilitation hospital. Advanced technology can be incorporated later into the outpatient treatment program.

It is important to stress the timeframe of rehabilitation — it will always seem shorter than what it should be. Working with the

rehab team to plan ahead will be of the utmost importance for success. Discharge to the home is the next step of the journey, usually followed by in-home or outpatient therapies as appropriate. Family and caregiver involvement may be a crucial part of the rehabilitation process and long-term quality of life at home. Find your support system and call upon your higher power to guide the road ahead. Godspeed.

Dr. Boudakian takes care of patients at the California Rehabilitation Institute in Los Angeles.

ARE YOU READY?

How do the people at the trauma center know you're ready to go to rehab? Once the occupational and physical therapists agree you can withstand at least three hours of rehab therapy a day, you're pretty much good to go. If you no longer need intensive trauma care but are not quite medically able to deal with the rigor of daily rehab therapy, you may be transferred to a sub-acute unit or skilled nursing facility (SNF, or "sniff" in the lingo of rehab).

Skilled nursing facilities sometimes call themselves "post-acute rehabilitation centers," but it's important to know that SNFs are not the same as inpatient rehabilitation facilities (IRF). SNFs don't charge as much as inpatient rehab facilities (IRF), which may make them attractive to insurance payers. But SNFs offer far less in terms of expert care; they are usually run by nurses, or worse, CNAs, with few doctor visits and little or no physical therapy or specialized services. There is data to show that people who leave an IRF return home faster, and healthier, than those discharged from nursing care only. If you get sent to a SNF, you will want to transition out of there as soon as you can.

A SPECIALIST DOCTOR'S LIST FOR NAVIGATING REHAB

By Ann Vasile, M.D.

It is important to know who will be treating you at an inpatient rehab, and also whether that doctor or team will be around to follow your care.. Dr. Vasile explains:

Here are some questions to ask a prospective inpatient rehab hospital to make sure your medical team has the skills and experience to meet your needs:

How is the physical medicine and rehab (PM&R) staff assigned to a patient: rotation or by diagnosis? (Rotation may mean you'll be seen by a stroke or hip replacement specialist.) What Medical Board certifications do the physicians have, and how many years of experience?

Can you meet or at least talk to the PM&R people before you are admitted? How many days a week do the doctors personally see each patient?

Will there be a family conference with the treating MD? Family conferences are important but are no longer routine, often assigned only for 'problem' patients.

Will the medical staff follow

patients after discharge, and if not, what is the transition plan for outpatient care?

Dr. Vasile, a board certified spinal cord injury specialist for 25 years, treats patients at Tustin Rehab, Long Beach Memorial, and CareMeridian; her outpatient practice is in Long Beach.

THE REHAB TEAM

Ideally, your rehab experience will be overseen by a multidisciplinary team with training in neurology, rehabilitation nursing, occupational therapy (OT), physical therapy (PT), and speech and language therapy (SLT), under the leadership of doctors trained in physical medicine and rehabilitation (a physiatrist) or at least by neurologists trained or board certified in rehabilitation medicine.

There is no formula to successful rehab; it is a process that works best when tailored to the needs of each patient. Rehab is a collaboration between a person with a spinal cord injury and a team of experts in medicine, psychology, social services and technology. Here are the members of the rehab team you should find at centers that treat spinal cord injury:

Patient and Family: Of course the most important member of the rehabilitation team is the person with a spinal cord injury. Your enthusiasm and participation in the rehab process are essential. Your family and friends are important, but this is your time: use it well.

Rehabilitation Doctor: A physician with a specialty in physical medicine, called a physiatrist, leads the rehab team. He or she coordinates patient care services with other team members. Ideally, this doctor is board certified in the SCI specialty.

Rehabilitation Nurse: Rehab nurses and their assistants are on call 24/7 to help you set goals, plan your care and reach maximum independence. Nurses are fully involved in medical care and prevention of complications. Your nurse will be an important source for learning about SCI care, too. Some are specialized in important areas, such as pressure wound management. Ideally, your nurses are fully trained and certified in rehab care (CRRN).

Physical Therapist: Physical therapy (PT) is a crucial part of rehabilitation. Activity is an essential part of recovery. Your PT will help to restore function to the extent possible, working with you to improve movement, strength, and joint function.

Occupational Therapist: Occupational therapy (OT) is the key to improving independence. Your OT will coach you in activities of daily living (ADLs) related to work, school, family, and leisure activities, including eating, bathing and hygiene and home management. OTs recommend adaptive equipment and tools.

Case Manager: The rehab case manager is a specially trained social worker who makes sure you are connected to services and resources, particularly those related to insurance. A case man-

ager helps you plan your discharge from rehab to home.

Psychologist: Spinal cord injury is a life-changing event; a psychologist can help you process and cope with your new situation. The best centers also have specialized staff to deal with sex, intimacy and family planning issues. *(See p.117 for more.)*

Recreation Therapist: Your rec therapist helps get you out in the world and involved in social settings, including recreation, sports and leisure activities.

Chaplain: For those who seek counsel related to spiritual matters, the chaplain may help directly, or connect the hospital with your home church or place of worship.

Other Specialists: Spinal cord injury usually involves multiple body systems, and multiple aspects of life. Other specialists you will likely encounter include a urologist, pain management doctor, orthopedic surgeon, pharmacist, and perhaps one of the following:

Respiratory Therapist: Some injuries impact breathing. This is the therapist who treats airways and lungs.

Speech Language Pathologist: Some spinal cord injuries affect communication, swallowing, memory, judgment or cognition. Your SLP evaluates and helps manage these.

Wound Care: Skin is vulnerable after spinal cord injury. Let's hope you don't have to meet a nurse who specializes in restoring your skin to its healthy and infection-free state.

Dietitian: Nutrition is an important part of recovery. This expert will make sure you are eating what you need.

Seating Specialist: This person helps line up the proper mobility equipment – chair, cushion, etc. – to get you rolling and back into the community.

Vocational Therapist: These are the specialists who assess your job skills and help arrange equipment, training and placement for getting you back to work or school.

Driving Trainer: Getting back on the road is a worthy goal, but you will need special training and evaluation to adapt your driving skills. Many rehab centers offer an adaptive driver training program

WHEN DO YOU HAVE TO DECIDE ON A REHAB CENTER?

How much time do you have to decide on a rehab setting? Not much. Maybe just a few days after the time of injury. The sooner rehab starts, the better, and lengths of stay in acute trauma units are getting shorter. In the 1970s a person with a spinal cord injury was kept in a trauma hospital setting for about 24 days. That's down to an average of 11 days now, depending on complications, infections, etc., according to the National Spinal Cord Injury Statistical Center. (It's also true that IRF lengths of stay have declined – from 98 days 40 years ago to about 36 days currently – less if you factor out the more complex cervical injuries.)

How to decide? There are basic questions you can ask, per Drs. Boudakian and Vasile, above. There are more than 40 acute inpatient rehab facilities in Southern California. It may not be imme-

diately obvious, but inpatient rehab hospitals are not all the same; some have shiny new buildings, some centers deal with more cases of SCI than others, some have accreditations, and some may have special expertise.

After screening the rehabs *(listed on p.69)* and making sure you and your insurance company are on the same page, call the ones that appear to meet your needs. Have someone visit them if possible.

ments.

Rule of Thumb: The best rehabs are modern, specialized, offer a comprehensive treatment plan, and see a large volume of patients with similar spinal cord injuries.

There's another important factor in rehab choice: the place you want has to want you too. Patients have to be able to do the work and engage fully in therapy programs. You also have to know where you're headed when you are ready

"How much time do you have to decide on a rehab setting? Not much. Maybe just a few days after the time of injury. The sooner rehab starts the better."

Ask a prospective IRF if it participates in clinical trials for new treatments; that demonstrates a commitment to the SCI specialty. Does the center offer any cool new equipment (body weight supported treadmill devices, robotic ambulation training devices, brain-machine orthotics, exoskeletal ambulation training devices, etc.), and will you be able to use any of it?

While the closest place to home may be the most convenient, with advantages of support from family and friends, it may not offer the level of service your specific injury requires. The rehab at your community hospital may welcome you as a new SCI patient – hospitals like to keep the beds full – but if the facility doesn't see many spinal cord injuries, the rest of the rehab ward will include people three times your age, there for stroke, brain injury, or hip replace-

to leave rehab. Before you're even in the door, the rehab facility has to make sure you have a discharge plan to home or somewhere in the community. No plan, no admit.

FACTORS TO CONSIDER WHEN SELECTING A REHAB

Number of New SCI/Year: This is one of the more important measures; more volume means more expertise, more chance there will be others there with injuries similar to yours.

Staff-to-Patient Ratio: More staff generally means higher quality and more personalized care. There are minimum requirements set by the state, such as one nurse for every five patients. More staff is clearly linked to better functional outcome, including a reduction in complications such as pneumonia, urinary tract infections, or skin pressure wounds.

CHOOSING A REHAB

Percentage SCI Beds: inpatient rehabs take care of trauma patients, including SCI and brain injury; this may also be the ward for strokes and certain orthopedic patients (e.g., hip replacements). A lower percentage of SCI beds means most of the rehab activities involve other conditions, and most likely a patient population older than you.

Discharge to Home: This doesn't vary much between centers (around 80 percent) but the higher the number, the better patients are prepared for return to the community. Lower percentage means patients are headed back to the hospital, or to a nursing home – not such a good sign.

ACCREDITATION IS IMPORTANT

This means a rehabilitation hospital meets certain rigorous standards of care verified by independent outside inspections. There are two main accreditation agencies for rehabs, and one high level credential from the federal government.

The Joint Commission (JC) is an independent, not-for-profit organization that accredits and certifies about 21,000 health care organizations and programs in the United States. Just about every hospital gets a JC credential; until 2008, hospitals could not accept Medicare patients if they did not have JC approval. There are other Medicare accrediting agencies now, but JC still carries a lot of weight for Medicare compliance. Does a JC credential mean much for consumers shopping for acute inpatient rehab? Not so much; JC has a "gold seal" accreditation for certain disease categories – stroke, for example – but not one for spinal cord injury.

"Rule of Thumb: The best rehabs are very specialized, offer a comprehensive treatment plan, and see a lot of patients with similar spinal cord injuries."

Care for Ventilator Patients: Care for high cervical spinal cord injury, involving mechanical ventilation, is beyond the expertise of most IRFs. Very few rehabs in California work with ventilator patients.

Board Certified SCI Doctor: This means there's a physician on staff with specialized training in spinal cord injury care. Find out if this doctor will be your doctor. SCI is complex; board certification recognizes this.

Nursing Expertise: A better trained staff makes a difference; having nurses with an advanced credential in rehab (Certified Registered Rehabilitation Nurse, CRRN) is predictive of better patient outcome.

CARF: An accreditation that is much more relevant to SCI rehab is that of CARF (Commission on Accreditation of Rehabilitation Facilities). To be awarded CARF accreditation, a facility must have specific staffing and programs,

and must pass an in-depth audit of its services. *(See p.69 for more on CARF.)*

OTHER FACTORS TO CONSIDER

Special medical care is also needed in urology, respiratory therapy, wound management, spasticity, pain treatment, etc.

Psychological Services: This is obviously important for the newly injured person trying to adjust, but it's an important factor for families and loved ones too. Everyone is coping with loss and anxiety. Professional counseling can make a huge impact. Is there a psychologist accredited in the specifics of rehab psychology?

Key Services: Ask about driver training. Nutritional counseling. Seating and positioning specialization.

Recreation Therapy: Social activities, including sports and recreation, are helpful toward reintegration in the community.

Peer Support: Very important. Does the rehab you are considering have a support group?

Family Supports: Does the rehab have counseling or programs to help family members?

Outpatient Care: Rehab does not last long enough to prepare people with new injuries for the long road ahead. Access to an outpatient program is essential; this assures continuity of medical care in the hands of people with expertise you won't find in a general clinical setting.

GETTING THE MOST FROM REHAB: HIT THE GROUND ROLLING

By Andrew Skinner

OK, you're leaving the intensive care hospital, headed for rehab. Yes, it sucks, the whole deal is a nightmare. And you may be thinking you'll ride it out, that everything will be OK. That may be true, you may walk out of there. But just in case you don't, you need to maximize your recovery and prepare for going home. Get yourself ready for rehab.

If you don't think you're ready physically or emotionally for five or more hours of therapy every day – you may still be healing up from broken bones and surgeries – consider a transition to a skilled nursing facility until you are ready for rehab. Remember, you only get a set number of rehab days. Don't burn them if you can't really use them.

Listen, this is an important time. Inpatient rehab stays are very short, and you have a lot to learn. So be prepared to hit the ground rolling .... be ready to get out of bed and work your body, learn new skills.

So, what to expect. You will see your doctor and nurses and learn about things like catheters and bowel programs. Not fun. You will get a lot of one-on-one physical therapy, working your active muscles. PT is what you make of it. This cannot be said enough times: exercise is medicine. Work hard on getting stronger. Ask

your PT if there is work you can do when your sessions are over; many rehabs have a gym you can use.

You'll meet a lot with your occupational therapist, too. OTs teach you skills for managing your activities. You'll work with many other therapists, including a psychologist – this thing isn't easy and there are coping strategies they can show you, and your family, so you can better come to terms with your injury.

One last thing: a key part of figuring this thing out is connecting to people who have been where you are. There are many ways to connect with your peers – your rehab unit probably has a peer group. Also see the first chapter of this book.

Good luck. Don't be afraid to reach out for help.

Andrew Skinner, a quadriplegic since 2004, founded the Triumph Foundation, a supportive network for people living with paralysis. triumph-foundation.org

WHAT YOU CAN EXPECT TO HAPPEN WHILE YOU'RE IN REHAB

by the Rehabilitation Team, Casa Colina Hospital and Centers for Healthcare, in Pomona, led by David Patterson, M.D., board certified physiatrist; casacolina.org

As you navigate the path to recovery and independence after a spinal cord injury, inpatient rehabilitation may be your best option for exploring new ways to move and adjust to the physical, psychological, and emotional challenges that come with SCI.

Rest assured that you will have the help of an entire multidisciplinary team led by a physical rehabilitation and medicine doctor (physiatrist) and composed of nurses, case managers, physical therapists, and occupational therapists all dedicated to your recovery. They will help you decipher medical terms like "neurological level," "autonomic dysreflexia," and "motor return." And the team will develop a comprehensive plan to maximize your function and recovery potential and help you set realistic and obtainable goals.

So what can you expect next? Action! Plan to work hard in physical and occupational therapy to optimize your body function, conditioning, strength, balance, functional mobility, and activities of daily living. Your occupational therapist will teach you the necessary techniques and self-care skills to increase your independence—tools you will use long after your hospital discharge.

Your physical therapist will probably be a fanatic about getting you moving, whether with a wheelchair or on your own two legs. Your team will guide you through the selection of any specialized medical equipment you need, which may include a custom wheelchair evaluation by an experienced therapist.

A certified assistive technology professional may evaluate your functional ability and train you on any appropriate assistive devices, including speech-generating devices, text readers, touch

screens, etc. Your team will let you know about home modifications, such as a ramp or widened doorway.

Many individuals with SCI assume their injury means the end of their sexual identity. Don't. Your doctors and therapists will talk to you about what you can expect for sexual activity and fertility. Nurses will also work with you to understand bowel and bladder changes that often accompany SCI.

The goal of your inpatient rehab experience is to give you the proper tools and training to get you home safely, confidently, and as independently as possible while educating you on the prevention of secondary complications like pressure sores, pneumonia, and blood pressure issues.

But the work does not end there. Upon discharge from inpatient rehab, you will be directed to professionals who will help you set new goals to achieve your highest potential. Depending on your healthcare provider, you may be admitted to a short-term residential program that will further fine-tune your daily living skills. Outpatient services like adaptive driving, aquatic therapy, electrical stimulation, and robotic technology are often available to smooth your transition back home, as are SCI community support groups and outdoor recreation and fitness programs.

So remember, while every SCI rehabilitation experience is unique, each shares the same vision: overcoming disability and giving you the opportunity to enjoy your life.

SOCAL INPATIENT REHABS

There are at least 40 acute inpatient rehabilitation facilities (IRFs) that admit patients with acute spinal cord injury in Southern California.

Rehabs vary in size, experience, and in quality. Some of the higher volume hospitals you may have heard of, others are community hospitals with a rehab unit that may see one or two spinal cord injured patients a year.

All units have a Joint Commission (JC) accreditation for general hospital. This accreditation is important mainly to allow Medicare billing.

Accreditation by CARF is a key qualifier. CARF is an independent international agency that provides accreditation services at the request of service providers. The agency has established rigorous standards for physical medicine and rehabilitation, including a specialized certification for spinal cord injury.

The CARF SCI specialty certification assures coordinated, case-managed, integrated services. According to CARF guidelines, "These key components of care include, but are not limited to, emergent care, acute hospitalization, other inpatient rehabilitation programs, skilled nursing care, home care, other outpatient medical rehabilitation programs, community-based services, residential services, vocational services, primary care, specialty consultants, and long-term care." The SCI specialty includes a strong education component for those injured and for their families. The rehab focus

includes interaction with others with similar injuries; life-long follow-up that takes into consideration activity, participation, and quality of life; as well as participation in research and its application in clinical medicine. *(See carf.org)*.

It is important to note that while a CARF designation for Spinal Cord Specialty sets a higher standard for quality care for people with new SCI, a rehab that has a basic CARF accreditation for **Comprehensive Integrated Inpatient Rehabilitation** must have the capacity and expertise to offer a 24-hour integrated, interdisciplinary acute rehab program, led by a trained rehab doctor. If the program admits a patient with spinal cord injury it must meet specific standards for SCI care. A certified IRF must offer or arrange care for bowel, bladder, cardiac, respiratory, spasticity, metabolic function, and musculoskeletal issues. The center must also offer expertise and counseling for peer support, nutrition, sexual health, substance abuse, driver training, environmental modification, vocational rehab, and assistive technology. CARF certified IRFs must also have staff, equipment and skills to address skin integrity and wound care issues.

Rehab units are also cited below for having a **Magnet Certification** from the American Nurses Credentialing Center; this recognizes a well-trained nursing staff in a low-turnover environment that focuses on nursing excellence and quality patient outcomes. *(see nursecredentialing.org)*

The Medicare system offers an Internet tool to help consumers choose an inpatient rehab; you can check it out at *medicare.gov/inpatientrehabilitationfacilitycompare (Note: there often isn't enough information provided for each center to enable a reasonable evaluation.)*

Before you choose an IRF, contact each one that seems to meet your needs. Ask about their SCI rehab facilities, staff, programs and specialties; talk to the doctor who treats SCI. Importantly, ask about patient volume – are you going to be the sole spinal cord patient in a ward of strokes and orthopedic injuries?

Inpatient rehab units are grouped by level of accreditation, starting with Model Systems SCI designation. Next are the units with CARF SCI specialization, followed by IRFs that are CARF accredited for Comprehensive Integrated Inpatient Rehabilitation;

The last group are not accredited other than by JC, but state publicly that they have staff and facility to provide services for spinal cord injury.

CALIFORNIA'S MODEL SYSTEM CENTER

Rancho Los Amigos National Rehabilitation Center, Downey, is one of only 14 federally designated Spinal Cord Injury Model System centers, and the only one in California. The hospital also is accredited by CARF for Comprehensive Integrated Inpatient Rehabilitation.

Rancho has taken care of people in need going back to 1888 when this big campus took care of indigents as the county poor farm. Rancho was a major polio

hospital through the 1950s. Now, as the rehabilitation arm of the Los Angeles County Department of Health Services system, Rancho is the largest IRF in the state and sees the most new spinal cord injury patients, at about 115 new traumatic cases a year. The outpatient program follows a huge number of patients, about 7,000. Rehab services are staffed by a team of physical medicine specialists, including orthotics and prosthetics, seating, rehab engineering, driver training, and lately, neural prosthetics. Average length of stay is about 26 days, compared to the national average of 19 days for acute rehab. Discharge to community is 79 percent, which is about average.

Rancho is home to KnowBarriers, a life-coaching and skill-building program to help clients develop the confidence and skills to move forward with their life goals; *knowbarriers.org*

Each year Rancho typically admits 10 or more severe injuries (C1-C4); these are patients who are more likely to require long-term post-rehab skilled nursing care. Rancho recently completed a $418 million renovation and campus beautification project, including a Wellness & Aquatic Therapy Center, new outpatient facilities, and improved seismic safety.

A recent clinical trial at Rancho, along with engineers from USC and Cal Tech, enabled a patient with a high cervical injury to bring a beer to his lips using only his mind to move a robotic arm. Rancho has also worked with USC for stem cell clinical research. Rancho supports a robust slate of programs in the arts, e.g. photography-as-therapy, and sports for its patients and alumni.

The campus is busy and it's growing, but there's still an old-school California charm to Rancho.
7601 Imperial Hwy,
Downey, CA 90242;
562-401-7111,
rancho.org

CARF SPINAL CORD INJURY SPECIALTY ACCREDITATION

Los Angeles County

California Rehabilitation Institute opened in 2016, on the West Side of Los Angeles. The rehab is CARF certified for Comprehensive Integrated Inpatient Rehab, and became accredited for spinal cord injury specialization for both adults and children in 2019. CRI has a CARF badge for stroke specialization.

CRI is a partnership between two prominent SoCal institutions, Cedars Sinai Medical Center and the University of California/Los Angeles, both of which support a major Level 1 Trauma Center. Select Medical is CRI's managing partner, and provides the 138-bed center with a reputation for quality and comprehensive care. Select manages several top-level rehabs, including Kessler Institute in New Jersey, a CARF spinal cord injury accredited and SCI Model Systems Center. Select also manages other large rehabs, including Baylor Institute for Rehabilitation, Cleveland Clinic Rehabilitation Hospital, and Emory Rehabilitation Hospital. Select handles about 400 new

traumatic SCI cases a year. All CRI rooms are private.
2070 Century Park East,
Los Angeles, CA 90067
424-5221-7111,
californiarehabinstitute.com

Orange County

St. Jude Medical Center, in Fullerton, is one of the most qualified SCI programs in California, and has been for a long time. St. Jude has a CARF spinal cord injury-specific certification for both inpatient and outpatient services and board certified spinal cord injury doctors on staff. The facility also has a nursing care Magnet certification.

This is the rehab designation for many spinal cord injured individuals in Orange County. The annual SCI patient volume is around 50 cases, including traumatic and non-traumatic injuries. Discharge to community is 78 percent. Length of stay, 14 days. Satisfaction from patients rated at 92 percent. Counseling, education and support are featured and emphasized across the full spectrum of trauma care and recovery.

A large outpatient center sits across town a few miles from the main hospital. St. Jude is also the home of Dr. Suzy Kim, a board certified SCI doctor and contributor to this book. The hospital is part of the 51 hospital Providence St. Joseph Health family, visit *stjudemedicalcenter.org*

San Diego County

Sharp Memorial Hospital, part of a system of four acute-care hospitals and three specialty hospitals, is located in San Diego; the rehab is CARF-accredited for the spinal cord specialty. This rehab also has a nursing care Magnet certification from the American Nurses Credentialing Center. The recently renovated rehab unit features private rooms (families allowed to stay overnight) and has a well-established outpatient medical program. Sharp features a comprehensive continuum of services with emphasis on patient and caregiver education, extensive support groups, recreation therapy, adapted sports teams for wheelchair rugby and lacrosse, continence clinic, adaptive driving program, environmental control lab for home adaptation, and a wheelchair seating clinic. SCI patient volume is about 100 new SCI patients a year, which includes both traumatic and non-traumatic injuries. The return to home percentage is well above average, at 95 percent.
2999 Health Center Dr.,
San Diego, CA 92123;
858-939-3400,
sharp.com

Note: *there are two large VA spinal cord units in the Southern California area, one in Long Beach and one in San Diego. Both are CARF accredited in the spinal cord injury specialization for both inpatient care and outpatient services. These rehab facilities are available only to U.S. service veterans. (See p.82 for more about eligibility for VA health care services.)*

CARF ACCREDITED FOR COMPREHENSIVE REHAB (CIIR)

Ballard Rehabilitation Hospital, San Bernardino, serves the four-million population Inland Empire. This 60-bed IRF opened in 1993; it is certified by CARF for Comprehensive Integrated Inpatient Rehabilitation for both adults, and for children and adolescents. Ballard also has CARF accreditation for stroke. Ballard sees about 30 new spinal cord injuries annually, which represents about 10 percent of all rehab admissions. The unit features transitional apartments with full bedroom, bathroom and kitchen so patients can practice self-care skills. Ballard is part of the Vibra Healthcare network, comprising IRFs, long term care and skilled nursing facilities in 18 states.
1760 West 16th St.,
San Bernardino, CA 92411;
909-473-1200, *ballardrehab.com*

Casa Colina Hospital began in 1938 in Chino, 40 miles west of LA, as a treatment center for children with polio. The hospital moved to nearby Pomona in 1961 – opening 68 beds right about the time acute polio was no longer a problem. Casa shifted its focus to traumatic injury. Casa Colina is a large, very attractive and architecturally integrated campus on 20 acres, with private and semi-private rooms in the acute rehab unit, and a new 31-bed med/surg unit. Casa Colina is accredited for Comprehensive Integrated Inpatient Rehabilitation. The center also has a CARF-accredited 42-bed transitional living center where residential clients develop and refine daily living skills. Other specialty areas include a full-service seating program with pressure mapping technology, to assure fit, comfort and mobility. A state-of-the-art exoskeleton program is available to qualified patients. Ventilator weaning is available for select patients. Casa has a well-developed outpatient medical program, and is well known for its recreation and sports department. Affordable short-term housing is available for families. Casa sees around 150 new SCI cases a year, which includes traumatic and non-traumatic SCI. Inpatients report 100 percent satisfaction with their experience here. In recent years Casa Colina has participated with UCLA and Cal Tech to test brain implants for neural control of computers.
255 East Bonita Ave.,
Pomona, CA 91767;
909-596-7733, *casacolina.org*

Cottage Rehabilitation Hospital used to be called Santa Barbara Rehabilitation Institute before joining the Cottage group in 2007. The 38-bed facility has a history dating to 1955 treating stroke, brain injury, complex orthopedics, and spinal cord injury. Though not currently accredited in SCI, Cottage had that specialty CARF designation until a few years ago (it maintains CARF accreditation in Comprehensive Integrated Inpatient Rehabilitation, and for stroke and brain injury, including pediatric). Most patients here are from the northern reaches of Southern California; the patient volume is

about 100 new SCI cases (includes both traumatic and non-traumatic SCI) annually, which fills 18 percent of the beds. Stroke and orthopedic rehab represent more than half of all patients. Over 80 percent of patients here are over 51. Local residents with SCI are cared for at the Keck Center for Outpatient Services. Specialty services include an assistive technology center, wheelchair seating and positioning, driver training, aquatic wellness and fitness center, a wide range of recreation options, and caregiver services; the Coast Caregiver Resource Center *(See p.134)* is part of Cottage. The hospital owns an exoskeleton, available for qualified patients. Discharge to home is about 83 percent; 9.7 percent go to skilled nursing facilities. Cottage preserves a warm, friendly Santa Barbara vibe.
2415 De La Vina St.,
Santa Barbara, CA 93105;
805-569-8999, *visit cottagehealth.org*

Loma Linda University Medical Center began in 1905 when Seventh-day Adventists bought land in San Bernardino County and built a medical missionary school. This became a medical college and over the next century a sprawling medical and teaching complex that includes the only Level 1 Regional Trauma Center for the Inland Empire counties of Inyo, Mono, Riverside, and San Bernardino. The Loma Linda rehab unit has a CARF credential for Comprehensive Integrated Inpatient Rehabilitation, including pediatric rehab. The unit also has a CARF credential for stroke care. The center's East Campus opened a new 24-bed rehabilitation hospital in 2010; they describe it as "an evidence-based healing environment including its connection to nature, access to social support, variety of options, elimination of environmental stressors, and positive distractions." The patient rooms in the Tom & Vi Zapara Rehabilitation Pavilion are private, very resort-like, featuring patios, healing gardens, and an event park for concerts. Loma Linda sees about 115 new SCI patients a year, about half of those from traumatic injury. SCI patients fill about 10 percent of rehab beds. Outpatient services are robust. Strong peer-support and community recreation access via the Loma Linda PossAbilities program, which also features grants, scholarships, discounted dental and prescription programs, and Paralympic training. Discharge to home percentage is 78.1 percent, which is about average.
25333 Barton Road,
Loma Linda, CA 92354;
909-558-4484, *see east-campus.lomalindahealth.org*

Long Beach Memorial is part of the MemorialCare Health System, which includes Miller Children's & Women's Hospital *(See p.104)*. The rehab unit has a CARF accreditation for Comprehensive Integrated Inpatient Rehabilitation. The facility also has a Magnet certification from the American Nurses Credentialing Center. This rehab unit is not a campus, nor does it resemble a resort; LBM's SCI unit is a wing

of a big busy community hospital complex, with a large group of physical medicine specialists and the usual rehab therapists (PT, OT, etc.). Volume is around 65 new SCI cases a year, many non-traumatic. Length of stay is 14.5 days, compared to the regional average of about 18. Discharge to home rate is 80 percent.
2801 Atlantic Avenue,
Long Beach, CA 90806,
562-933-2000; *memorialcare.org/long-beach-memorial*

Northridge Hospital Center for Rehabilitation Medicine opened in 1974 as a program of the Dignity Health Network (39 hospitals in Arizona, California, and Nevada); the main hospital includes a Level II Trauma Center. The hospital has a CARF accreditation for Comprehensive Integrated Inpatient Rehabilitation. The inpatient rehab (about 18 percent SCI, vs. 40 percent stroke) includes SCI medical specialists (there is a board-certified SCI physician here) who care for about 25 new traumatic SCI patients a year. There is also a large outpatient program. Services include driver training, wheelchair sports, and therapeutic recreation. Average age of patients is 62 but 16 percent of patients are under the age of 44. Northridge has an active peer support group. This is the only facility in the Valley to offer the ReWalk exoskeleton, helpful for some patients to ambulate again. Discharge to home is about 75 percent.
18300 Roscoe Blvd,
Northridge, CA 91328;
818-885-8500,
dignityhealth.org/northridgehospital

Scripps Memorial Hospital, Encinitas, has CARF accreditation for CIIR, also for stroke and brain injury. Magnet certified. This full service not-for-profit rehab unit is a good acute rehab option for North County residents. About 12 percent of the hospital's operating expenses are devoted to community benefit services. Monthly SCI support group open to the community.
354 Santa Fe Dr.,
Encinitas, CA 92024;
760-633-6501, *scripps.org*

OTHER CIIR REHAB UNITS

Emanate Health (formerly Citrus Valley Centers for Rehabilitation), West Covina, CARF accredited for Comprehensive Integrated Inpatient Rehabilitation (CIIR), and for stroke;
1115 So. Sunset Ave.,
West Covina, CA 91790;
626-962-4011, *cvhp.org*

Eisenhower Medical Center, Rancho Mirage, is CARF accredited for CIIR, also has Magnet certification.
39000 Bob Hope Dr.,
Rancho Mirage, CA 92270;
760-340-3911, *emc.org*

Mission Hospital, Mission Viejo, has CARF accreditation for CIIR, and also for pediatric rehab and brain injury for adults and children. Has a Magnet certification.
27700 Medical Center Road,
Mission Viejo, CA 92691;
949-364-1400, *mission4health.com*

CHOOSING A REHAB

Palomar Health Rehabilitation Institute, has accreditation for CIIR, also pediatric rehab.
555 East Valley Parkway,
Escondido, CA 92025;
760-739-3000, *palomarhealth.org*

Providence Holy Cross Medical Center, Mission Hills, has CARF accreditation for CIIR and also for pediatric rehab, and for stroke. Also Magnet certification.
15031 Rinaldi St.,
Mission Hills, CA 91345;
818-365-8051,
california.providence.org/holycross

Providence Little Company of Mary Medical Center, San Pedro has CARF accreditation for CIIR, and also for stroke; Magnet certification.
1300 West Seventh St.,
San Pedro, CA 90732;
310-832-3311,
california.providence.org/san-pedro

Providence St. Joseph Medical Center, Burbank, CARF accreditation for CIIR, and stroke.
501 South Buena Vista St.,
Burbank, CA 91505;
818-843-5111,
california.providence.org/saint-joseph

South Bay Rehabilitation Center at Paradise Valley Hospital, National City, has CARF accreditation for CIIR, also for stroke;
2400 East Fourth St.,
National City, CA 91950;
619-229-3249,
paradisevalleyhospital.net

Encompass Health Rehabilitation Hospital of Tustin. Formerly HealthSouth. Home base for SCI specialist Dr. Ann Vasile.
14851 Yorba St.,
Tustin, CA 92780;
714-832-9200,
encompasshealth.com search 'Tustin'

JC ACCREDITATION ONLY

Alhambra Hospital,
100 South Raymond Avenue,
Alhambra, CA 91801;
626-570-1606,
alhambrahospital.com

Arroyo Grande Hospital,
345 South Halcyon Road,
Arroyo Grande, CA 93420;
805-489-4261, *dignityhealth.org*

Bakersfield Rehabilitation Hospital/HealthSouth,
5001 Commerce Dr.,
Bakersfield, CA 93309;
661-323-5000,
healthsouthbakersfield.com

Centinela Hospital,
555 E. Hardy St.,
Inglewood, CA 90301;
310-673-4660, *centinelamed.com*

Desert Regional Medical Center,
1150 N. Indian Canyon Dr.,
Palm Springs, CA 92262;
760-323-6511, *desertregional.com*

Garfield Medical Center,
525 N. Garfield Ave.,
Monterey Park, CA 91754;
626-307-2130;
garfieldmedicalcenter.com

CHOOSING A REHAB

Glendale Adventist Medical Center,
1509 Wilson Terrace,
Glendale, CA 91206;
818-409-8000,
adventisthealth.org/glendale

Glendale Memorial,
1420 So. Central Ave.,
Glendale, CA 91204;
818-502-1900,
dignityhealth.org/glendalememorial

Henry Mayo Newhall Hospital,
Acute Rehabilitation Unit,
25727 McBean Parkway,
Valencia, CA 91355;
661-253-8992, *henrymayo.com*

Hollywood Presbyterian,
1300 N. Vermont Ave.,
Los Angeles, CA 90027;
213-413-3000,
hollywoodpresbyterian.com

Huntington Memorial Hospital,
Pasadena, Magnet certification,
100 West California Blvd.,
Pasadena, CA 91105;
626-397-5000,
huntingtonhospital.com

Methodist Hospital of Southern California,
300 W Huntington Dr.,
Arcadia, CA 91007;
626-898-8000,
methodisthospital.org

Presbyterian Intercommunity,
12401 Washington Blvd.,
Whittier, CA 90602;
562-698-0811, *pihhealth.org*

San Diego Rehabilitation Institute/Alvarado Hospital,
6655 Alvarado Rd.,
San Diego, CA 92120;
619-287-3270,
alvaradohospital.com

St. John's Regional Medical Center,
1600 North Rose Ave.,
Oxnard, CA 93030;
805-988-2500, *visit dignityhealth.org/stjohnsregional*

St. Vincent Medical Center,
2131 West Third St.,
Los Angeles, CA 90057;
213-484-7111, *stvincent.verity.org*

Tri-City Medical Center,
4002 Vista Way,
Oceanside, CA 92056;
760-614-2673, *tricitymed.org*

UC Irvine Health,
has a Magnet certification,
101 The City Drive South,
Orange, CA 92868;
714-456-7890, *ucirvinehealth.org*

UC San Diego Medical Center,
has a Magnet certification,
200 West Arbor Dr.,
San Diego, CA 92103;
858-657-7000, *health.ucsd.edu*

University of Southern California/Keck Medicine,
1500 San Pablo St.,
Los Angeles, CA 90033;
323-442-8789, *keckmedicine.org*

Valley Presbyterian Hospital,
15107 Vanowen St.,
Van Nuys, CA 91405;
818-782-6600, *valleypres.org*

NOT IN SOCAL BUT A TOP TIER CALIFORNIA SCI REHAB CENTER

Santa Clara Valley Medical Center in San Jose, the largest SCI rehab center in Northern California, reports a patient volume of about 85 acute traumatic spinal cord injuries annually. SCVMC is a Level I Trauma Center; the hospital features an ICU-type Rehabilitation Trauma Center, where patients receive early and aggressive care. For many years Valley Med was a Model Systems SCI Center; it is now CARF accredited in spinal cord injury specialization for both adults and adolescents, and for both inpatient and outpatient services. SCVMC is also CARF accredited for Comprehensive Integrated Inpatient Rehabilitation, as well as for stroke and brain injury. The hospital website claims more SCI-board certified physicians than any other rehab center on the West Coast. The rehab's Women with Disabilities Health Care Clinic addresses the unique needs of women with SCI. SCVMC has a strong peer support/alumni network.
751 S. Bascom Ave.,
San Jose, CA 95128;
408-885-5000, *scvmcrehab.org*

NOT IN CA BUT AS GOOD AS SCI REHABILITATION GETS

Craig Hospital is everything you could ask for a in specialized spinal cord and brain injury hospital. Craig is a 93-bed, high-volume facility located in the Denver suburb of Englewood. This is by most measures the premier rehab facility in the country for spinal cord or brain injury – for many reasons: narrow focus on neurotrauma; very high medical staff specialization with very little turnover; willingness to take the most difficult cases; strong focus on family support, including free housing for out of town families; top-tier outpatient services; dedication to patient education; top-notch rehabilitation research department.

Craig admits about 500 new trauma cases a year; there are about 55 inpatients at any given time with spinal cord injuries, and 30 with traumatic brain injuries, plus 50 or 60 outpatients. About 1,400 outpatients visit the hospital each year. Discharge to home percentage is 91, well above the national average. The PEAK (Performance, Exercise, Attitude and Knowledge) Center is Craig's large community fitness/wellness center, also part of the Reeve Foundation NeuroRecovery Network. Half of Craig patients come from out of state. A number of California patients with acute SCI travel to Craig every year; it's a two-hour plane trip from most airports in the Southland. There is a culture of hope and possibility at Craig.
3425 S. Clarkson St.,
Englewood, CO 80113
craighospital.org

FREE CRAIG NURSING ADVICE LINE

A service for any and all patients, family members or health care providers who need expert advice for non-emergency medical issues related to spinal cord injury; call 800-247-0257, or 303-789-8508.

INSURANCE AND REHAB CHOICE

It would seem that the SCI consumer has lots of choices when it comes to inpatient rehab, but do you really get to pick the one you like? If money were no object, the answer would certainly be yes. But money happens to be a pretty big object in the world of acute SCI.

Spinal cord injury is rare, but it is expensive. Only about 1200 new injuries a year occur in the SoCal region but this will cost patients, their families and the health care system plenty – billions of dollars, year after year. First year costs for a cervical injury, for example, can easily break a million dollars, and could run five or ten times that over the lifespan. The point is, your choice of rehab setting has to begin with how it will be paid for, which of course brings us to the topic of health care insurance.

If you have private insurance, or coverage through the Affordable Care Act, contact your insurance company as soon as possible to see what is covered. Catastrophic injury insurance comes with many variations of coverage and deductibles, and perhaps caps on payments. If possible, get hold of your policy documents and be prepared to read the fine print. Spinal cord injury, it won't take long to discover, is very complicated, and ridiculously expensive.

Do you have an insurance policy? Keep reading. Don't have insurance? Skip to the No Insurance section, p.81. You're going to get treatment and care but you will most likely face more limitations on choice.

There are many varieties of health insurance. Private insurance includes policies you get at work, which might be partly funded by your employer, your union or other organization. Many individuals or families are covered by private plans – usually set up as networks of clinics and hospitals. These include Preferred Provider Organizations (PPO), or Health Maintenance Organizational (HMO), or something called an Exclusive Provider Organization (EPO).

As you know if you have shopped recently for insurance, there are countless ways coverage works, with a wide range of monthly pre-

mium fees, deductibles that come out of your pocket, and limits to what the insurance company will cover. (A deductible is the amount you may have to pay medical care providers before receiving any benefits from the health policy. You may also be asked to pay coinsurance, a percentage of the total amount billed.)

California. It's a huge program, expanded all the more by ACA legislation. One third of the state's population is covered by Medi-Cal, at a cost of $17 billion to the taxpayers. There are income and residency requirements. Note: you don't have to be a U.S. citizen or have a green card to get Medi-Cal emergency services or long-term

"As you'd expect, the least expensive health insurance includes the most restriction on choice of providers and the most out of pocket costs for consumers."

As you'd expect, the least expensive health insurance includes the most restriction on choice of providers and the most out of pocket costs for the consumer. For consumers shopping in the Covered California insurance marketplace, under the Affordable Care Act aka Obamacare, there are four tiers of coverage: bronze, silver, gold and platinum. They offer the same essential health benefits but vary in premiums and out-of-pocket costs: bronze plans have the lowest premiums but highest out-of-pocket costs, while platinum plans cost more per month but offer more.

For those who qualify, there's Medicare – generally you have to be over 65 for this to kick in but if you're under 65 and have a disability, you are automatically enrolled in Part A and Part B after you have received Social Security benefits for 24 months.

Medicaid, the federal/state health insurance assistance program, is called Medi-Cal here in

care. In 2016 Medi-Cal expanded coverage to about 170,000 undocumented immigrant children under age 19.

Those who get both Medi-Cal and Medicare are called dual-eligibles, or Medi-Medis. As of 2014, a program called Cal MediConnect bundles all medical, behavioral health, long-term institutional, and home- and community-based services into a single health plan. *See calduals.org*

U.S. service veterans may have VA coverage. It's important to know if you qualify – the VA has highly skilled rehab care for spinal cord injury in both San Diego and Long Beach. *(See p.82.)*

Workers Compensation policies kick in when you are hurt on the job. Workers comp insurance was designed as a sort of bargain between employer and worker: employees give up potential lawsuits for pain and suffering in exchange for the employer agreeing to cover medical bills, loss of wages related to the accident,

and compensation for permanent physical impairments. Your employer should be contacted immediately if you have a work-related injury. There are specific claim forms, as well as timelines and rules. Know what your rights are. Know also you may have to be assertive.

In California, workers comp medical care has become much more aligned with managed care networks. This may not matter much in the early, acute stage of a spinal cord injury but it could become an issue if disputes arise regarding coverage or provider choice. Patients have certain rights to seek specialized care out of network. California's workers' comp system uses an independent medical review process to resolve disputes about medical treatment.

Because SCI is so complex, some workers comp cases are managed by third parties. Paradigm Outcomes, for example, sets a high bar for getting injured workers top-tier rehabilitation, care and equipment – the company guarantees a better outcome for the injured worker, believing that investing in specialized medical attention up front provides for a greater quality of life and is less expensive over time. Travelers Insurance, the largest private workers comp insurer, manages more than 250,000 workers compensation claims a year. In some cases the company offers a nurse concierge service to facilitate access to care and to guide injured workers through the rehab process; the company says this reduces costs, and anxiety.

It would be a wonderful thing for the spinal cord injury world if all patients got the high level service and concern for outcome across the lifespan that some injured workers get. But in the consumer SCI insurance world, your case is on a clock; when the time runs out, when the reimbursement maximums have been met, you are no longer the company's worry.

NO INSURANCE?

It's not the end of the world. It means you will be enrolled in Medi-Cal as soon as possible. In the greater Los Angeles area, no insurance often means you're headed for the LA County system and Rancho Los Amigos Hospital in Downey. That's a busy place, but a top tier rehab in SoCal, and nationally. In San Diego, uninsured SCI patients are often referred to the University of California/San Diego. That facility contracts with Sharp Rehab for acute rehab, another top tier rehab and a very good choice.

Some private rehabs will accept uninsured spinal cord injured patients as "Medi-Cal pending." They'll admit you to the hospital, cover your 30 days or so of rehab, uninsured, with the expectation the state will step in with reimbursement. This is something that has to be carefully worked out with medical staff and case managers at the rehab; don't be afraid to ask about this option.

In the bottom-line-driven managed care world, it is possible that no insurance is better than having lousy insurance. A Medi-Cal pending arrangement may offer more choice of rehab facility

than what might be reimbursed by your bronze level HMO. Say your HMO has a contract with a specific rehab unit after you leave the trauma hospital. You don't choose, they do. (Patients have the right to appeal an HMO designation, see below.) A person with no insurance, however, can approach any rehab; there's no certainty a particular facility will accept you as a Medi-Cal pending, they are not required to, but many hospitals will.

READ THE POLICY

Policies have language regarding catastrophic claims, and it's a safe bet most of us do not buy insurance based on the quality of this coverage. Like most insurance consumers, you probably have no idea what is covered if something major happens.

So, the first thing you must do is contact your insurance company's customer service office. Major insurers usually have their own case managers who will be assigned to your case while you are in the trauma hospital. Find out who this person is and how to be in contact. Always document or record all discussions with your insurance company, including the date, reason for the call, who you spoke with and what was said.

Get a copy of your policy documents (if you can't remember what drawer you stuck them in, ask the company to provide you with the full policy). Someone on the patient's side must dig in and read the fine print. Ask the trauma hospital to assign you a case manager.

The insurance policy will spell out rehabilitation benefits. Your options should be clearer once coverage is figured out. Decisions then have to be made. Insurance companies like patients who remain passive and go along with them. You don't have to. Be prepared to fight for your rights.

The VA and the Department of Defense (DoD) have an agreement directing all active duty new injury SCI patients to the VA SCI Unit closest to them, or closest to where they plan to live after discharge. Such referral is supposed to occur within three days of the injury onset, though it doesn't always work that fast and many DoD case managers don't know about the agreement.

ARE YOU A VET?

Are you a veteran and are you eligible for VA health care benefits? This is essential to know because the VA has two major SCI rehab units in SoCal, one in Long Beach, the other in San Diego. They are fully accredited as comprehensive specialty care units and are a great option – if you are a vet.

VA SCI Centers run an acute med-surg unit for vets with SCI, but also feature CARF accredited beds for both acute rehab and outpatient services, too.

To find out if you are eligible for VA services, call 1-877-222-VETS (8387) Monday - Friday between 5 a.m. and 5 p.m. Pacific time. Also, you can apply online at *1010ez.med.VA.gov*. Eligibility can be complex but most often if you have a copy of your

discharge papers (DD-214) the VA centers can establish eligibility within two working days.

Another invaluable resource for vets is the Paralyzed Veterans of America, a national service organization that has a large staff of benefits counselors. *See pva.org*

THE APPEAL PROCESS

Let's say the therapists and medical team at the trauma hospital say you are ready to discharge and move on to rehab. And let us also assume that your insurance company has figured it all out for you. They've looked at your case and your diagnosis, cross referenced that with your coverage package, and then with a list of acute rehab hospitals they do business with. They say, OK, here's where you're headed, for this many days.

But what if this rehab hospital is not on your list. It lacks the features and programs that you want. Is there anything you can do?

Yes. Insurance companies often deny coverage. Know this: You have a guaranteed right to question any decision made by your insurance plan. Yes, this is a stressful time, first dealing with a life-changing trauma situation, now adding the stress of pushing back against the insurance company. This may seem to be too much to take on. But these decisions are too important to watch them fly by from the sidelines.

Patients who are just days post-trauma alone cannot be prepared for any sort of negotiation with their insurance coverage. It's up to family, or friends, or even an outside advocate, to jump in and take on the insurance company. This may start with a discussion, may evolve into a negotiation, and could escalate to the realm of threat (with lawyers, or a newspaper reporter), or perhaps onward to all-out litigation.

You have to think of an appeal in simple terms: Your insurance company is not your friend, and not your enemy. It is simply a company you have a contract with. As our friends at the Patient Advocate Foundation *(See p.86)* like to say, an appeal is a contract dispute over the interpretation of your plan and its coverage.

The process of appealing an insurance company decision starts with some dialog between you, or your designated advocate, and a case manager from the company. Ask the case manager specifically for the coverage you want. You may not succeed in an appeal with a phone call. You'll likely need to file a more formal appeal, in writing. Filing a complaint is a clearly defined right; the insurance company is required to tell you how to do this.

Try to understand the language in your plan – most have sections called Covered Benefits, and Non-Covered Benefits and Exclusions. Be aware also of some basic rights you have in California, especially for managed care plans. For example, you have the right to a second opinion, and the right to see a specialist when you need one.

If your insurance coverage is employer-based, your employer may intervene on your behalf

and try to direct what the plan approves.

Can you get the rehab hospital of your choice to help you? Since you are not a patient there, that hospital has no standing with you; they can assess you, and can indicate their willingness to admit you, and perhaps be ready to negotiate a single case agreement if they don't have an existing contract with your insurance plan. This is not uncommon but it won't happen unless there is pressure from the patient side.

The strongest appeal usually includes support from your medical provider. If your doctor is on board, you can get a letter explaining the reason the treatment (or rehab facility) in question was requested and why your side thinks it's necessary. Unfortunately, it can be difficult in a busy trauma hospital to establish rapport with a physician. The short-term trauma setting does not lend itself to forming relationships with providers. Still, the key to appealing rehab assignment is establishing medical necessity. You must make a case that the treatment (rehab care) offered by your plan is below the standard of care, or "best practice," of the rehabilitation field.

How are you, a lay person with limited exposure to trauma care or physical medicine, supposed to know what the standard of care is for an inpatient rehab hospital? You are not an expert. But you can state the case that spinal cord injury is a complex medical condition that must be treated by the highest level of expertise. Explain that you don't think the necessary level of expertise is available at the hospital the insurance company has designated for you; the specialized services and expertise you have identified at your choice of rehab are not found at the one your plan has submitted. Use the narrative on p.60-69 to establish what is generally considered the standard of care for treating spinal cord injury – especially categories for patient volume and accreditation.

Ask the insurance company to reconsider, and to cover treatment at the facility you have indicated. Your plan manager may say, "no, your choice is out of network, this other place is where we pay for rehab." If you are denied coverage this way, your insurer must provide to you in writing the specific reason your coverage request was denied, including what you need to do to appeal. You have the right to the see the full version of the plan's medical policy that was used to make the denial decision.

If you are not satisfied with your plan's response, you can request an external review. An independent third party looks at the health plan's decision, and will either uphold the insurance company or decide in your favor. Your insurance company is required to participate in any external review process. In California, members of HMO plans can file for a review with the Department of Managed Health Care.

A big issue in acute trauma care, of course, is timing. You need a decision made before the trauma hospital is ready to discharge. So

don't wait. You or your advocate can request an expedited appeal by calling the insurer directly; the insurer then must make a decision within one to three business days. As always, keep track of all correspondence and record all contacts with the insurance plan.

You may have options even when the plan denies your appeal. It takes a great amount energy and resources, but if you're committed and engaged, you can hire an attorney to escalate the contract battle with the insurance company. Most rehab referral cases don't require the patient side to lawyer-up, but tenacity does pay off in dealing with insurance issues. If you're not getting the care you need, keep fighting.

Some very motivated patients and their families have been known to contact Congressional representatives for help, or local news media to attract attention to their situation and to their need for the specialized care that is being denied; insurance companies avoid this kind of publicity, so this can sometimes work to your advantage during negotiations.

BAD FAITH INSURANCE CLAIMS

California insurance companies owe a duty of good faith and fair dealings to those they insure. It is not unusual for insurance companies to deny coverage, in fact, they do it all the time. So it is important that you know that you have a guaranteed right to question any decision made by your insurance provider.

The idea of going up against your insurance company may seem daunting, especially when you are dealing with the aftermath of a traumatic injury. But the decisions you make now are important, and it is imperative for you to make sure the insurance company is acting in good faith, fulfilling its legal and contractual obligations, and not violating the basic standards of honesty.

If you believe you have been treated unfairly by your insurance company, you should contact an experienced bad faith attorney to help guide you through the process and advise you of your legal rights.

You may be entitled to bad faith damages, punitive damages, and potentially attorney's fees as well.

TIPS ON APPEALING INSURANCE DENIALS

Sometimes it is necessary to challenge a decision made by your insurance carrier, usually because the company has denied a service or treatment. ***Bernadette Mauro****, Director, Information and Resource Services for the Christopher & Dana Reeve Foundation Paralysis Resource Center, has a few tips for families making a appeal for an injured loved one.*

1. Ask your insurance company to assign you a catastrophic case manager and stay in touch with this person throughout your discussions. Keep track of what is said.
2. Make the injured person real. Send pictures of your friend or loved one to the case manager, before the injury and in the ICU. Tell his or her story. Be

sure and include future goals and aspirations.

3. If your insurance coverage is from the company you work for, ask the human resources department to help. They may have some leverage to negotiate to your advantage.
4. Stand firm but don't yell at the insurance company. Be nice. Treat your contacts with respect.
5. Make as strong a case as you can that the service or treatment you want is medically necessary, and get your physician to back you up.
6. If you're trying to get coverage for inpatient rehabilitation, for example, make the case that your choice has more expertise and is better prepared to put your loved one back on track, with fewer complications, at a lower potential cost over the long run.

SOME KEY APPEALS RESOURCES

Patient Advocacy Foundation is a national non-profit that provides professional case management and mediation services to Americans with chronic, life threatening and debilitating illnesses. PAF case managers, assisted by doctors and healthcare attorneys, serve as liaisons between the patient and insurer. *See patientadvocate.org*

Covered California Issues? Assistance is available if you have concerns about your health insurance plan. Contact the Health Consumer Alliance, which can help you work with your health insurance company, the Department of Managed Health Care and the Department of Insurance; 888-804-3536 or *healthconsumer.org*

Managed Care Appeal: The state Department of Managed Health Care offers Independent Medical Review when health care service or treatment has been denied, modified or delayed. Independent doctors not part of your health plan will review your case. Says the DMHC: "You have a good chance of receiving the service or treatment you need by requesting an IMR." They say 60 percent of appeals tilt toward the consumer, not the insurance plan. *See dmhc.ca.gov* or call 1-888-466-2219.

Medi-Cal Managed Care Office of the Ombudsman: This office helps solve problems from a neutral standpoint to ensure that Medi-Cal members receive all medically necessary covered services for which plans are contractually responsible. By phone: 888-452-8609

Medicare Appeal: If you disagree with an initial decision from your Medicare coverage, you can ask for a reconsideration; you must do so within 60 days of the date of the first denial. There are five levels of appeal, including an independent review, a hearing before an Administrative Law Judge, an appeal to the Medicare Appeals Council, or you can take the case to federal court. If you believe you are being discharged from a hospital too soon, you have the right to

immediate review by Medicare's Beneficiary and Family Centered Care Quality Improvement Organization (BFCC-QIO). The hospital can't force you to leave before the BFCC-QIO reaches a decision. *medicare.gov/Contacts*

SOCIAL SECURITY BASICS

There are two main Social Security programs that support people living with disabilities: Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI). It's a good idea to apply for both SSDI and SSI as soon as possible after becoming injured. Don't wait; it may take over a year to get a decision.

Social Security Disability Insurance is based on one's inability to work. This is the safety net for those who cannot be helped by the reasonable accommodations in the ADA. You are considered to be disabled if you cannot do work that you did before your injury, and if it is decided you cannot adjust to other work because of your condition.

Expect to be denied. A high percentage of initial SSDI claims are rejected. But don't give up. There are three levels of appeal; there are lawyers that specialize in SS claims *(e.g., see the referral service at nosscr.org)*. To win a claim, you must provide medical evidence of a disabling condition that is expected to last at least 12 months. This evidence needs to come from your doctor.

Besides the rules on disability, you must have worked long enough, and recently enough, to qualify for benefits – at least 5 of the 10 years immediately before the disability.

If you are under 65 and approved to receive disability benefits from Social Security, you are automatically eligible for Medicare after 24 months.

Supplemental Security Income is a program that provides monthly payments to people who have limited income and resources. SSI benefits are not based on your work history. To qualify for SSI, you must be able to show you are pretty much broke. Says the SS office: "The value of the things you own must be less than $2,000 if you're single or less than $3,000 for married couples living together. We don't count the value of your home if you live in it, and, usually, we don't count the value of your car."

Attention married couples: you don't have to divorce. There are some ways to legally protect assets, setting up trusts. You will need an attorney.

California adds funds to the federal SSI amount; also, SSI recipients in California automatically get Medi-Cal coverage for doctor visits, hospitalization, medications, etc.

Social Security is complex; you may need expert navigation. Many rehabs have knowledgeable staff. Independent living centers can also help.

Social Security: *ssa.gov/disability*, contact the Social Security office nearest you, or call 1-800-772-1213

POST-ACUTE CARE

People with traumatic injuries may no longer need the intensive services of an acute hospital but may not yet be strong enough to move on to rehab. In that case, there are options for post-acute care, including nursing homes, and long-term acute care (LTAC) hospitals. Is this a good choice? Ask this question: does care need to be directed by a physician? If so, that points toward long-term care. If a doctor is not needed on a daily basis, it may mean transfer to a skilled nursing facility (SNF).

Generally speaking, it's a good idea to avoid nursing homes. SNFs offer little or no therapy or rehab, and minimal physician contact. Of course skilled nursing is a necessary step for many patients – you may be trying to wean from a ventilator, or perhaps you have been deemed "medically complex," needing to get healthier before you can move on to rehab, and then to home.

There are hundreds of nursing homes in the SoCal area, some of them full of long-term care patients (the old folks home model). Your doctor or social worker/case manager should be able to make a recommendation. There are all sorts of factors to weigh. Is the facility nearby, and is it safe? Does it smell OK? Is the food good? Can your pet visit you? Do you have to adhere to a strict schedule for meals? Be sure and have someone visit facilities that seem right.

The Medicare website features a comparison tool that lists every nursing home in the U.S. The homes are graded on overall rating, health inspections, staffing and quality measures. For example, a search of Los Angeles turns up 324 nursing homes within 25 miles of the city; you can, for example, filter out only the facilities that have a "much above average" rating (there are 74 such units). *See medicare.gov/nursinghomecompare*

If more doctor-directed care is required, there are a number of LTAC facilities in SoCal. These subacute units are also called a transitional care units. Most patients in long-term care stay for about four weeks.

CARF offers certification for skilled nursing and LTAC; none are

listed in either category in California.

Remember, the goal is to move toward the best possible inpatient rehabilitation facility (IRF). Skilled nursing facilities sometimes make the case that they provide adequate, equivalent rehab care. Not always so. IRFs are required to have significantly higher staffing levels and provide much more direct care to patients than SNFs do.

Here are some options to consider for post-acute care in the greater Southern California area:

Centre for Neuro Skills (CNS) specializes in intensive traumatic brain injury rehabilitation; because those with spinal cord injuries often have a brain injury too, CNS also offers post-acute care for SCI. With facilities in Bakersfield, Los Angeles, San Francisco, and Dallas, CNS offers patient-centered, real-world-based rehab services aimed toward measurable treatment goals. CNS believes that given the right therapy at the right time by experienced professionals, clients can regain a "normal rhythm of living" and steadily work towards successful community re-entry. CNS is CARF accredited for Interdisciplinary Outpatient Medical Rehabilitation with a brain injury specialty, and for Residential Rehabilitation. *neuroskills.com*

Casa Colina Transitional Living Center is a 42-bed, CARF-accredited, short-term residential treatment facility that offers a bridge between acute rehabilitation care and home. Residents benefit from up to six hours of individual and group therapy, six days a week, from a team of rehabilitation specialists that includes physical and occupational therapists, speech pathologists, and neuropsychologists, all overseen by doctors specializing in physical medicine. Services include residential, day treatment, plus home and community rehabilitation care. Daily programming includes community outings that provide opportunities to practice skills in real-world settings to prepare for challenges clients may face at home, in the community, or at the workplace. 909-596-7733, ext. 4100; *casacolina.org*

CareMeridian is a large multistate provider of post-acute rehabilitation services for people with brain and spinal cord injuries. The services are delivered in community-based settings; participants receive structured support integrated with work and community participation. In Southern California, CareMeridian operates what they call sub-acute neurorehab units in Artesia, Chatsworth, Cowan Heights, Escondido, Garden Grove, LaHabra Heights, La Mesa, Northridge, Oxnard, Santa Ana, Santa Barbara, Woodland Hills.\CareMeridian offers family counseling and training for the family to make the transition to home as smooth as possible. *See caremeridian.com*

Kindred Hospitals, a national chain of rehabs, provides specialized care to medically complex

patients who require longer recovery time. The company operates long-term acute facilities in Baldwin Park, Brea, La Mirada, Los Angeles, Ontario, Rancho Cucamonga, Perris, San Diego, West Covina, Santa Ana, Gardena, Westminster. *kindredhealthcare.com*

Promise Hospitals is a national group of long term care facilities, including units in East LA and San Diego. *promisehealthcare.com*

Rehab Without Walls is a sort of customized home delivery rehab model. The goal, says the company, "is to provide care in a comfortable, familiar environment, to help patients experience better outcomes." Treatment plans, which may include up to six hours of therapy a day, are based on a physician's orders, and address specific patient goals.

Rehab Without Walls, accredited by CARF for Home and Community Services, works closely with insurance payers; they have been able to apply outpatient, home health, SNF, and inpatient benefits, as well as workers compensation. RWW operates in 12 states, including three divisions in California. The SoCal office covers Los Angeles, Orange, Riverside, San Diego and portions of San Bernardino and Ventura counties. *rehabwithoutwalls.com*

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ABOUT US

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9667 Reseda Blvd. Northridge, California 91324

LIFELONG REHAB: ACTIVITY AND EXERCISE

Exercise is the gateway to health and well-being. True fact, and this goes for everybody. For people with any sort of mobility limitation, it is even more essential to work the heart, stretch the joints and move the body. Activity may lead to recovery for some; vitality and quality of life are assured for all. You can often use any public facility if you're really motivated. But here are some SoCal fitness centers that tailor their programs for the wheelchair community. Note: insurance reimbursement is possible but pretty rare. Most likely you're on your own. A medical release may be required.

Challenge Center, La Mesa Challenge Center in La Mesa, near San Diego, opened in 1988, the first community based, disability-friendly gym, the first non-institutional facility promoting accessible exercise. "If there is a cure-all beneficial to most every condition that a person can suffer," said founder Bill Bodry, a paraplegic, "exercise is it." He wasn't sure what he ought to do to get fit, and of course he could not find a facility that would accommodate him. So Bodry pulled a non-profit board together, got local government to subsidize some rent, hired a physical therapist and opened Challenge Center.

Bodry, who died in 2017, witnessed "little miracles" at Challenge Center on a regular basis. He says he and the staff never made bold statements to clients about recovery. "We never guaranteed any particular result. But we did guarantee that whatever is possible will be possible here." Challenge Staffed by licensed physical therapists. *See challengecenter.org*

Abilities Recovery Center, West Los Angeles ARC offers specialized fitness programs combined

with state of the art equipment to give clients access to standing exercises. Says ARC: "We work with people who have become paralyzed following a severe injury or illness, by enhancing the connection to their nervous system, so that they may move, feel, function and walk again." Founder Jeff Lefkovitz has training in massage, chiropractic and medical acupuncture.
2285 Westwood Blvd,
Los Angeles, CA 90064,
310-948-4948;
visit arc-la.com

"If there is a cure-all that is beneficial to most every condition that a person can suffer, exercise is it." — Bill Bodry, Challenge Center"

The Perfect Step, Claremont Hal Hargrave, just out of high school, was spinal cord injured, C5/6, in 2007. Just days after leaving Casa Colina Rehab, he became a regular at a twice-weekly intensive exercise program called Project Walk in Carlsbad. After six years, motor function recovery was modest but Hargrave got a lot of mental, emotional and social benefits. He's healthy, much more confident and self sufficient, he says, and that's a direct payoff: "Exercise, if you stick to it, it's medicine."

Hargrave and his family started the Be Perfect Foundation, a charity that provides financial and emotional aid for people living with paralysis and promotes health and well-being through exercise-based therapies.

The Perfect Step is an exercise-based therapy program started by the Hargrave family and Mike Alpert of The Claremont Club. TPS began in a small space – actually, a racquetball court – donated by the club. Hargrave brought in a trainer to work with a group of his spinal cord injured friends, and has grown rapidly ever since, and now headquartered in a brand-new 7000 square-foot location.

TPS takes a non-traditional approach to fitness, working with out-of-wheelchair movement patterns, high-intensity exercises, and load bearing to optimize results. From TPS: "Most of our clients have conditions where most medical professionals tell them 'there is no real hope for you.' We have challenged these traditional beliefs and have developed innovative treatments that have shown amazing results. We help our clients make progress and live their healthiest life."

Perfect Step is working with Kaiser Permanente researchers to show that exercise is beneficial. Says Hargrave, "This is an approved research study to gather data showing that exercise really is medicine, that it can improve quality of life and keep people out of the hospital." He hopes such documented outcomes will encourage insurance companies to pay for fitness and exercise.

CHOOSING A REHAB

Financial Aid: The Be Perfect Foundation offers scholarships for therapy to qualified recipients; *see beperfectfoundation.org*

Ever consider owning your own gym business? TPS offers partner opportunities.
1775 Monte Vista Ave,
Claremont, CA 91711,
888-436-2788;
theperfectstep.com

CORE, Northridge The Center for Restorative Exercise (CORE) is a state-of-the-art fitness facility in Northridge, owned by Taylor-Kevin Isaacs, a clinical exercise physiologist and kinesiologist. "We exist to fill the important health and wellness gap that exists between physical therapy and independent fitness," says Isaacs. "After physical therapy has been successfully completed there is a continued need and benefit for ongoing physical activity conducted in a safe environment."

CORE is a spacious, 4,500 sq ft. gym facility equipped with loads of specialized fitness gear, but says Isaacs, "The most important piece of equipment is you, the client."

"Movement is your medicine," says Isaacs. "Exercise is for every body."

CORE provides an attractive, welcoming space. The friendly staff makes sure new clients are not intimidated or overwhelmed. It's busy, upbeat, with a warm, community vibe. The fully accessible center also hosts social events and lectures.

The CORE staff is degreed in kinesiology and offers a unique plan for each client. "As we say, one size fits nobody," says Isaacs. "Our exercise programs are tailored to each individual to enhance strength, flexibility, cardiovascular health, balance and stability, posture, gait, and performance. We work as a team alongside healthcare professionals to support and supplement any medical interventions or treatment clients are currently undergoing. Our one-on-one training also emphasizes education to help clients take control of their health and to be active participants in their wellness.

"In a nutshell, CORE focuses on conditioning to enhance function and independence, and to prevent and/or reduce the secondary complications and degenerative changes that typically accompany a disabling condition or sedentary lifestyle.

"We believe the more you move your body, the more your body moves. Focus on strength and cardio, along with emotional, psychological, and nutritional coaching."

"People ask, 'How long will it take?' We say, 'How far do you want to go?' We have a saying here at CORE: Better has no finish line." Fitness and well-being, he says, are a long-term, lifetime endeavor.

CORE does not accept insurance

but says some clients have gotten reimbursement by working with their carriers. Financial aid may be available, *(See p.167 for potential funding agencies)*. Visitors are welcome.
9631 Reseda Blvd,
Northridge CA, 91324;
818-718-CORE (2673); *see centerofrestorativeexercise.com*

NeuroEx brings the workout to you. This is a mobile training and exercise program founded by kinesiologist Eric Harness, one of the originators of activity based post-rehab therapy (Project Walk, 1999). "By bringing our gym to your home, we remove the added stress and cost, as well as time lost traveling to and from a dedicated facility. Our vehicles carry all of the necessary equipment to allow us to assist you in your exercise program in the comfort of your own home."

The program promotes neuromuscular recovery by targeting the affected areas of the body; increase neuroplasticity through repetitive movements and activities; decrease secondary complications; improve quality of life by increasing sensory and motor function. *neuroex.net*

Rancho Don Knabe Wellness Center at the Rancho Los Amigos Rehab in Downey promotes health and physical activity for people with disabilities, their families, and for the community. Many classes are available for stress reduction, physical activity, improved energy, healthy eating, and for promoting a healthy balance of mind, body and spirit. The program includes yoga, Zumba, Pilates, Tai Chi, adapted dance, gardening, and lots of cardio-fitness. The Aquatic Therapy Center is new. Membership is $25 a month, unlimited use. *rancho.org*, click on 'patient programs.'

NextStep Fitness, Lawndale
Janne Kouri, then 31 , was paralyzed at C5/6 diving into the ocean at Manhattan Beach. He got the usual rehab but it wasn't enough. He wanted to at least hear the word "recovery." "I wanted to go to a proactive, progressive place, not one where you just learn how to live your life in a wheelchair." Kouri saw nothing in California, but discovered Frazier Rehab Institute in Louisville, KY, the lead center in the NeuroRecovery Network (NRN), an activity-based research program set up by the Reeve Foundation. "They were the only place that gave us hope," says Kouri.

He stayed in Kentucky for a year. "After about four months of five-days-a-week of locomotor [treadmill] training, I was able to wiggle my big toe," Kouri said. "But the more meaningful results were better muscle tone, cardiovascular health and improved blood pressure."

There were no locomotor training sites back home in California – this was especially frustrating since the locomotor program in Louisville was invented at UCLA. "I wanted to live here and I wanted to get better. So my wife and I decided to build our own center." In 2008, Kouri opened NextStep

Fitness, based in Lawndale, operating as a non-profit. It's based on a fitness club model, not on medical rehab. It's a member center in the NRN. NextStep has expanded with centers now in Atlanta, Kansas City, Orlando, Raleigh, Las Vegas, and in Tauranga, New Zealand.

In 2019, Kouri drove his power wheelchair 3,037 miles from LA to Washington, D.C., raising funds to provide progressive rehab and fitness to people living with paralysis, and raising awareness about the lack of adequate healthcare and affordable rehabilitation services. *Check out nextstepfitness.org*

VIP NeuroRehabilitation Center, San Diego is managed by David Charbonnet, a former Navy SEAL, spinal cord injured, L1, in a parachute accident in 2011. David wasn't getting the intensity of rehab he wanted from the VA. He came across a doctor who had an under-utilized Lokomat machine, a quarter-million dollar robotic device that facilitates patterned walking suspended over a treadmill – locomotor training but without the need for three or four therapists. VIP also features FES bikes (ergometry), Giger tables (moves all four extremities at once) and even a climbing wall. VIP is a serious gym but it's friendly and accommodating. Says Charbonnet, "We operate as a family, striving to customize every therapy program specifically to the needs of each patient." *vipneurorehab.com*

Adapt Functional Fitness Center, Carlsbad Adapt is a rehabilitation facility in Carlsbad, San Diego. Adapt's facility aims to blend modalities and disciplines in order to provide a personalized and integrative approach for overcoming the challenges of disability. *adaptmovement.com*

ONLINE FITNESS PROGRAMS

W.O.W. - Wonders On Wheels is an online subscription fitness program whose mission is to provide wheelchair fitness instruction and inspiration for all wonders on wheels. Delivering continuous general fitness for wheelchair users via online platforms while promoting healthy happiness!

Every Body Fitness is an online subscription fitness program created by Ph.D. degreed physical therapists. Included are strengthening and cardio classes, plus adaptive yoga, nutrition advice, etc. Tailored to people with all levels of ability, as well as caregivers, starting at just $25 a month. *Check out scitotalfitness.com*

OTHER SOCAL FITNESS PROGRAMS

NeuroLab 360 provides specialized Neurological Rehabilitation and Wellness in San Diego, CA. They offer physical therapy and wellness, group exercise classes, and virtual membership. *neurolab360.com*

Precision Rehabilitation aims to maximize function using a comprehensive therapy program that stresses mobility, balance and gait. The facility offers a full-service

seating and mobility clinic, body-weight supported treadmill training, FES bike program, ReWalk exoskeleton training, occupational therapy, speech therapy, massage. There's a full-featured gym for use by clients and former clients.
3294 E Spring St,
Long Beach, CA 90806,
precisionrehabilitation.com

Movement Performance Institute, aka [re+active] Physical Therapy and Wellness, specializes in neurologic disorders, including brain and spinal cord injury, and offers personalized treatment guided by evidence-based physical therapy practice. Also offers seating and positioning evaluations, Pilates, yoga, dance, boxing.
11500 W. Olympic Blvd, Suite 415, or 3848 W. Carson St., Suite 110;
reactivept.com

San Diego State University Adaptive Fitness Clinic is a community outreach program through the School of Exercise and Nutritional Sciences. The program serves individuals of all ages with physical and neuromuscular disabilities, as well as training for students majoring in pre-physical therapy and fitness specialist emphasis.
Peterson Gym, 5340 55th St,
San Diego, CA;
ens.sdsu.edu/fitnessclinic

Center of Achievement, Cal State Northridge offers several advanced, long-term adapted exercise programs. The facility features a very robust aquatic program with four pools, including one with a moving treadmill-type floor.
18111 Nordhoff Street,
Northridge, CA 91330;
818-677-1200, *for more visit*
csun.edu/center-of-achievement

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SCI: FIRST 90 DAYS

PEDIATRIC SCI

• SPINAL CORD INJURY IN CHILDREN

SPINAL CORD INJURY IN CHILDREN

Spinal cord injury in children is challenging across the spectrum from trauma management to acute care, to rehab and beyond. In this brief overview of pediatric SCI, it's important to remember that children are not the same as little adults. Their care requires a unique, specialized approach. This subspecialty in spinal cord injury is complex medically, psychologically, in rehabilitation, in prescribing assistive equipment, in terms of long-term follow-up, in the schools and community settings, and of course, in the family.

Traumatic injuries almost always affect entire families, but spinal cord injury among children can be far more dramatic and devastating. Services to treat pediatric SCI require a family centered approach, with a large dose of education and care directed toward parents. Getting kids out of the hospital and back into the community is really up to mom and dad; therefore, pediatric rehab in large part is about training parents to take care of their child's needs.

With good medical care and appropriate rehab, kids survive and live long and healthy lives very close to the nondisabled norm.

Fortunately, spinal cord injury is rare in children; the incidence is usually stated as about 5 percent of all traumatic SCI. In Southern California, that would predict in the neighborhood of 50 new pediatric SCI cases a year. These kids face many of the same issues as adults with SCI, including loss of function, pain, breathing issues, bowel and bladder management, pressure wounds, spasticity, osteoporosis, and autonomic dysreflexia.

Because of continued growth and development of a young body, pediatric SCI can also lead to other complications that require unique expertise. Issues that have to be carefully monitored include scoliosis and hip dislocation. There is a very high rate of developing scoliosis if a child is injured before puberty.

Diagnosis of SCI in kids can be tricky: assessment has to consider that the flexibility of the backbone may resist breakage, yet there can still be damage to the nerve tis-

sue of the cord, causing paralysis. That's called SCI without radiological abnormalities (SCIWORA); this almost never occurs in adults, whose spinal bones are more prone to break.

Males are more commonly affected than females during the teen years; at younger ages, the number of females with SCI is equal to that of males. Two in three children injured prior to age 12 are paraplegic, and about two-thirds have complete lesions, a figure much higher than in the adult-onset population.

About half of kids with SCI were involved in motor vehicle accidents. Forty percent of cases are related to medical/surgical events, including injuries at birth. Sports injuries, violence and falls make up the rest.

It's important to stress that because of their young age at injury and long anticipated lifespan, kids with SCI are likely at risk for a variety of aging-related complications, including overuse of arms, hands and shoulders, cardiovascular disease related to inactivity, and metabolic issues, decreased bone density and thus increased risk of fracture, and muscle atrophy. Regular follow-up visits are important, every 6 to 12 months, by an interdisciplinary SCI team.

Injured kids grapple with "why me" issues, and with feelings of isolation, loss of control, and sadness. They benefit from psychological counseling; so do parents, who may be dealing with anger and guilt. But studies show that kids with SCI are no more or less depressed or anxious than kids in general. The kids who adjust the best have strong family and social supports. It's been reported that kids learn to deal with SCI better than those who are injured as adults.

Experts in pediatric disability stress how essential it is to get kids moving. Mobility, even for very young kids with SCI, is important for the growth of the brain, for cognition and learning, and for socialization. A delay in mobility and motor development can delay overall development. If a child lacks independent mobility, he or she may acquire what clinicians call learned helplessness. That means the child may become passive, never feeling in control, retreating from social interaction, avoiding decisions or problem solving.

Pediatric therapists fit kids as soon as possible with wheelchairs or in some cases, braces, to keep them involved in daily life, interacting with friends and family, and especially with other kids their own age. Children require special attention when it comes to customizing mobility gear. Seating and positioning experts must accommodate the growing body; changes in bone and muscle can greatly affect overall function, much more so in kids than in adults.

The rehab field is evolving beyond just supplying devices to compensate for lost function. Research is emerging that intensive activity-based therapies, such as weight-supported treadmill training, can improve mobil-

ity. For more about an innovative research group conducting pediatric clinical trials (in Kentucky), *see victoryoverparalysis.org*.

A PEDIATRIC DOCTOR ON CHOOSING A REHAB CENTER FOR A CHILD WITH SPINAL CORD INJURY

By Lawrence Vogel, M.D.

It's hard to imagine a worse scenario than having to face a myriad of decisions after your child has sustained a spinal cord injury. Once the child has been cared for in a trauma center, hopefully in a pediatric facility, the next choice a parent needs to make is where their loved one should be transferred for intensive rehabilitation. So what factors need to be considered?

Location: close to home is so important for the needed support of family and friends. Familiarity is a key factor.

The rehab facility must be pediatric-focused and just as importantly, have extensive experience with pediatric spinal cord injuries. Unless your child is a very mature young adult, all kids 18 years and younger should be cared for in a pediatric-focused rehab center.

The best judges of a pediatric SCI rehab center are former patients and their parents. You may be able to tap into this expertise by way of peer-to-peer networks *(See p.10-14)*.

What makes a great rehab center is the SCI team: physical, occupational and speech therapists, the social workers, psychologists, child-life specialist, recreational therapists, dietitians, nurses, and the doctors. Doctors are important, of course, but the truth of the matter is what makes or breaks the experience is the team, their experience, passion and commitment.

The rehab should embrace the child with the SCI and his or her parents as a critical component of the treatment team.

Equipment is also an important part of a pediatric rehab program and should include a therapeutic pool, locomotor training, and functional electric stimulation equipment for both the lower and upper extremities.

Lawrence Vogel is chief of pediatrics at Shriners Hospitals for Children, Chicago; he is also medical director of the spinal cord injury program.

PEDIATRIC TRAUMA CARE

Emergency responders are trained to transport seriously injured children up to age 16, sometimes 18, to a Level I or II trauma center that specializes in multidisciplinary pediatric care. Treating a child requiring ventilator support, for example, must occur in a top-notch trauma setting; the child's life depends on the skills and expertise on hand.

Level I pediatric trauma centers in Southern California include Children's Hospital LA; Ronald Reagan UCLA Medical Center; Loma Linda University Medical Center; and Rady Children's Hospital, San Diego.

Level II pediatric trauma centers

include Northridge Medical Center; Cedars Sinai Medical Center, Los Angeles; LA County-USC Medical Center; Harbor-UCLA Medical Center, Torrance; Long Beach Memorial; and Riverside County Medical Center.

CHOOSING REHAB FOR PEDIATRIC SCI

A general rehab setting may not be appropriate for a child with spinal cord injury. Parents should seek a facility that offers comprehensive care in a kid-friendly environment, staffed by professionals skilled in working with children. Refer to the narrative on choosing a rehab for adults starting on p.56.

Here are the acute inpatient rehabs most suited for treating kids with SCI in Southern California:

Shriners Hospitals for Children (located in Northern CA) is an 80-bed pediatric (to age 18) medical rehabilitation center for children with complex medical needs, with a unique specialization in spinal cord injury. All kids are treated regardless of ability to pay. Located in Sacramento, and affiliated with the UC Davis School of Medicine, Shriners offers full continuum of care for pediatric SCI, including acute care, primary rehabilitation and special reconstructive surgical services. Patients come there from all over the Western U.S., Canada and Mexico. While Shriners may not be ideal for SoCal families for acute rehab, due to distances and logistics, the hospital should be considered, especially for outpatient services, and for situations involving longer term care. *See shrinershospitalsforchildren.org*

Valley Children's Hospital: Families in Santa Barbara, San Luis Obispo and Kern Counties are within the coverage area for Valley Children's Hospital, near Fresno. This is a large, pediatric specialty center with 358 beds, 550 doctors and 3000 staff. It is a teaching hospital for Stanford medical students. Valley Children's is the only center in California accredited in pediatric rehabilitation by CARF. *valleychildrens.org*

Children's Hospital Los Angeles treats thousands of kids every year in 350 pediatric specialty programs. It is a Level I Trauma Center. The Margie and Robert E. Petersen Foundation Rehabilitation Center, a specialized 22-bed acute inpatient facility, treats complex diagnoses, including brain and spinal cord injuries. Most rooms are private and accommodate parents with beds and showers. *chla.org*

Totally Kids Rehabilitation Hospital provides Acute Inpatient and Outpatient Rehabilitation, Subacute Programs, and Intermediate Care Programs for infants, children, adolescents and young adults up to 21 years of age. The Totally Kids campus is located in Loma Linda and is 100% devoted to children, *totallykids.com*

HealthBridge Pediatric Specialty Hospital in Orange County provides care for children who are recovering from complex medical issues stemming from SCI or any other life-altering event. We also provide pediatric ventilator nursing care for patients who need it. They treat children

in a non-institutional environment that feels like home while they receive highly specialized care. *healthbridgecc.com*

Miller Children's & Women's Hospital is a large facility that's part of the Long Beach Memorial system. Inpatient pediatric rehab includes medical care and the full array of therapies, plus a school re-entry program. Miller also maintains a robust outpatient clinic, with expertise in scoliosis. *millerchildrenshospitallb.org*

Rady Children's Hospital is dedicated exclusively to pediatric healthcare, serving San Diego, Imperial and southern Riverside counties. Rady has 551 beds and is the largest children's hospital in the state, based on admissions. Rady's inpatient rehab unit includes spinal cord injury care. The hospital, a Pediatric Level I Trauma Center, provides care to about 700 patients a year. A full range of outpatient services is also available. *rchsd.org*

Rancho Los Amigos Hospital in Downey, is part of the LA County medical system. Rancho has a storied past in taking care of polio patients, many of them children. The rehab unit has a pediatric department as part of its nationally recognized Model Systems comprehensive SCI program. A new Wellness & Aquatic Therapy Center opened on the campus, expanding Rancho's commitment to the outpatient community. *(See p.70) dhs.lacounty.gov*

California Rehabilitation Institute, Westside Los Angeles, is a full-service inpatient rehab, a partnership between UCLA and Cedars-Sinai, managed by Select Medical. Minimum age of SCI patients is 14. *(See p.71) californiarehabinstitute.com*

Casa Colina Children Services Center offers licensed physical, occupational, and speech therapies to help children with SCI maximize their functional abilities and daily living skills. 909-596-7733, ext. 4200, or *visit casacolina.org*

Sharp Hospital in San Diego is the only CARF accredited program in Southern California with a specialty in pediatric spinal cord injury. *(See p.72) sharp.com*

OUTPATIENT OPTIONS FOR PEDIATRIC SCI SERVICES

Mattel Children's Hospital is on the UCLA campus, located on the third and fifth floors of Ronald Reagan UCLA Medical Center. *Visit uclahealth.org/mattel*

Orthopaedic Institute for Children takes care of kids at the downtown Los Angeles Campus or on the Westside (The Renee and Meyer Luskin Children's Clinic) at the Santa Monica-UCLA Medical Center. *Visit ortho-institute.org*

GETTING FINANCIAL HELP FOR KIDS

Each state receives funds from the federal government for early intervention programs to coordinate services for infants and toddlers from ages 0 to 3, and their caregivers. After the age of 3, children may be eligible for services from physical, occupational, and speech therapy through the public school system.

The federal Individuals with Disabilities Education Act (IDEA), Part C, supports kids with dis-

abilities and their families. In California, the Early Start system is intended to enhance the capability of every family with an infant or toddler with a disability to meet the child's developmental needs. *dds.ca.gov/earlystart*

All school districts in California are responsible for providing early intervention and education services to eligible infants and toddlers younger than 3. The school district must develop an Individualized Family Service Plan (IFSP) within 45 calendar days of the date it receives a referral for early intervention services.

Specially designed instruction is available to children with disabilities at no cost to parents. This allows kids be educated with their peers as much as possible, in the least restrictive environment. *cde.ca.gov*

Navigating the special education system can be complicated but parents should know that there are disability rights laws and programs, and experts who will help. An excellent SoCal reference is TASK (Team of Advocates for Special Kids), a federally funded nonprofit for parents, teachers and schools to make sure kids have the accommodations and resources they need to succeed in school and community. The vision: "to ensure that all children with disabilities receive a high quality education, are included in the world, and adequately supported so that they acquire the necessary skills, experiences and accommodations to be successful, contributing members of society and as self-sufficient as possible."

See taskca.org; for Spanish speaking parents, see fiestaeducativa.org

OTHER RESOURCES FOR KIDS AND FAMILIES

Ability Tools, part of California's federally funded Children's Services, provides physical therapy and occupational therapy, and medical therapy conference services for children with neurological or musculoskeletal disorders, including spinal cord injury. *abilitytools.org*

Easter Seals services include rehabilitation, physical therapy, occupational therapy, speech and hearing therapy, job training, employment, child care, adult day services and much more. *easterseals.com/southerncal*

Family Voices offers resources and advocacy for family-centered, community-based, care for child and family. *familyvoices.org*

Parent Advocacy Coalition for Educational Rights (PACER) addresses special needs for all stages of childhood and all disabilities, and identifies resources and services available to help families learn and grow. *pacer.org*

Variety Children's Charity delivers medical equipment and services, healthcare and well-being to individual children and children's health organizations. LA office: 323-954-0820; *usvariety.org*

Wheel to Walk Foundation helps children with disabilities up to age 20 obtain medical equipment or services not provided by insurance. *wheeltowalk.com*

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SCI: FIRST 90 DAYS

BODY AND MIND

- SECONDARY CONDITIONS
- PSYCHOSOCIAL ISSUES & COPING
- SEXUALITY

SECONDARY CONDITIONS

Spinal cord injury affects numerous body systems. Here are some of the health issues you must manage over the long term. *Note: this is very basic information; two places to learn more are the Reeve Foundation (christopherreeve.org) or the Model Systems Knowledge Translation Center (msktc.org).*

AUTONOMIC DYSREFLEXIA (AD)

This is a potentially life-threatening emergency that affects people with injury levels at or above T6. AD is a blood pressure regulation condition triggered by an irritant below the level of injury. Of course one cannot feel this pain or discomfort, and thus the nervous system responds in a confusing way.

For most susceptible people, AD is easily treated, and easily prevented. The key is knowing what the symptoms are, knowing your baseline blood pressure, and knowing the sorts of triggers that set it off.

AD requires quick and correct action; there is a possibility of stroke if misdiagnosed or untreated.

This is important to know: Many health professionals are not familiar with AD, so it becomes essential that those at risk for AD, and people close to them, must recognize the symptoms and know what to do.

Symptoms of AD vary but may include high blood pressure, pounding headache, flushed face, sweating above the level of injury, goose flesh, nasal stuffiness, nausea, and a pulse slower than 60 beats per minute.

Triggers for AD vary too, but most often are related to the bladder. Urinary tract infection, blocked catheter or overfilled collection bag can be the cause. Other causes: tight clothing; ingrown toenails; bowel issues (constipation or gas); skin sores; broken bones; burns; cuts; and abrasions. Sexual activity can cause AD, as can menstruation in women.

AD is complicated. You need to understand how the workings of the autonomic nervous system – this is the part of the nervous system that works without us thinking about it. It controls blood pressure, heart rate, body tempera-

ture, sweating, digestion, etc. A noxious stimulus (pain you can't feel) tries to send a message to the brain but it doesn't get past the site of injury. The pain signal does, however, activate a reflex in another part of the nervous system, a subset of the autonomic system called the sympathetic system. This causes blood vessels to narrow, which in turn causes blood pressure (BP) to rise. Once BP goes up, this gets detected by nerve receptors in the heart and circulatory system, which gets a message to the brain. The brain slows the heartbeat and opens the blood vessels above the level of injury. Since the brain can't send messages below the level of injury, BP there is not controlled. Your body is dysreflexive – confused and unable to balance out the blood pressure.

So, what do you do? At the first sign of AD, check your blood pressure against your baseline read (if you are at risk for AD, keep a home blood pressure monitor handy). Sit upright. Loosen tight clothing. Check if bladder is too full. Look for other things, e.g., a skin or bowel issue. Remove the cause and AD will almost always calm down.

If an episode of AD continues even after the cause has been removed, and if your systolic blood pressure is greater than 150 mmHg, consider applying nitropaste to the skin above the level of injury. Other BP drugs such as hydralazine, mecamylamine, diazoxide, and phenoxybenzamine might also be used.

AD can be prevented but most people with a T6 level of injury or above will experience it. This may be scary the first few times it happens but you will learn to recognize symptoms and to know your particular triggers.

If you ever go to a clinic or hospital with AD, be prepared to school the medical personnel on what is happening and what needs to be done. Many ER doctors don't know anything about it and may try to treat you improperly. You can get a wallet card from the Reeve Foundation describing AD and its treatment to use in an emergency. *See ChristopherReeve.org, search 'wallet card.'*

BLADDER

Spinal cord injury knocks out the circuits that control your ability to pee. Either you can't stop urine from flowing, or you can't get it to flow at all. Learning how to manage the bladder is an essential part of rehab, and keeping the bladder healthy is a task that lasts a lifetime.

Early after injury the bladder is affected by spinal shock: the detrusor muscle, which causes the bladder to squeeze, is relaxed. It won't empty. This shock will wear off, usually within a week or two after injury. At that point, depending on level and extent of injury, the bladder will either squeeze on its own (spastic), or stay loose (flaccid). The bladder outlet, the sphincter, is also either tight or relaxed. A closed sphincter will create bladder pressure – not good for the kidneys. A loose sphincter will leak – not good for your hygiene or lifestyle.

Your rehab team will assess the bladder, running some tests measure pressures, volume, etc. A management program will be prescribed, with the goal of keeping you dry and your kidneys healthy.

Intermittent catheterization (IC) is the most common type of bladder management. This means that a catheter, a thin plastic tube, is inserted (by you or someone else) by way of the urethra (the opening where pee passes to the outside) to drain the bladder on a regular schedule, usually four to six times a day. You may need to keep track of your fluids so your bladder doesn't overfill and get overstretched, especially at night. IC helps to maintain your normal bladder size. You may need to take anticholinergic drugs (e.g. Ditropan) to keep your bladder from being too overactive, which could lead to leakage.

Indwelling catheterization uses a catheter that stays inserted in the bladder for about a month at a time, with a urine collection bag. Sometimes the indwelling cath is routed to the bladder though the abdomen, by way of a port made by a surgical incision. This so-called suprapubic indwelling catheter allows easier access and may be preferable to a urethral indwelling catheter for sexuality activity: the catheter is not in the urethra and not in the way.

Advantages of any indwelling cath include unlimited fluid intake. Some people get bladder stones using an indwelling cath; these can block the catheter and create back-pressure that's bad for the kidneys.

Reflex voiding is an option for men with spastic bladder and relaxed sphincter; it uses an external catheter affixed to the penis by a condom device, and drains to a collection bag. There is no equivalent reflex voiding system for women, except diapers.

"Early after injury the bladder is affected by spinal shock: the detrusor muscle, which causes the bladder to squeeze, is too relaxed. It won't empty."

Urinary tract infection is a chronic issue for almost any bladder management program. It's all the more important to avoid a UTI because there are few antibiotics available to treat it. There are catheters on the market that allow a sterile drainage, but even that is not a foolproof way to prevent infection. Meticulous hygiene is essential. Some people swear by cranberry extract to keep bladder infection away; some take D-mannose, a type of sugar.

BOWEL

A spinal cord injury knocks out the bowel, which leads to problems moving waste through the intestines and colon, or constipation. Stool may not move at all without some help, or it might pass at the wrong time, the dreaded involuntary, when you're out in

public. Bowel management won't completely control the bowel but it can retrain the body to have a regular movement, and therefore remove a lot of the anxiety.

As with the bladder, SCI can cause tightness (spasticity) or looseness (flaccidity) in the rectum, sphincters, and pelvic floor. Those with incomplete injuries have more muscle strength and sensation and therefore fewer bowel issues.

The goals of a bowel program are to pass a soft, formed stool on a daily or every-other-day basis. A program involves eating a good diet, drinking lots of fluids, using any bowel medications recommended by your doctor, and using techniques that activate the reflex to empty the rectum.

Diet recommended for better bowel care includes natural fiber from fruits and vegetables to increase the bulk of stool, making it easier to move it through the colon. Drink lots of water so you won't get constipated. Bowels move better after a meal. Being active is good for overall health, including bowel function.

Your doctor may prescribe stool softeners, stimulant laxatives (bowel bullets) for the colon or bulking laxatives to prevent diarrhea and add shape to stools. Also, rectal laxatives may help with rectal emptying.

Techniques you can do at home or with help from a caregiver include digital rectal stimulation to remove stool. Enemas, flushing warm water into your rectum, help to empty it.

FDA-approved bowel irrigation devices such as the Peristeen (coloplast.us) and PIE (Pulsed Irrigation Evacuation, piemed.com) have been shown to help with some difficult bowel programs.

BONES

Bone loss post-SCI is dramatic, especially in the first two years after injury; at that point you will lose half your bone density, just the same as occurs in a non-injured 70-year-old woman. This matters because weak bones break more easily.

Bones melt away in anyone who is inactive or stuck in bed. But SCI breaks down bone at a much faster rate, due to metabolic issues that are not fully understood. You can't cure bone loss but you can do some things to keep them healthy. Increase physical activity, especially weight-bearing or resistance exercises.

Biphosphates, e.g. Fosamax, work in the general population for osteoporosis and are sometimes prescribed in SCI. Calcium supplements may be recommended.

Get some sun, and if you can't, take vitamin D. Don't smoke, limit alcohol and try not to fall. Some use vibration machines for bone health.

HEART

Heart disease is the leading cause of death in the U.S. and this includes those with SCI. Sedentary living plus a series of metabolic changes in the body combine to elevate your risk for cardio issues. What can you do? Physical activity. Diet. Weight management.

IMMUNE SYSTEM

SCI does a number on the immune system, right from the beginning. That's not good because of the constant risk for infection. There is evidence that the immune system is closely related to the gut and to the central nervous system. Managing the health of the gut, for example with a probiotic supplement, may confer benefits to the whole body.

MUSCLE ATROPHY

Don't use them you'll lose them. You will lose a lot of muscle tone. Exercise is good; for the muscles you can't use on your own, functional electrical stimulation (FES) builds muscle.

DENTAL CARE — AT HOME

Don't forget your teeth. You know what they say, just floss the ones you want to keep. Having trouble getting to the dentist? Or have an emergency? A mobile service in the LA area called In Motion Dentists will come to you — full service care, including cavities, crowns and even root canals, and with a portable clinical chair to transfer to. 626-594-0374; *inmotiondentists.com*

PAIN

The majority of people with spinal cord injuries deal with chronic pain, the relentless kind of burning, stabbing or tingling that keeps hanging around. Normally, pain has a purpose, as an alert to move your finger from the flame, or to stay off an injured ankle. But chronic pain is a worthless friction wearing away your quality of life. To some degree it can be treated, or perhaps made peace with, but pain is difficult to eliminate altogether.

The treatment arsenal for managing pain is limited, moving quickly, and mostly by trial and error, from aspirin to opiates, with a few antiseizure or antidepressant medications in the mix. While complete relief asks too much of modern medicine, living better with pain is a reachable goal.

Doesn't seem fair, does it, when pain occurs in the paralyzed lower part of your body where there is little or no other sensation? That's what nerve pain, or neuropathic pain, is. Research scientists do not fully understand nerve pain. It is apparently the result of crossed-up messages between nerves damaged by your spinal cord injury and the brain. The brain, your body's central switchboard, misreads the messages and turns up the volume on signals in area of injury – so you feel pain where you feel nothing else.

Musculoskeletal or mechanical pain can be caused by overuse, stress and strain of muscles, joints or bones. It is a common problem for everyone, especially as we get older. Upper extremity (shoulder, elbow and hand) pain can be aggravated by doing transfers or pressure relief maneuvers, or from pushing a wheelchair. Back and neck pain may be a problem for a paraplegic who had spinal fusion surgery. Neck pain might occur in quadriplegics who use chin- or mouth-operated joysticks.

Visceral pain is often described as cramping and/or aching. It is

usually located in the abdomen and can be set off by constipation, a kidney or gall stone.

There is no ideal way to treat chronic pain; it varies greatly between individuals, and people don't all respond the same way to treatments. You and your doctor may need to try combinations of drugs, therapy and other treatments, including psychological treatments. It's never as easy as 'take this pill' for relief. You may have to try a number of things before finding something that helps.

Non-steroidal anti-inflammatory drugs (also known as NSAIDs) include aspirin, ibuprofen (Motrin, Advil) and naproxen; these are commonly used to treat general muscle pain. Side effects may include stomach upset, liver damage, or bleeding.

Antiseizure medications such as gabapentin (Neurontin) and pregabalin (Lyrica) work for some people's neuropathic pain. Side effects include dizziness and sleepiness. Lamotrigine is another drug in this category that works for some people with incomplete injuries; side effects include skin rash, fever, and fatigue.

Antidepressant medications used for chronic pain include venlafaxine (Effexor), and amitriptyline (Elavil). Side effects include dry mouth, sleepiness, and dizziness.

Some people get pain relief using cannabis, legal for medical purposes in more than half the states in the U.S.

Narcotics (opiates) such as morphine, codeine, tramadol, hydrocodone and oxycodone are very effective against neuropathic and musculoskeletal pain. Side effects are considerable, include constipation and sleepiness, and of course these can be addicting. You may develop dependency and have unpleasant withdrawal symptoms if you suddenly stop taking them.

A few options for chronic pain require surgery: Some neurosurgeons may recommend snipping certain nerve roots: The dorsal root entry zone (DREZ) procedure destroys specific sensory fibers where they enter the spinal cord. Nerve cutting would be a last resort, considered perhaps after trying an implanted spinal cord stimulator (common for back pain), or maybe an implanted intrathecal pump to deliver morphine or baclofen directly to the spinal cord.

PAIN MANAGEMENT STRATEGIES

Keeping yourself healthy will help reduce pain.

- Physical activity can reduce pain; exercise can also improve mood.
- Physical therapy or massage can help with musculoskeletal pain.
- Deal with depression: it can make pain worse.
- Transcutaneous electrical nerve stimulation (TENS) may help musculoskeletal pain.
- Deep brain stimulation may help some cases of chronic pain.

- Botox or chemical nerve blocks work for some people.
- Relaxation techniques and/or biofeedback can teach you to modify muscle pain.
- Self-hypnosis (mindfulness, or meditation) helps many people to reduce chronic pain.
- Distraction, when all else fails, may help with chronic pain. Do fun things, find meaningful activities. The pain is still there but at least it is not dominating your life.

RESPIRATORY HEALTH

The lungs are not affected by paralysis but the muscles that control the lungs are. Spinal cord injury, especially in the cervical area, C5 and above, usually means weakness in breathing function. Some higher injuries will require a tracheostomy (an airway through the neck) with a ventilator (an air pump) to make sure you get the oxygen you need to survive. Those with C3 or lower injuries have the potential to wean from the trach.

There are electrical stimulation devices on the market that help some people breathe off the vent *(averylabs.com or synapsebiomedical.com).*

People with high thoracic and lower cervical injuries won't need mechanical assistance but due to abdominal muscle loss, may have to work harder to breathe. This may mean it's harder to get a good cough, and thus trouble clearing sticky mucus from the lungs, and thus at an increased risk for respiratory health problems. Quadriplegics and their caregivers are taught some techniques to encourage cough. There are also machines that facilitate a productive cough *(coughassist.com)*

Those with respiratory weakness have to be very careful to avoid infection, either bronchitis (infection in the tubes that deliver air to the lungs), or pneumonia (infection in the air sacs in the lungs). These infections create extra mucus, which can result in atelectasis (a collapse of the lung).

Sleep apnea, a type of breathing obstruction, is an issue for some with higher level injuries: this may require use of a night-time ventilator (BiPAP, bilevel positive airway pressure).

Be aggressive about prevention: Avoid smoking, and secondhand smoke. Clear secretions in the lungs. Drink plenty of water, watch your weight; overweight or obese people may have problems with their lungs, and are at higher risk for sleep apnea Avoid people who may have a cold or flu. Get vaccinations for flu and pneumonia. Get some exercise.

SKIN CARE

The thing to know about skin sores, aka pressure injuries or decubitus ulcers: no pressure, no ulcer.

It's easy to say that pressure sores are entirely preventable – with few exceptions, they are – but they happen, quite commonly, among people with spinal cord injury or disease who can't feel pain or discomfort. Skin wounds are stubborn; they can result in long, boring, expensive, non-productive stays in the hospital. Skin

issues interrupt your life, and may lead to more serious health issues.

Sores begin with the force of the body against a sitting surface – often on the bony part of your butt or hips, or heels. This happens when you remain in a single position long enough to pinch off blood flow (ischemia), which then leads to cell death (necrosis). Another type of force is sheer, the stretching and folding of skin, which can also restrict blood vessels leading to tissue damage.

Check your skin! Every day. Be relentless. Use a mirror, take a picture with your phone, or have someone check. Pressure sores don't become dangerous overnight – they form in stages. The earlier you spot one, the easier it is to get rid of.

Stage I is the most superficial: redness with hot or cold skin that does not go away after pressure is relieved. These usually vanish soon just by keeping the pressure off.

Stage II involves actual damage to the skin surface, similar to a blister or abrasion. See your doctor; this type of wound will heal without much intervention other than pressure relief, but it may take a few weeks.

Stage III sores, difficult to heal, go deeper into skin tissue. At this point you and your wound specialist doctor need to get very aggressive, especially if there is fever, or if the wound starts to smell foul.

Stage IV goes even deeper, forming a deep cavity in the skin, perhaps invading muscle or bone, and making you vulnerable to life-threatening spread of infection to other parts of the body. A deep sore may require surgery or skin grafting – very expensive and a serious crimp in your lifestyle. These nasty wounds can take as long as two years to clear up.

Advice: Keep skin dry and clean, watch your weight (too skinny, no padding; too heavy, excess pressure), do those weight shifts, just as they teach you in rehab (every 15 to 30 minutes for 30 to 90 seconds). Use an appropriate seating surface for pressure protection. Therapists can map the pressure on your buns to spot the most sensitive areas, and therefore make sure you are using the most appropriate protection. *(See p.137-140)* for more on seating.

Watch out for hot water. Don't sit too close to the fireplace. Don't get sunburned. Don't forget cold-weather protection, too; frostbite can happen very fast. Eat well – you need protein to keep skin healthy. Drink lots of liquids (beer and wine don't count). Don't smoke.

SPASTICITY

Spasticity, the uncontrolled tightening or contracting of the muscles, is part of the experience for most people with spinal cord injury. It is the result of damage to nerve reflex circuits that no longer have a direct connection to the brain. It can happen on its own, or because of a trigger, such as stretching a muscle or moving a limb. Irritations such as pressure sores or urinary tract infections can aggravate spasticity.

Spasticity is not a medical risk,

per se, but it can be annoying and limiting, sometimes painful, and occasionally, dangerous. Some people with SCI can experience spasms strong enough to jerk them out of their chair.

Spasticity does not always have to be treated. Sometimes it is helpful to maintain muscle tone, and can be useful for functional activities such as standing or transferring.

Physical treatments to mute spasticity include regular stretching (range of motion). Weight bearing, in a standing frame, can help too.

Drugs for managing spasticity: baclofen, valium, dantrolene, and tizanidine are all common. The effectiveness of these drugs varies and each has side effects, including fatigue or drowsiness, weakness, nausea, or low blood pressure.

If spasticity can be localized, anesthetic drugs, e.g. phenol or botox, might be useful. The benefits are only temporary, so injections must be repeated.

A fairly common surgical treatment for severe spasticity involves surgical implantation of a battery-powered pump with a tiny catheter to deliver medication directly to the spinal cord (called the "intrathecal" space). Intrathecal baclofen has fewer side effects than taking the drug orally.

Rhizotomy, the surgical cutting of nerves, is an option that needs very careful consideration – once you snip a nerve it is not reversible.

UPPER EXTREMITY PRESERVATION

Arms were not made to be your legs, so it's common to overuse the upper extremities, including the wrists. Preserve your upper body! Avoid extreme positions on the shoulders or wrist during transfers, or when reaching. Manual wheelchair pushers, use the lightest one possible. Consider a power assist device to make going up hills easier. Consider a power chair if pushing is getting too hard.

WHAT YOU SHOULD KNOW GUIDES

The Consortium for Spinal Cord Medicine offers a series of What You Should Know guides, derived from the Consortium's authoritative clinical practice guidelines.

- Sexuality/Reproductive Health
- Bladder Management
- Respiratory Management
- Upper Limb Preservation
- Autonomic Dysreflexia
- Pressure Ulcers
- Expected Outcomes
- Depression
- Neurogenic Bowel
- Cardio-Metabolic Risk

Guidelines are free from the Paralyzed Veterans of America, *pva.org*, click on 'publications.'

PSYCHOSOCIAL ISSUES AND COPING

There is no recipe, or timeline, for gracefully emerging from the scary darkness of the spinal cord injury experience. It probably won't be graceful at all. Spinal cord trauma is not for sissies; it's a long slog into an alternative reality. There's all the medical stuff, and the many ways the body no longer works the way it used to. But there's also the noise inside your head. Why you? You might as well ask why not you. Who knows. This much is true: No two people process the intensity of SCI quite the same.

It's generally the case that your personality survives intact; you're the same person after SCI as you were before, which suggests that you'll deal with this much the way you have always handled problems. Well, not exactly. You may be having a hard time looking at yourself in the mirror. You worry that you are broken, that you will be a burden to your family, that no one can possibly love you ever again. Everybody you know has amplified your catastrophe all over social media; they all know about your situation and the last thing you want is their pity. You feel totally alone but without a shred of privacy.

We have said this before and it bears repeating: it gets better. You have more capacity to cope with this than you can possibly imagine. It will take time.

Adjustment happens, and you must expect that it will happen, although seldom in the first 90 days.

DATA: IT DOES GET BETTER

Data from the U.S. Model Systems SCI program, which tracks 32,000 people living with spinal cord injury, shows that a measurement of satisfaction with life increases after one year post-injury and keeps rising for every year data is tracked, up to and beyond 40 years post-injury.

Also, a measure called "Perceived Health Status by Post-Injury Year" indicates that at one year post-injury, 62 percent of SCI survivors report their overall health as good, very good or excellent. At year five, that number goes up to almost 70 percent, at year 25 it is reported at 77 per-

cent.

You will figure this thing out. You won't believe how much stronger you will be and how far you will have progressed a year from now. You know what they say, patience is a virtue. Stay strong, and push on.

YOU ARE NOT A TRAGIC CHARACTER

There's actually quite a bit of research about the psychology of spinal cord injury. A key message from the medical literature is that quality of life for people living with paralysis is not dramatically lower than what is found in the general population. Ever see a person on the street in a wheelchair and think, oh that poor guy, I don't know if I could possibly live like that? Guess what? That person is not a rolling tragedy or the object of pity. He or she has more than likely figured things out, has a job, a family and a future. You will experience people misjudging your situation and soon enough you will know it isn't so much the disability that's the problem as much as it is other people's attitudes and responses to it.

Besides an uncertain future and the full range of health issues that come with SCI, e.g. pain, spasticity, incontinence, other factors confound the adjustment process. Someone hurt taking a known risk, say a motorcycle racer, may deal with paralysis differently, maybe better, than someone plagued by guilt for doing something really stupid, say crashing the car while texting. And someone victimized in a random accident or surgical error may be full of blame and resentment, therefore having a very bad time with major life-changing injuries.

Someone with a wide network of family and friends will usually deal with SCI better than the lone wolf on his own. Women, as a rule, are better prepared for the consequences of SCI than are men. Research has shown that people who see setbacks as temporary and changeable – optimists – do much better in reducing the stress of trauma than those who are more negative, or passive – pessimists. People who are assertive participants in rehab are usually less depressed and better at social integration, compared to passive people who gladly accept being nurtured.

In this section we'll review some of the psychological aspects of spinal cord injury. There may be a helpful message here, or a tool to discover a glimmer of hope to hang on to. The point is to find ways to live your life as a functioning human with a manageable future – without dismissing the facts. You may not fully accept your new reality but it's important to recognize the implications of this reality, and to make the necessary adjustments to get reorganized.

Rehab psychologists are an important resource if you're lucky enough to have a good one available. These professionals will tell you it is possible to teach optimism and resilience, and therefore better coping skills. They can help reset your perspective so you can see up the road; they may be able to help you break through your

isolation. So, by all means, if it is offered, take advantage of counseling.

Early on, you may hear about models of grief, such as the Kübler-Ross inventory of feelings that were first applied to death and dying. First there is denial, then anger, bargaining, depression and, finally, acceptance. Those stages might still hold for discussing death, but stage theory suggests a sequence of mental states. But these reactions rarely fall in to any order, and don't really predict how people will deal with sudden onset of spinal cord injury. In the very early days post-injury, before denial and way ahead of anger, you may feel gratitude. You and your family may feel anxious, and helpless, but glad you're alive. It's scary, it's insane. But you survived. That's where emotional recovery has to begin.

Anybody around an SCI rehab knows that denial is almost always part of the picture. It's not always a bad thing; denial is an important coping mechanism, a place to hide out. You may have an exaggerated optimism and a distinct vision of walking out of that trauma hospital or rehab. You don't want to talk to the peer counselor because you can't relate to that dude rolling into the room in a wheelchair. That's not your destiny! That's fine, it's a way to stay hopeful, and it may help you through the turmoil and uncertainty of the early days. Distorting reality in the long-term, living your life in the fog of denial, will not serve you well.

Anger is common with SCI (ask a spinal cord injury nurse, who often bears the brunt of the aggressive, pissed off patient).

Guilt is a type of anger, directed inward. This is a major factor for some, especially with injuries related to injudicious behavior. There are visual imagery tools the rehab psychs may use to channel some of this angry energy into something less toxic.

Sadness, powerlessness, and loss of control are also part of the acute SCI inventory, but it's good to know that these are generally not permanent states of being.

Depression – not just having the blues but lack of appetite, insomnia, hopelessness, existential dread – can be a side effect of trauma but maybe not the dominant one many people, including professionals, assume. (According to Model Systems data, more than 25 percent of people with SCI had difficulties with depression before they were injured; the post injury incidence isn't much different).

Most people with SCI do not get depressed, and therefore passing through depression is not a required stage to reach the promised land of acceptance.

If depression lingers, it becomes a clinical issue that may be treatable. What's the plan? Generally, the rehab team mobilizes against depression by providing a sense of realistic hope, supporting you to take small steps toward self-reliance and independence, using education and perhaps assisted technology to facilitate your ability to make choices, to reintegrate with family or community.

Your rehab docs may also prescribe prescription drugs.

Speaking of medicating angst, people with SCI are at some risk for becoming substance abusers, or for continuing to be abusers, since drugs or alcohol may have been at the root of the injury in the first place. Drug use won't cut it in rehab, and certainly won't help your body return to its maximum efficiency.

On the far end of depression and sadness, some have suicidal feelings (more common in SCI than in the general population, but rare and not considered a normal response, despite what some Hollywood movies may show about the futility of life with paralysis).

Suicide is a difficult area – ultimately it is your existential choice to end it all, and as of 2016 in California, you have the right to ask for physician assistance. But even if you are fully competent and cognizant, the rehab team will do everything they can to talk you off the ledge, hoping to offer tools to allow you to pause and reflect, and perhaps to reframe your outlook.

The goal of rehab is to get you ready to return home with some sense of control, with some balance between life now and life as you knew it, and able to make choices in the world you live in.

Rehab psychologists sometimes use easy-to-learn techniques for relaxation. Learning to be mindful, or to meditate, benefits almost everybody dealing with stress (including family and loved ones of SCI folk).

Someone in rehab may help you discover the value of mindfulness – a great way to quiet the barking dogs in your head. Check out the many resources at the Mindful Awareness Research Center at UCLA, *marc.ucla.edu*; Mindful USC, *mindful.usc.edu*; or the UC San Diego Center for Mindfulness, *health.ucsd.edu/specialties/mindfulness*

Another tool psychologists might use is called cognitive behavior therapy, a technique to listen to patients and then help isolate negative thoughts and patterns, and to teach strategies to identify and solve problems. This therapy has been successful one-on-one and in groups to ease anxiety and to relax fear.

STYLES OF COPING

Sherman Gillums
Paraplegic, Veterans' Advocate
Learn from those who've been there, then challenge yourself to exceed expectations. Limitations cannot define you without your permission.

Ellen Stohl
Paraplegic, Teacher, Mom
Working through the pain makes us stronger, more creative. You can let this stop you dead in your tracks or you can accept that this is the way it is.

Gary Karp
Paraplegic, Author, Speaker
Make the transition from Walking Mind to Wheeling Mind. We all seek to feel OK about ourselves as we are; over time our attention naturally shifts to what's possible rather than what we've lost.

Karen Hwang
C3-4
Disability doesn't change us into saints or superheroes. Most of this comes from bad luck or bad judgment. Don't look for meaning in your disability, just appreciate the absurdity.

Jeff Cressy
C6
Don't beat yourself up over what you can't do. It takes a while to come full circle, to the point when you quit comparing yourself to what was, and are satisfied with what you have.

THE SOCIAL SIDE

Self-renewal is part of your adjustment but it isn't the whole story. Yes, successful rehab involves being motivated. It helps to have a fighting spirit. But that might suggest succeeding in this process is all on you. Not so. You cannot discuss the rehabilitation experience outside of its social context.

There is a school of thought that believes folks with new spinal cord injuries are not defined by unique psychological issues, per se. It's more that they have problems coping with a world designed for non-disabled people. Therefore, part of the rehab process needs to arm you with information and skills to cope with this environment. The kind of non-personal variables that might impede your progress toward self-determination include lack of money, limited access to health care, or quality equipment, or accessible housing, or education, recreation or work.

Spinal cord injury comes with a social stigma, and sometimes outright discrimination. These are socio-environmental stressors and have nothing to do with motivation, attitude or coping strategy. You can't fully control these social barriers but you need to be informed about them. The rehab experience should include resources and education about disability legal rights, public benefits, job options, funding assistance, assistive technology, transportation, and personal care resources.

Rehabilitation is about making adjustments so you can get back into circulation in the community, as much on your own terms as possible. It may seem impossible but people do it all the time.

You may get lots of advice on how to handle getting slammed with spinal cord injury. Many say the best advice is to get active, whether that means sports, travel, school or work. Here's an evergreen from the annals of rehab advice: don't think about the 10,000 things you can't do; just concentrate on the 9,000 you still can do. This is another good one, about getting up and getting going, from the late Christopher Reeve: "Either you decide to stay in the shallow end of the pool or you go out in the ocean."

You will hear many atta-boy pep talks about the power of the human spirit. There are those in the SCI world who go on about their triumph over adversity, and how meaningful that was. Or you might meet people who say they

learned patience, or gained a fuller appreciation for others, only by joining the SCI club. You may have a hard time believing it, but some people with SCI say the experience has been so profound that they would not turn the clock back to their uninjured state.

You don't have to be a Pollyanna to make peace with spinal cord injury. One day, however, if you happen to look back and remember tapping into a deep resilience inside that carried you through this, feel free to share that with those who have recently arrived on Planet SCI.

The following article is by Dan Gottlieb. He is a clinical psychologist who has a cervical spinal cord injury. He has found resilience, and more, to manage his terrible loss while living a meaningful life. The article appeared in slightly different form in the Paralysis Resource Guide, reprinted by permission of the Reeve Foundation.

LIVE THE LIFE YOU HAVE

Dan Gottlieb is a practicing psychologist and a spinal cord injury survivor (C5/6), the result of an automobile accident that was not his fault. He didn't do too well with paralysis, describing 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."

After his injury, says Gottlieb, he was absorbed in self-pity. He felt victimized. And the school of life kept dishing it out. His parents and sister died; his marriage broke up and his ex-wife later died of cancer. His grandson was born with a type of autism. His own health took many unpredictable spirals.

Eventually, Gottlieb says, he quit fighting with his life. He discovered a powerful resilience. Tapping into his reserves of compassion, he armed himself to ride out the storms. Gottlieb found peace in the wake of suffering. "There is no relationship between disability and happiness. 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."

"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 that will happen. It's either when we walk again, or when our bladder starts working, or when we lose those pounds, or when our spouse wakes up and becomes human, or when the insurance company comes through – we get a picture in our head of the circumstances we need to make ourselves happy."

Says Gottlieb, "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 whose hopes and happiness hinge upon a specific 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 circum-

stances. Hope is the belief that tomorrow can be better than today, without a picture, without a photograph in your head, about what it should look like, or what it must look like."

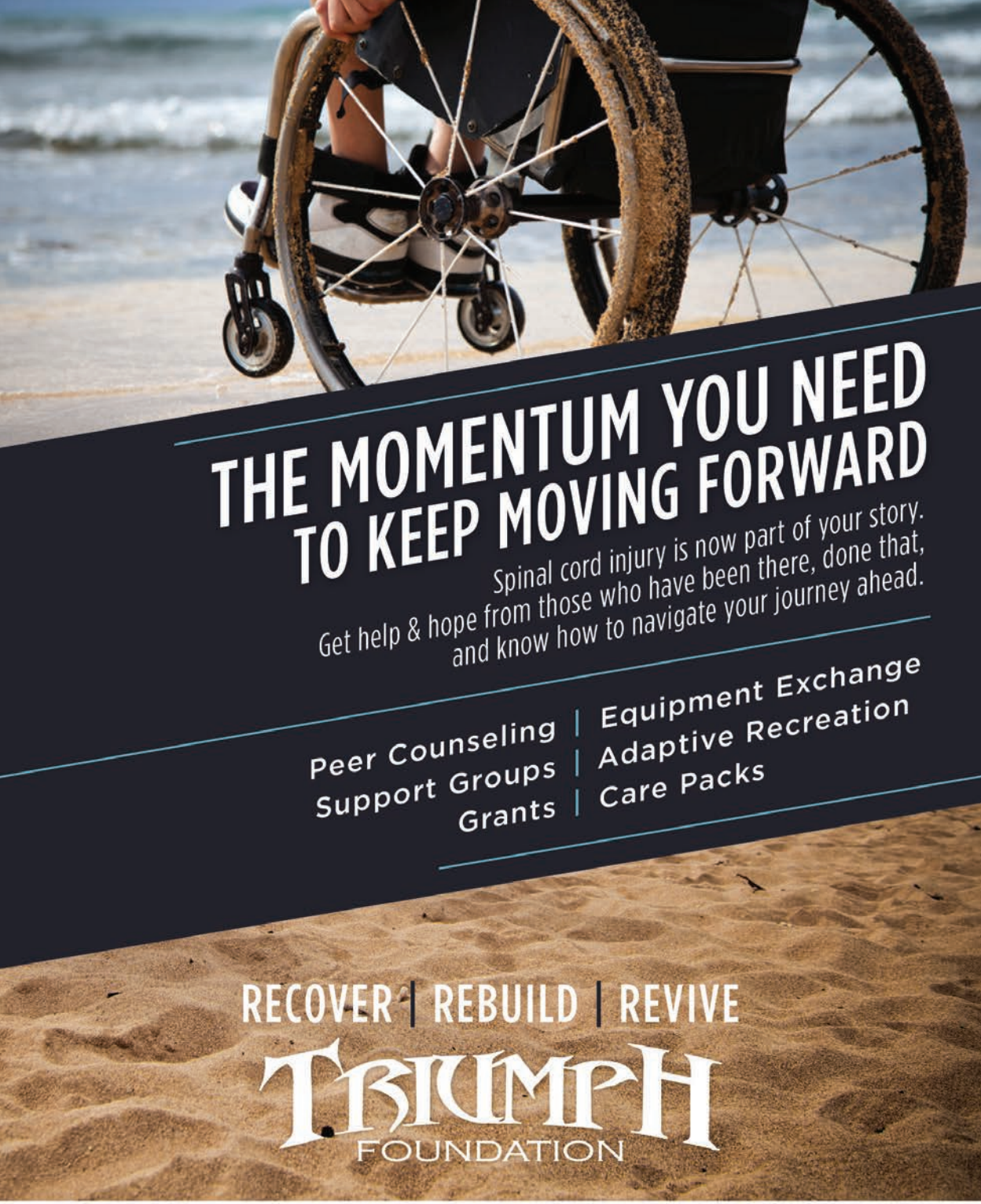
Gottlieb, a teacher at heart, freely dispenses advice on the Reeve Foundation website *(christopherreeve.org, search for "Dr. Dan.")*

"If we take ownership of our lives, we can teach that we can be vulnerable and strong. We can be dependent without losing dignity. We can have lives that may be difficult but we can live our lives with grace and gratitude."

One technique Gottlieb encourages is mindfulness, the "in the moment" feeling that people who meditate describe. "Being mindful takes you out of your narrative. The only thing we know for sure – the only truth we have – is what we experience. Other than that, it's all narrative."

The "big secret," says Gottlieb, is that none of us really wants to change. "And yet we keep demanding of ourselves that we change. That we'll be okay when we change. We really don't want to change. And I think the most profound change we can make in our lives is when we stop trying to change ourselves. And live, not just in the body we have, but the person we have. Imagine feeling compassion, kindness for the person that we are. Imagine that. And there is ample research out now about how that changes life profoundly, profoundly. That's the secret."

TRIUMPH-FOUNDATION.ORG



THE MOMENTUM YOU NEED TO KEEP MOVING FORWARD

Spinal cord injury is now part of your story.
Get help & hope from those who have been there, done that,
and know how to navigate your journey ahead.

Peer Counseling | Equipment Exchange
Support Groups | Adaptive Recreation
Grants | Care Packs

RECOVER | REBUILD | REVIVE

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SEXUALITY, DATING, ETC.

Spinal cord injury doesn't cancel out sex, it redefines it. Paralysis affects arousal, orgasm, and fertility, depending on your level and severity of injury. It also takes a psychological toll on your sexual persona and body image. You may feel less attractive or desirable, at least in the early days.

Let's start with men (since there are four times as many males as females living with SCI). Can you still get it up? Yes, most guys injured above the lowest part of the back (the sacral area) can get what's called a reflex erection, the response to direct stimulation. Some men, usually those with incomplete injuries, are able to get a psychogenic erection – the result of thinking about or seeing something sexy.

The hard-on may not be hard enough for penetration but some guys find that erectile drugs, e.g. Viagra or Cialis, are effective for sexual activity. Can you feel it? Depends. In most cases, no.

Besides drugs, there are other options for getting hard: vacuum devices, implanted pumps, and even implants. See a urologist familiar with SCI to run down the choices, and the precautions.

Are orgasm and ejaculation possible? Maybe. Most guys with complete injuries are not able to experience orgasm, although when it does occur it is sometimes the case that the sperm go backwards, toward the kidneys. Ejaculation, though, can be accomplished by most men; sometimes vibrators or electrical probes are used.

How about making babies? No doubt. Most men with SCI are able to father children; sperm volume remains pretty normal, although the degree of motility, or movement, can drop. Some special low- and perhaps high-tech stimulation techniques might be required for collecting the sperm, and introducing it to the egg.

Women's sexuality is affected by SCI, but not in the desire department or in the ability to conceive a child. Vaginal lubrication is typically reduced. Orgasm is possible if some function remains in the pelvic area.

Some women may miss their

period after injury, but menstruation usually becomes regular again after a few months. Getting pregnant is not usually a major issue, nor is vaginal delivery. Autonomic dysreflexia (see p. 102) during childbirth must be considered for women with higher level injuries (T6 and up). Obviously, you want an obstetrician who understands pregnancy, labor and delivery for women with SCI.

The number one issue many women with SCI report is the difficulty in finding a sexual partner; that is a real barrier, reinforced by the well-ingrained social stigma that people with disabilities are asexual. Not much you can do except resist the stereotype by being your sexy self, and by putting yourself out there to meet potential partners.

Can sex still be pleasurable? Sure. Sex can be fun even when not defined by orgasm. It's common that men and women with SCI discover new pathways for sensation and pleasure. There's something clinicians call phantom orgasm, a way to mentally reassign sensation toward parts of the body one can feel. Keep an open mind, be flexible and wiling to experiment. Communicate your needs. It's not always easy to talk freely and honestly about sex but take your time to explore ways to make both partners comfortable.

Relationships: can a couple survive if a partner is paralyzed? Yes, many do, especially if communication has always been open and honest. Some don't.

Safe Sex: better not ignore this if you want to prevent pregnancy. Condoms are considered the best choice. Women should avoid intrauterine devices and diaphragms; the pill is not usually recommended because it increases your risk for developing a blood clot (deep vein thrombosis).

Dating: This is a challenge for everybody. First you have to get yourself in circulation. No ask, no date. If you're online, should you disclose that you have a disability? Generally, yes, it's a good idea to avoid the surprise factor. There's a couple in SoCal who met online, both are wheelchair users, and both declined to disclose this. They hit it off anyway and are married with children now.

SEXUALITY RESOURCE

Sexuality & Reproductive Health After Paralysis is a booklet produced by the Reeve Foundation with Craig Hospital. It's a straight-talk guide to post-SCI sex and intimacy, redefining "the talk," dating, psychological adjustment, how sex changes after injury, arousal, orgasm, ejaculation, women's issues, reproductive health and a list of resources to learn more. Free, download at *christopherreeve.org, search publications.*

WIVES & GIRLFRIENDS OF SCI

WAGS of SCI is an outreach, advocacy and support group for the wives and girlfriends of partners living with SCI, founded in 2017 by Elena Pauly and Brooke Pagé.

The unique roll as a caregiver and lover is a challenging but rewarding dynamic; our role is not something many people understand.

Says WAGS, "We are the ones who are there when everyone goes home, back to their own lives, back to their own normal. We see the things others don't. We have a vulnerability with our partners that cannot be duplicated. We live this life alongside our partners, and are committed to providing community and outreach to women like us in a positive, constructive and resourceful way. We choose this life, and love our partners for who they are, regardless of any disability. When we connect with those who are like us, we feel a sense of relief and sisterhood, unexplainable and desperately needed. Our resources and insight are essential. We celebrate successes, encourage self-care in a supportive, empowering atmosphere where no topic is off limits."

Are you a WAG of SCI? Connect with other women who are living similar lifestyles:
Instagram @wagsofsc;
Facebook search 'WAGS of SCI;'
email wagsofsci@gmail.com, or
visit the Reeve Connect Forum, community.christopherreeve.org

MARRIAGE AND PARALYSIS

by Kirk Ingram

A spinal cord injury can stress a relationship. And no doubt having a disability can make it harder to find a mate. But if you're married (or want to be) and wondering how to keep it together, here are some tips:

1. Find others in your situation and ask how they handle it. People have done it. Learn from them.
2. Be open and honest with your partner. You are both going through many changes and a grieving process. Share your feelings. Listen to each other. Love wins.
3. You can still sleep together. Solve the bed situation by putting the spouse's bed next to the medical bed (to prevent pressure sores) to help maintain intimacy.
4. If your partner is willing, personal care attendant (PCA) training is an option. Once registered as a PCA, your spouse (or other family member) may qualify for reimbursement via Medi-Cal waivers).
5. Money is another stressor. Seek advice from a trusted legal and financial advisor. Understand your financial options. People might tell you that you can't stay married or that you must go completely broke before you can get public benefits – not necessarily true. Most people with SCI qualify for Social Security benefits and some form of medical assistance (state/county), for yourself and your children too. To help protect your assets and your working spouse, you may want to set up a Supplemental Needs Trust for money donated by others, or a Special Needs Trust with some of your own assets to help qualify for assistance. Again, get reliable advice.
6. At your weakest moments, lean on your faith. Be patient. As has been said, it gets better.
7. Parenting: The most important job in the world is being a mom or a dad. And it is one of the most fulfilling. Even with an SCI, you can and should stay involved in your children's lives. Kids are wonderful adapters – they don't see the chair, they see mom or dad. Spend time with them. Talk. Find games you can play. Watch, listen to and praise your child – that's often what a kid wants most from their dad or mom.

   Here's a website from a mom in a wheelchair with more parenting tips, including the important topic of getting pregnant (yes, this may stir up new fears about being an adequate provider and caregiver, but women living with paralysis do this; they figure out the babymaking part): *parentsinwheelchairs.com*
8. Concerned about getting

married? Love will find you. You just need to be open to it. As weird as it may sound, a fulfilling relationship starts with your own happiness. People are attracted to those who are happy and fun to be with.

Kirk Ingram, C4, is Chair of Get Up Stand Up to Cure Paralysis (GUSU.org). He is a husband and a dad.

MORE RESOURCES ABOUT SEX

"Sex and the Single Guy" is one of many essays published online by Stanley Ducharme, a sex therapist who works with SCI folks. His advice: sex is not performance, it's a shared experience. That means creativity and humor must come into play. Some random thoughts:

"Establishing a relationship requires that we put ourselves on the line and face uncertainty as well as issues regarding attractiveness and appeal to another person. There is just no easy and painless way to meet a potential partner ....

"As difficult as it can be to discuss the mechanics of sex and personal issues about your body, it is absolutely essential that some of these issues be shared. If not, anxiety is a sure bet ....

"I often encourage men to take things slowly as they initially become sexually active after injury. I typically encourage men to avoid trying to have intercourse during those first few intimate encounters following an injury. Instead, enjoy the sensations of being touched, kissed or licked."

Ducharme offers lots of other essays and resources to explore sexuality after SCI, and to keep it fun: *stanleyducharme.com*

Says sexologist Mitch Tepper, a quadriplegic for 35 years, a successful therapist and sexuality advocate. "If you think your disability is limiting your sexual potential and you want more out of life, if you are looking for a sex and relationship coach who has been there and has overcome every obstacle to succeeded in all areas of life, you came to the right place ... You don't have to break your neck to be a great lover, but you can learn a lot from someone who has!"

Tepper's tagline, and the core of his clinical practice, is "regain that feeling." That's also the title of a book he wrote about the path toward his own self-discovery. For more from Tepper, *visit drmitchelltepper.com*

SCI: FIRST 90 DAYS

CAREGIVING

• SCI AFFECTS THE WHOLE FAMILY

CAREGIVING

It doesn't take long to see that spinal cord trauma sweeps up whole families, and even networks of friends, into the confusion and uncertainty.

Once graduated from rehab, many people living with SCI still require help – usually this comes from a member of the family. Being a family caregiver is a tough job, both physically, and emotionally. Caregivers never ask for this job; the job asked for them. You don't get paid. You might even have left a paying job to take on this new one. You can't delegate. You can't just take a day off. A caregiver has to be a sort of executive director for the injured party. He, or most often, she, must deal with medications and homecare details, meals, transportation, bill paying, and keeping the household from falling apart.

Yes, taking care of a loved one is a common feature of life on Planet SCI. And indeed, it can be a burden. But caregiving is an essential job; it is often fulfilling and rewarding.

But just as the injured person asks, you ask: "Why me?" Same answer: Why not you? Nothing fair about it. At some point, you have to make a turn from feeling victimized to accepting and choosing the role of caregiver. If you don't embrace it at some level you're going to have a tough time dealing with anger and even resentment.

If caregiving has a sort of passage to acceptance, it's important to recognize that caregivers mourn. They mourn what their loved one is going through, the loss of independence. Caregivers have their own issues, too. Isolation, loss of personal time, exhaustion, plus feeling like nobody gets what they're dealing with.

HOW TO DEAL WITH THIS?

The first rule of caregiving is take care of yourself. Keep some balance in your life, as much as possible. Take time for yourself. You can't be an effective caregiver if you're a sleep-deprived, burned-out mess. Surveys have shown that caregivers are more depressed and anxious than the general population; 40 percent of caregivers have back problems, three in four don't go to the doctor as often as they should, and the majority report not eating very well.

How does a family caregiver get a break? Start by learning how others manage what you're trying to do. Connect to other caregivers. It's easy to find an online support group (look at Caregiving

on Facebook, see the Caregiving forum at CareCure, for example *(carecure.net)*, or visit the Reeve Foundation blogs and forums *(christopherreeve.org)*. People use the forums to learn, but also to vent, or whine – that's OK, it's better than stewing in self-pity.

Find a local resource *(see list below)*. By sharing your experiences you can learn some problem solving strategies from other caregivers, and maybe help someone else along the way. Resist being all on your own; get on the same bandwidth with others in your situation.

Learn as much as you can about your loved one's situation. This is important: You need to think of yourself as a member of the healthcare team. That way you can speak with doctors or therapists with greater confidence and ease, and with greater impact. You will also be well-served by gaining knowledge of the system: the difficult insurance and benefits details that never seem to get fully sorted.

You must speak out. You may be the only one to advocate for your loved one's best interests. That includes financial planning, or perhaps managing legal affairs.

Don't forget how to ask for help. If a neighbor says, can I do something, the answer is yes. How about you have someone watch the home front while you take a two hour break to meet a friend. Have a friend run an errand, or fix a meal. If you have a network at church, or work, they may want to help. Let them. There's no shame in admitting your caregiver role is consuming your life. Don't let it.

Learn to manage stress. Meditation, or mindfulness, can be very effective in dealing with the noise and distractions running through your head. This is easy to do: start by setting aside 10 or 20 minutes, breathe slowly and deeply, focus your attention on an object, or a mantra if you want. Visualize your tension releasing, your body and mind relaxing. Many communities, schools and hospitals offer classes. There are also lots of mediation and relaxation apps available online.

Can you get a break? There are caregiver respite services in some communities; there are also a number of agencies that provide respite care services for a fee (see for example the respite locator at the National Respite Coalition, *archrespite.org*; see also resources below for regional caregiver support centers. Some provide no-cost respite services.

HIRE AN OUTSIDE CAREGIVER?

Families sometimes can't do it all, especially for people with high-level injuries who are unable on their own to get out of bed, or bathe, eat, or take care of personal hygiene. Finding good caregivers is difficult. Some places to look include Internet services such as *care.com*, or even *Indeed.com*. Some people find good caregivers on college campus bulletin boards. There are quite a few agencies in California that screen potential caregivers. There are advantages to using an agency but cost savings is usually not one of them.

Before you start doing interviews, think of this as if you were

running a business, which in fact, you are. Write out a job description. Do you require special training or experience? Do you need a driver, somebody who can lift? Once you find someone who fits the bill, and who seems simpatico with the care recipient, draft a contract, or at least a letter of understanding, to formalize the agreement between you, the employer, and the employee.

You could of course hire an attorney to draft an agreement but that may not be necessary. There are guidelines for what to include available from the Family Caregiver Alliance *(caregiver.org)*. Include the following: wages and benefits (mileage, meals, vacations, etc.), hours of work, detailed description of duties, things you don't want (smoking, for example) and the terms by which you can both terminate the arrangement.

CAN YOU USE STATE MONEY TO PAY FRIENDS OR FAMILY?

Question: If I need a caregiver at home, can I get reimbursed to pay a friend, my wife, my child?

Answer: Yes. In California a Department of Social Services program called In Home Supportive Services (IHSS) allows qualified people with disabilities to hire, manage and pay their caregivers, including family and friends. To qualify (already on Medi-Cal) there may be income limits.

The program is part of a wider Medi-Cal waiver program, an outreach intended to keep elderly and disabled people in their own homes and not in institutional settings (nursing homes). IHSS gives the consumer much more choice in who to hire. There is a bit of red tape, of course, but it's easy to find a case manager (program is managed by county governments) to help get you qualified. The rate for attendant services is about $25 an hour. To find your office *see cdss.ca.gov search 'county IHSS offices.'*

HOUSING WAIVER RESOURCE

Another stay-out-of-nursing homes waiver program to know about: California has an Assisted Living Waiver that helps move Medi-Cal eligible seniors and persons with disabilities from a nursing facility to a community home-like setting in a Residential Care Facility (RCF), an Adult Residential Care Facility (ARF), or public subsidized housing. Consumers pay their room and board, the state reimburses. For more, including lists of available facilities in participating counties, *see dhcs.ca.gov, look up 'Assisted Living Waiver.'*

COMMUNITY HOUSING RESOURCE

Freedom to Live provides affordable housing in SoCal for people with SCI and other disabilities.

FTL offers qualified recipients subsidized rent based on financial need. Temporary housing is provided in shared, safe living environments in community settings. Tenants learn adaptation skills and gain confidence while taking control of their own lives. This prepares those leaving an institutional setting, or a home where independence has not yet been

achieved, to move into a permanent home in a community setting. FTL operates several "Freedom Homes" in the San Fernando Valley, LA. *Visit freedomtolive.org*

CAREGIVING RESOURCES

In California, a network of Caregiver Resource Centers offers help to family caregivers. Services are free or low cost, and include specialized information, consultation, counseling and planning, respite care, support groups, legal and financial help, and training. Each center provides unpaid caregivers with support so they can provide competent care to their loved ones at home.

Coast Caregiver Resource Center (a program of Cottage Rehabilitation Hospital) based in Santa Barbara, serves San Luis Obispo, Santa Barbara and Ventura Counties.
2415 De La Vina Street,
Santa Barbara, CA 93105;
805-962-3600, *coastcrc.org*

Caregiver Resource Center of Orange (a program of St. Jude Medical Center in Fullerton) serves Orange County.
130 W. Bastanchury Rd.,
Fullerton, CA 92835;
714-446-5030, *caregiveroc.org*

Inland Caregiver Resource Center serves Inyo, Mono, Riverside, and San Bernardino Counties.
1430 East Cooley Dr., Suite 124,
Colton, CA 92324;
909-514-1404, *visit inlandcaregivers.com*

Southern Caregiver Resource Center serves San Diego and Imperial Counties.
3675 Ruffin Rd., Suite 230,
San Diego, CA 92123;
858-268-4432,
caregivercenter.org

USC Family Caregiver Support Center, serves LA County (formerly Los Angeles Caregiver Resource Center), is a program of the USC School of Gerontology,
3715 McClintock Ave.,
Los Angeles, CA 90089;
855-872-6060, *fcscgero.org*

OTHER CAREGIVER RESOURCES

Caregiver Action Network provides free education, peer support, and resources; *caregiveraction.org*

Easter Seals offers resources to support and care for caregivers; *easterseals.com, search caregiver.*

Facebook offers online support groups, including The Caregiver Connection and SCI Caregivers Only (membership required). Search by 'caregiver,' on *facebook.com*

Family Caregiver Alliance addresses the needs of families and friends who provide long-term care for loved ones at home; *caregiver.org*

National Alliance for Caregiving is a coalition of organizations focused on policy and advocacy; *caregiving.org*

The Rosalynn Carter Institute for Caregiving, named for the former First Lady, is an advocacy, education, research, and service unit of Georgia Southwestern State University; *see rosalynncarter.org*

National Respite Coalition and National Respite Locator Service, helps parents, family caregivers, and professionals find respite services to match their needs; *archrespite.org*

Smart Patients is an online community for patients and caregivers; *smartpatients.com*

Veterans: Caregiver Support Line, 1-855-260-3274

SCI: FIRST 90 DAYS

GETTING MOBILE

- SUPPLIES
- EQUIPMENT
- TOOLS
- HOME MODIFICATION

GETTING MOBILE

This section is about tools, gear, medical supplies and cars. You wouldn't know most of this stuff existed until you wake up on Planet SCI. It all seems pretty complicated. It's not, but options vary all over the place, depending on your exact specifications and preferences, and of course, funding.

Every year there's a three-day disability trade show in LA called the Abilities Expo *(abilities.com)*. You should go, first because almost all the stuff in this chapter is there to see and try out. Second, because the Expo is a good place to meet the community, the dealers and vendors, the SoCal agencies and programs that serve you, and your fellow wheelie poppers – the folks who know the ropes about what gear works best.

THE WHEELCHAIR

First Chair: People don't often leave rehab in their very own set of wheels; they go home in a loaner or rental chair. That's because wheelchairs are not one-size-fits all; they have to be custom fitted and special ordered, which can take a month or two. Also, if your injury is new, your body may be changing over the first few months; this could delay prescribing your chair (you do need a prescription). At some point, though, you'll be assessed by a seating specialist, usually an occupational or physical therapist. Besides your weight and height, it's important to know how strong you are, what you can do functionally and how that might change, how well you can transfer in and out of a chair, how much trunk stability you have, etc. Your wheelchair spec ought to take into account where you are going to be using the chair (e.g., will you be driving a car from the chair? Is there a lot of carpeting at home, are you likely to play sports, will you use the chair on rough terrain?).

Unless you are familiar with all the options, the first chair will be selected for you. This may not matter now, but it will. You can try to steer the process toward better style and function. Even if your first chair is a generic model, at least make sure it fits. Maybe your next one can be more sporty

or colorful, and more suited to the way you want to roll.

MANUAL CHAIRS

It takes a fair amount of effort but most people below about C6 are able to push a manual wheelchair. Manual wheelchairs are built like bicycles – easy to transport and sturdy, and they offer riders a bit of exercise (careful though, overuse of the shoulders, arms and wrists can also lead to repetitive injuries, which makes it critical to get the right fit, and to learn efficient technique).

Forty years ago, the standard wheelchair was a clunky chrome commodity that weighed twice what a manual chair does today, and there is simply no comparison in handling and performance. Modern lightweight chairs come in a rigid frame model, which offers more torsional stability and better handling, or a folding frame, which offers more portability.

The durable medical products industry offers several categories of manual wheelchair: there are some good only for temporary use. For long-term users, there are lightweights and ultra lightweights. Lightweight frames are usually steel; ultras are aluminum, magnesium or titanium, or carbon fiber. There is a clear case to be made for the medical necessity of an ultralight – they are not only easier to push but adjustable. The authoritative SCI clinical practice guidelines (Consortium for Spinal Cord Medicine, *pva.org*), addressing preservation of arms, shoulders and wrists, recommend a "high-strength, fully customizable manual wheelchair made of the lightest possible material."

Go Lightly: Titanium chairs can weigh under 10 lbs., without wheels; you'll see a lot of riders in TiLite chairs. Aluminum chairs can weigh under 13 lbs. Magnesium is light and strong, but not cheap *(see lashersport.com)*. A carbon fiber frame can weigh less than 10 lbs. (see the very fine looking Apex from *motioncomposites.com*). Some riders say carbon chairs are too stiff but others dig the look, the dampened ride, and the reduced fatigue profile in day-to-day use.

Insist that your seating specialist set up you up in an ultralight; these may be more expensive than some steel frame chairs, but the medical literature also points out that they are not only better for long-term arm and shoulder health, but are also more cost-effective – they last 13 times longer than the so-called depot chairs you see at the airport.

Unless you have an experienced advocate on board, the choice of chair will usually come down to the product preferences of the rehab team, and the durable medical equipment (DME) vendors they like to work with. Get as involved in the process as you can. Explore your options.

Chairs come in lots of colors now, and there are many ways to customize your ride. The wheelchair companies try to out-hip each other when it comes to naming their products – you have the Spazz, the Aero Z, the GT, Ballistic, Veloce, or Terminator. Check out many of the brands at websites like *spinlife.com* or *sportaid.com*

Chair Mods: many people need to put a back on their lightweight chair to maximize fit and trunk stability. You can might check out a trick suspension system. The Shockblade chair from SoCal-based Colours Wheelchair *(colourswheelchair.com)* offers a four-wheel suspension system; the company claims it helps reduce spasms and fatigue, and thus may be justified as medically necessary. Aftermarket front casters *(see froglegsinc.com)* also smooth the ride and can be very important to minimize spasms in new injuries. These add-ons can also be medically justified, e.g., you can get them paid for.

There are options for strong, lightweight rims (*spinergy.com* is a good place to start). The lighter the rim the easier it is to push the chair, and the easier it is to load it in the car. There are many types of tires, with an eye on off-roading, or sports. There are choices for the push rims, too, taking into account ergonomics, comfort and function *(see out-front.com)*.

Special Chairs: there are models specifically for racing, basketball or tennis *(topendwheelchair.com)*, for very large users (up to 1000 lbs.), for accessing the beach *(beachwheelchair.com)*, for playing golf *(solorider.com)*, for riding across streams and down mountains *(reactiveadaptations.com)*, or for offroading in mud and sand *(actiontrackchair.com)*.

Box Wheelchairs: you probably won't get one as a first chair but you might want one later; they're crafted by hand — comfortable, durable and custom fit. Box makes a lot of the chairs for extreme sports, including the ones the top rugby and WCMX guys use; *boxwheelchairs.com*

MEDICAL NECESSITY

Medical necessity is the name of the game in reimbursement. To get your supplies or equipment paid for, you have to justify the expense; you must supply your insurance company, Medi-Cal or Medicare with a letter of medical necessity (LMN). Rehab doctors write these all the time; vendors of reimbursable products are often willing to help with advice and even LMN templates.

"Titanium can weigh under 10 lbs, without wheels; aluminum chairs can weigh under 13 lbs. Magnesium is light and strong, but not cheap. Carbon fiber is another option."

PUSH TECHNIQUE

Long smooth strokes are better than short strokes; your hand should drop below the push rim at completion of push. Adjust the rear axle as far forward as possible (easier to push), without making the chair too tippy. Learn how to pop and hold a wheelie. This will help you across choppy terrain and over curbs.

GETTING MOBILE

CUSHIONS

You have to use a cushion on a wheelchair to protect the skin, and for a firm sitting base. There are a number of choices, including foam, air or gel. Your seating therapist will make the recommendation based on your body, level of activity and perhaps a map of your seating pressure points. ROHO is a popular air cushion for good reason; they work *(roho.com)*. Jay *(sunrisemedical.com)* cushions are filled with slow-flow gel, which molds to the body and offers protection. Aquila *(aquilacorp.com)* features a dynamic system that alternates pressure.

POWER WHEELCHAIRS

Can't push a manual chair? Get motorized. Power wheelchairs start with a base – the motors, batteries, drive wheels, casters and electronics, to which a seating system is attached. There are rear-wheel drives, front-wheel drives (more maneuverable than rear-wheel), and mid-wheel drives (may turn on a dime but are less robust outdoors). Your choice will depend on your specific needs and abilities, and where the chair will be used. A newer chair called Whill offers an all wheel drive "personal electric vehicle." It features a sleek, non-medical design *(whill.us)*.

Several considerations regarding power: the drive control can be operated using various kinds of joysticks or switches (such as sip-n-puff). Many with high level injuries rely on recline and/or tilt-in-space chairs to relieve pressure. Recline flattens the back; tilt moves the seat and back as a unit, reducing stretching of skin.

Power wheelchairs can also be fitted with elevating seats or a mechanism to stand the user upright. Elevating seats can help with transfers, as it is easier to transfer from a higher position. The SCI clinical practice guidelines (Consortium for Spinal Cord Medicine, *pva.org*) recommend that anyone with SCI who uses a power wheelchair and who has good arm function should be provided with seat elevation, or at least standing functionality.

Scooters may be an option, especially if you don't need one full-time. Scooters come in three- and four-wheel rigs.

BATTERIES

Battery life is a crucial issue for power chair users. Batteries must be charged regularly to maintain battery performance. Power chair batteries must be of the 24-volt deep-cycle variety, discharged over long periods, as opposed to a car battery used for short bursts of power. There are three types of batteries: old school wet/lead-acid batteries that may require special handling, especially when you fly; gel batteries, which are more expensive; and absorbent glass mat (AGM) batteries, best for flying but most expensive.

POWER-ASSISTS

These are add-ons to manual wheelchairs to provide a burst of power when you need it. They are extra practical if you live in a hilly area. Using a minimal push, a user can go faster and up steeper terrain. Plus, they don't change the

low-profile look of a basic manual chair.

If you have a higher level injury but prefer not to use a full-on power chair, power assist may be the ticket. If you're a para with weak arms or shoulder issues, this option will really ease the strain and add to your mobility.

The power-assists are not cheap and they may add quite a bit of weight to the chair – a major consideration if you plan to transfer from wheelchair to car without someone to help load the chair.

Choices for wheel-mounted units include e-motion or twion *(alber-usa.com)*, Quickie Xtender *(sunrisemedical.com)* or NaviOne, from Yamaha, *(yamahanavi.com)*. Attachable power assists are available from SmartDrive *(max-mobility.com)* or Zx-1 *(spinergy.com)*. Alber also has an attachable, the smoov.

The companies that sell power assist products will help you figure out the medical necessity paperwork. Basically, if you lack physical strength to push a manual wheelchair all day long, or if you have arm, wrist or shoulder pain, you can make a case for reimbursement.

KIDS' CHAIRS

Because children's bodies are growing and changing, their wheelchairs must be adjustable, and must also be replaced more often than an adult's chair. The market has added some fun to pediatric chairs. Colours offers the Little Dipper, or the Chump *(colourswheelchair.com)*. Likewise, the Zippie *(sunrisemedical.com)* and the Orbit *(Invacare.com)* are made for younger wheelers who want to ride with a bit of style.

STANDING

A standing chair, whether manual or power, looks like a normal chair but can rise to put the user in a standing position. Being eye to eye with walking folk, and able to reach things, can be very beneficial at home, school or workplace. It helps to prevent pressure sores, improves circulation and range of motion and, for some people, reduces spasms and contractions. Standing has physical benefits and medically justified purposes, but is often difficult to get covered by insurance. *Check out stand-aid.com*, *primeengineering.com*

Even if you don't want or need a chair that stands, a standing frame may be a good idea. You can buy a frame *easystand.com* or even make one at home (look up how-to videos on YouTube).

CHAIR RESOURCES

Shop around. LA-based filmmaker Jenni Gold, herself a powerchair user, made a series of videos for the Reeve Foundation on sourcing either manual or power chairs. Good info. *(To find the videos go to christopherreeve.org, search for Jenni Gold)*.

The CareCure community Equipment Forum offers a very lively and nerdy discussion about gear and supplies *(carecure.net)*.

UROLOGICAL SUPPLIES

Most people with SCI are taught clean self-intermittent cathe-

terization; that means you insert a plastic tube called a catheter through your urethra and into the bladder each time your bladder is full. If you lack hand dexterity to self-cath, you'll likely be fitted with a catheter that stays inserted in your bladder, known as an indwelling, or Foley. Either way, your doctor will prescribe size and style of catheter.

In the hospital setting, they often will have only one brand that they stock, but may show you additional options if you ask. Once you go home, you will usually have some discretion for the brand of cath you choose, even though there may not be a significant difference in function or pricing for urological products.

Catheter manufacturer companies offer various incentives, including these: Coloplast *(coloplast.us)* offers a personal advice program for urology and ostomy users. Cure Medical *(curemedical.com)* catheter products are carried by many suppliers; the company, founded by a quadriplegic in Newport Beach, donates a percentage of its income to SCI cure research. Catheter distributors like ABC Medical *(abc-med.com)* provides lots of resources for sports and active living; and Apple West Home Health *(applewesthms.com)* and Urology Professionals *(urologypros.com)* have reps with SCI that offer peer-counseling.

There are several kinds of intermittent caths on the market, some with special hydrophilic coating to make them super slick, thus heading off damage to the urethra; there is also some evidence in the medical literature that hydrophilic units, such as Lofric *(wellspect.us)* or SpeediCath *(coloplast.us)*, reduce bladder infection. There are also self-caths that are infused with nitrofurazone, an antibacterial, or with a silver coating, intended to make them more hygienic; those cost nearly double a regular one-time use cath, so you and your doctor will have to document medical necessity.

Medicare changed the rules ten years ago (with private carriers following suit) allowing users up to 200 catheters a month. It used to be you got four, and had to wash and reuse them, over and over again.

You may hear about so-called closed or touchless systems; all the companies make them. In this case, sterile gloves are used; the catheter itself is never exposed outside sterile packaging. The cath features an introducer tip, bypassing the part of the urethra exposed to the fairly germy perianal area. This is designed to prevent contamination of the catheter, blocking bacteria from getting a ride into the bladder. The urine drains into a self-contained bag and the whole unit gets disposed.

Closed or sterile catheter systems have been shown to reduce but not prevent UTI; people who use sterile caths still get infections. Closed systems cost about eight to ten times as much as straight catheters, roughly $1,000 a month, which over many years is a lot of expense. Not everyone agrees these systems are worth the money, including insurance companies. You can't get a supply

of closed catheters reimbursed unless you live in a nursing home, are a woman who is pregnant, or can show a history of bladder infections. Yes, that's right, go figure, you have to get sick so you can get a product that may prevent you from getting sick.

For those who have trouble inserting a normal cath use one with a curved (coude) tip, which makes passing the catheter easier.

Some men with bladders that are always flexing, or lack hand dexterity to self-cath, prefer to void constantly, using a condom catheter attachment that drains into a leg bag.

In the beginning, you'll likely be fitted with a catheter that stays inserted in your bladder, known as an indwelling, or Foley, but when considering long-term use these can be irritating and for some people, demoralizing . Another option is a supra-pubic catheter, that is like a Foley except inserted into the abdomen above the pubic area below the belly button.

Another option for people who have difficulty with self-catheterization through the urethra or have discomfort with self-catheterization have had the Mitrofanoff procedure. It is a surgical procedure to assist with bladder emptying, creating a self-sealing channel using the appendix or with part of the colon. The channel runs from the surface of the abdomen to the bladder to be used for intermittent catheterization.

Cathing through the urethra isn't practical for many women, and reflex voiding using a condom catheter is a non-starter. So the supra-pubic catheter and Mitrofanoff have been especially successful in helping women manage emptying their bladder.

"Before you leave rehab, someone – preferably an occupational therapist – must help you and your family understand access issues in your home."

PREPARING TO TRANSITION HOME

is a booklet produced by the Reeve Foundation with Craig Hospital. Available free, *see christopherreeve.org*, click on "publications." The booklet gives you ideas of what to think about before leaving inpatient rehab. Top of the list is continued medical care and as much physical and/or occupational therapy as possible. You'll also need to consider what kind of assistance you may need at home, transportation, accessibility and equipment needs, and funding resources.

HOME MODIFICATION

Is your home going to work for you? First, of course, can you get in the front door? And then, importantly, can you use the bathroom? Before you leave rehab, someone from discharge planning – usually an occupational therapist

– along with your family or friends, must know about access in your home, and what your options are for adapting it, or getting something else.

The discharge people at the rehab may be able to suggest a few modifications, and they may also have contacts to suppliers and contractors.

Of course home modification can be as far reaching as your imagination, but if you want to start moving walls or adding an elevator, or lowering all the kitchen counters six inches, you are going to run up an enormous tab. There are resources that might help with some basic mods. The federal Community Development Block Grant program funds state and local agencies that in many cases offer home modification and repairs. Start by contacting your local community development office. In Los Angeles, for example, contact the Community Development Commission, *lacdc.org*

Some home mods are not too costly, such as adding a ramp to the outside door, or widening a door (32 inches is the ADA minimum requirement for a wheelchair). One cool and inexpensive adaptation is installing offset door hinges – these swing the whole door away from the opening, adding two-inches to the width, at a cost in the $500 -800 range, installed.

Transferring from a chair to a bathtub can be tricky. Grab bars are a good idea around the tub (this goes for the toilet area, too). Many varieties of shower transfer seats are available. A chair slider system is on the market to transfer you to an existing shower stall without major remodel *(shower-buddy.com)*. Roll-in showers are a very handy solution, if there's room in the bathroom after taking out the tub. Prefabricated shower floors, some about the same size as a standard 5-foot tub, are an option.

Renters: Can you make any home modifications if you are a tenant? Yes, per the Fair Housing Act, a landlord cannot refuse to let you make reasonable modifications to your dwelling or common use areas, at your expense. You have to agree to restore the property to its original condition when you move, if the landlord requests. Download a copy of "California Tenants—A Guide to Residential Tenants' and Landlords' Rights and Responsibilities," written by the CA Department of Consumer Affairs office; *dca.ca.gov*

Note for tax deductions: IRS rules state that you can deduct medical expenses for special equipment installed in a home, or for improvements, if their main purpose is medical care for you or your dependent (the deductions are offset by any increase in the value of your property). The IRS rules include costs for constructing ramps, widening doorways, modifying hallways and doorways, installing railings, support bars, or other modifications to bathrooms, kitchen modifications, or porch lifts.

ASSISTIVE TECH LOANS AND FUNDING RESOURCES

California Foundation for Independent Living Centers *(cfilc.org)* is a coalition of the state's independent living centers whose programs include access to equipment by way of Ability Tools and Freedom Tech.

Freedom Tech is an equipment loan program with affordable financial loans ($500 to $15,0000 to purchase needed assistive technology. The program can lend you money to purchase a variety of assistive technology including computers and adaptive accessories and software, adaptive driving equipment, or home modifications such as ramps, accessible showers, and grab bars; *freedomtech.org*

Ability Tools, formerly the AT Network, is California's federally funded Assistive Technology Act Program. The program provides equipment exchanges, device lending libraries, loan programs for assistive gear, etc. The California Assistive Technology Reuse Coalition. supports organizations that accept and donate assistive technology and durable medical equipment (DME) to people in their communities for free or low-cost. *See abilitytools.org*

Here are the SoCal reuse programs and equipment lenders:

Dayle McIntosh Center,
Anaheim 714-621-3300;
daylemc.org

ILC of Kern County,
Bakersfield, 800-529-9541;
ilcofkerncounty.org

Inland Hospice,
Claremont, 909-399-3289;
inlandhospice.org

SoCal Resource Services for Independent Living,
Downey, 562-862-6531;
scrs-ilc.org

Communities Actively Living Independent and Free,
Los Angeles, 213-627-0477;
califilc.webs.com

Riverside Community Access Center,
951-274-0358; *ilcac.org*

Physical Therapy For All,
San Juan Capistrano,
949-735-9955; *ptforall.org*

ALS Association, LA Chapter,
Agoura Hills, CA, 818-865-8067;
alsagoldenwest.org

Convalescent Aid Society,
Pasadena, 626-793-1696;
cas1.org

Assistive Technology Loan and Reuse,
OC Goodwill, Santa Ana,
714-361-6200; *ocgoodwill.org*,
search 'fitness center'

Durable Medical Equipment Aid Society,
Tarzana, CA 91356, 213-361-6788;
thedme.org

CompuTech for Humanity,
North Hollywood, 818-230-5182;
see computechforhumanity.org

HOME MOD RESOURCES

The National Resource Center on Supportive Housing and Home Modification is a national clearinghouse based on the USC campus. The center promotes independent living at home for all ages and abilities, and provides training, education, and information

regarding home modification services. Andrus Gerontology Center, 3715 McClintock Avenue, Los Angeles, CA 90089; 213-740-1364. *Find a lot of good resources on the website, homemods.org*

Accessible Construction is a Los Angeles-based contractor and product supplier for barrier-free design; *accessibleconstruction.com*

AARP HomeFit Guide offers ideas, and prices (spoiler alert: major home mods are very expensive); *aarp.org*

At Home Living Solutions offers design and contractor services for home modification. Based in Mission Viejo, serves all of SoCal. Free evaluation; *atHome4.com*

Center for Inclusive Design and Environmental Access at the University of Buffalo offers robust resources on architectural design, product development, and accessible housing. *idea.ap.buffalo.edu*

Independent Living Centers: some may have funds available to assist with housing or home modifications. *(See p.172 for full list.)*

Handyworker Program provides grants of up to $2,000 for minor fix up or home repairs up to $5,000 for low-income owners of single-family homes. Contact the community development office in your county.

National Association of Home Builders offers an online directory of contractors trained and certified in home modification. *nahb.org*

Rebuilding Together is a national network that helps to improve and revitalize communities. Some 100,000 volunteers complete about 10,000 rebuild projects nationwide each year. Affiliate offices in Kern County, Long Beach, San Diego, San Francisco, San Gabriel Valley Foothills, and Southern California Council, based in Irvine. *See rtsocal.org*

PossAbilities, a program of Loma Linda University Health, offers grants or scholarships for members for equipment; *teampossabilities.org*

Totally Accessible Homes designs, builds and installs. 912-585-7592; *totallyaccessiblehomes.com*

Triumph Foundation consults on home modifications in Southern California, and offers a grant program called Keep Moving Forward; *see triumph-foundation.org*

Catalogs: these online stores sell home modification and home healthcare products: *abilitysuperstore.com, liveoakmed.com, rehabtool.com, exmed.net,* and *silvercross.com*

CARS AND DRIVING

Driving is pretty much a SoCal birthright. Getting back on the road is certainly possible for many people dealing with paralysis, even those with limited hand and arm function. It's not really hard but you do have to learn new skills, using hand controls and perhaps power options for switches and controls. There are also some techy joystick controls for those with limited hand function.

First, get an evaluation from a driver trainer; this person should be part of your rehab team. For example, the Casa Colina Adaptive Driving Program prepares people to drive safely and competently, pass DMV testing, and regain

their driving independence; *casacolina.org*

If your rehab doesn't offer driving training, search the Association for Driver Rehabilitation Specialists *(aded.site-ym.com)* for a certified Driver Rehabilitation Specialist. Your evaluation will assess your strength, range of motion, reaction time and general fitness to handle a vehicle.

What car? There are all sorts of options, with the key factor being whether you drive from your own chair or transfer in. If you can transfer to the driver's seat, your best bet is a car with a big door – e.g. a coupe. Modified vehicles, especially vans and mini-vans, with lifts and raised ceilings, etc., are practical but pricey.

Standard hand controls attach to the gas and brake pedals, usually with a pull for go and push for stop. There are some cool controls that mount to the steering wheel for two-handed driving *(see kempf-usa.com, or guidosimplexusa.com)*.

Joystick technology is expensive, but generally safe and reliable. Lots of folks who can't turn a steering wheel are on the road using mechanical systems *(drivingsystems.com)* or digital systems *(emc-digi.com)*.

Insurance: coverage cannot be denied because of disability, and higher premiums are not allowed unless the company can prove you are a higher risk driver; that's hard to do because drivers with disabilities are generally considered to be a lower risk pool than the general public. Insurance companies may try to put you in a higher risk (e.g. "street racing") category if your rig is heavily modified.

Make sure your car policy includes replacement or repair of your wheelchair and other gear (some power chairs are more expensive than the vehicle that carries them).

Funding: vehicles and modifications are sometimes covered by private insurance, workers comp, or the VA. The California Department of Vocational Rehab *(dor.ca.gov)* also has programs for assistive technology, including vehicles, if it's to help you achieve employment goals.

There's a robust used accessible vehicle market in SoCal, check with the dealers listed below, or online *see disableddealer.com, or blvd.com*

Several car makers offer financial assistance programs, including Fiat Chrysler *(fcausautomobility.com)*, Toyota *(toyotamobility.com)*, Ford, *(fordmobilitymotoring.com)*, Volvo, Hyundai, and General Motors.

Be sure and check out the Mobility Ventures cars, not super stylish but designed from the start to be fully accessible *(mv-1.us)*.

A good resource to research adaptive vehicles and modifications is the **National Mobility Equipment Dealers Association** *(nmeda.com)*. Member companies in SoCal include MobilityWorks *(mobilityworks.com)*, in Los Angeles, Riverside, Van Nuys, Pasadena, and La Mesa; **Ability Center**, now named United Access, *(abilitycenter.com)* in Long Beach, San Bernardino, San Diego, and Stanton; **AERO Mobility**, Anaheim *(aeromobility.com)*, and

Goldenboy Mobility in San Diego *(goldenboymobility.com)*.

VEHICLE GRANTS

The National Organization for Vehicle Accessibility has a program to help people with disabilities who already have most of the money needed to buy vehicle modification products. Grants are awarded for up to 25 percent of the cost of the mobility equipment (lifts, conversions, driving aids – not wheelchairs or home mods), with a maximum award of $5,000. Equipment must be purchased from a NMEDA dealer (SoCal list this page). This program was started by Ralph Braun, a pioneer in the van conversion and lift industry. *Novafunding.org*

SERVICE DOGS

by Bob Vogel

A service dog can be a very cool, life-enhancing addition for wheelers. A dog can assist in a wide variety of tasks. Highly trained dogs perform upwards of 40 commands, from picking up objects off the floor, turning on and off lights, opening and closing doors, pushing buttons for elevators, or even bringing you a frosty beverage from the fridge.

Dogs also provide a great conduit for social interaction—awkward comments like "do you mind if I ask what happened to you?" tend to be replaced by "wow, that is a beautiful dog, what's its name?"

Service dogs are highly trained canine specialists that become an extension of their human partner and must be calm and well-behaved at all times. A service dog program will typically spend 24 months raising and training a dog before it attains service dog level.

It takes a unique dog to have the hardwired calm and attentive temperament to be a service dog; this is something that cannot be taught or trained. Only about 40 percent of the dogs selectively bred by service dog programs have what it takes to get placed with someone as full-fledged service dogs.

It is a seriously bad idea to purchase a service dog vest and pass a pet dog as a service dog. In 19 states, including Colorado, passing off an untrained dog as a service dog is against the law.

There are several ways to acquire a service dog. Non-profit programs such as Canine Companions or Paws With a Cause offer dogs at no cost (there is generally a waiting list of a year or more). There are also private, for a fee, service dog training programs. It is possible to train your own service dog; it is important to do this with the guidance of an experienced trainer.

Canine Companions: *cci.org*;
Paws With a Cause, *pawswithacause.org*.
Assistance Dogs International is an accreditation organization; its 13 California members meet high standards. *For more see assistancedogsinternational.org*

Bob Vogel is a Senior Correspondent for New Mobility magazine. He's, a dad, a dog guy, and uses a wheelchair due to spinal cord injury. He lives in Northern California.

Dr. Steve Heimberg

DOCTOR & LAWYER

Focused on Spinal Cord Injuries

> Steve Heimberg... a great friend of the spinal cord injury community for years.
>
> -Andrew Skinner, Founder, Triumph Foundation

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SCI: FIRST 90 DAYS

RESEARCH & RECOVERY

- THE SCI CURE: IS IT CLOSE?

THE SCI CURE: IS IT HAPPENING?

Is there a cure on the way for spinal cord injury? Yes, just don't put your life on hold waiting for it; it's still going to be a while.

There is a major effort in labs around the world to develop treatments for SCI. Researchers have come a long way in understanding the biology of spinal trauma, and what might be done to fix or perhaps bypass the damage. In some animal experiments, efforts to repair, reroute or regenerate damaged nerves in the cord have had limited success; at this time, however, there is no treatment even close to being approved for either acute or chronic SCI in humans. There are some exciting possibilities on the horizon, including some in clinical trials, but no one can offer a reliable timeframe for the arrival of new treatments.

It's only been since the 1980s that there was any real hope for restoring function after SCI. The age-old story was that damage to the central nervous system – the brain and spinal cord – can't be fixed. That dogma was put to rest when it was shown that SCI nerve fibers (axons) are indeed able to grow and reconnect again after SCI – but only after the area of damage was cleared of toxic debris that stopped growth in its tracks. Scientists also found it was necessary to nurture the repair effort with growth additives. This remains an active area of research; the injury environment can be made more hospitable to neurons. A number of molecules have been identified that either promote or repel growth.

Turns out, however, that it is not enough to culture the damaged area; the nerve cells themselves may need a jumpstart in order to regenerate past the damaged area and make a new connection. Scientists believe it is possible to reboot genetic coding in nerve cells to promote regeneration, even after long-term injuries. The idea is to activate the same programs the body used when the nervous system first formed, when we were infants. The codes are still there, just dormant. Scientists turned off a molecule (PTEN) that acts as a brake, and powered up another molecule (mTOR) that

fuels growth. They found that the long nerve axons in the spinal cord that connect the brain to the legs (corticospinal axons) are thus able to regenerate long distances with this genetic trick. This is still some time away from the clinic.

Another of the issues with regrowing spinal cord axons is the formation of a barrier, a type of scar, that surrounds the area of damage inside the spinal cord. Enzyme and peptide drugs have been employed to digest the scar, allowing axons to cross it. In laboratory studies, animals regained function after application of a scar-eating drug (chrondroitinase). Human trials are anticipated once technical and safety details are ironed out *(see spinal-research.org/chase-it)*.

Part of the basic dogma about SCI held that the nervous system is a single set of wires that, once formed, remain locked in place across the lifespan. Not so. The system is "plastic," or capable of being reshaped or retrained to take over lost function. Physical exercise, for example, is believed to promote the outgrowth of certain nerves and may be linked to motor function recovery.

CELL TRANSPLANTATION

This is an area of research that holds much hope, and much reason for caution. Several SCI-related cell replacement human experiments have been undertaken, transplanting various types of cells, including stem cells.

A current clinical trial is testing the safety of a nerve support cell (Schwann cell) implanted into patients at the Miami Project, among the largest efforts in the world focused on SCI repair and recovery *(themiamiproject.org)*. Several trials have tested a cell taken from the nose area (olfactory ensheathing glial cells, or OEG cells); a project in Europe reported recovery of significant function in a man who got an OEG transplant *(see walk-again-project.org).*

Because stem cells do not yet have a full identity, say as a bone cell, a heart cell, or nerve cell, they can potentially become any type of cell. This suggests that stem cells could perhaps replace damaged cells. The risk: stem cells can grow too much, forming tumors.

Stem cell trials are ongoing for stroke, diabetes, HIV, ALS, brain trauma and many other maladies. Several FDA-approved stem cell trials have included people with spinal cord injuries. The very first approved trail using embryonic stem cells treated 25 acute SCI patients with stem cells. No adverse effects were reported, and there is some indication that the cells might have improved function *(scistar-study.com, lineagecell.com)*.

There's a lot of excitement about a new type of stem cell called an induced pluripotent cell – this is a normal cell in the body, say a skin cell, that is reverse-programmed to a more primitive state, much like an undifferentiated stem cell. This cell could come from your own body, which avoids immune rejection and ethical concerns related to embryonic stem cells. Japanese researchers are already planning an iPSC trial.

No question, stem cells have great potential. Unfortunately,

many people, highly motivated for recovery, travel to unregulated overseas clinics promoting stem cell therapies that are offered at great expense and without basis in scientific research. If you are attracted by the message of hope from a clinic in India or Mexico, Thailand or Panama, please understand these procedures are not without risk. Stem cells are not fully understood. Because these cells can continue to grow indefinitely, they can cause harm.

Do not become a medical tourist without asking some basic questions: What is the source of the cells? What evidence is there that they work? How do they grow the cells? If the cells are not my own, will my immune system be treated to avoid rejection? How are the cells delivered, and how do you know they will show up at the right part of the body?

Be sure and read the science-based information online at *closerlookatstemcells.org* for more on stem cell tourism.

Stem cells may pan out, especially for acute SCI. But "the cure" is not likely to be a single therapy or magic bullet. Indeed, most SCI researchers agree that changing the course of SCI will most certainly require combinations of therapies, perhaps given at different time points after injury.

Another thing the research community agrees on is that physical activity and a new round of rehab will accompany all future treatments.

The best advice to those waiting for cures: Stay informed as you stay active, and stay healthy.

REDEFINING REHABILITATION

It wasn't that long ago that rehabilitation really meant just learning to compensate for lost function, using devices and tools. Now we know that rehab – in the form of physical therapy and activity based training – can facilitate recovery, to help the spinal cord below the area of injury to relearn how to control movement, without input from the brain. Scientists have come to understand that certain forms of patterned activity awaken dormant nerve circuits in the spinal cord, and that this can unlock some degree of function.

This is the basis for locomotor training – stepping with assistance on a moving treadmill. This sort of intensive rehab is not widely available but there are a few programs in SoCal. See for example, NextStep *(nextstepfitness.org)*, in Lawndale, part of the Reeve Foundation NeuroRecovery Network. Cal State LA also has a therapeutic exercise and locomotor training program *(calstatela.edu, search locomotor)*. Several community fitness centers offer treadmill training; *(See p.92-97)*.

Now, taking the idea of waking up spinal circuits a step further, researchers have added spinal cord stimulation to activity. A small number of patients have had epidural spinal cord stimulators implanted in their backs, which has produced significant recovery of function, including walking in some subjects, and also benefits in cardiovascular health, bladder and sexual function. More human trials are on the way at UCLA,

the University of Minnesota *(see EStand.org)*, the Mayo Clinic and in Switzerland *(gtxmedical.com)* and Austraila. The Minnesota trial is noteworthy because chronic SCI patients are getting functional improvements without the massive amounts of rehab required in other studies.

A big stim trial (with rehab) has begun in Kentucky; *reevebigidea.org*.

Spinal cord stimulation was pioneered at UCLA. These researchers recently discovered that it's possible to stimulate the spinal cord and restore some function in some patients without having an implanted unit. Human trials are continuing in Los Angeles, Seattle, Denver and overseas to better understand who the best candidates are for stim.

A study at UCLA recently showed that magnetic stimulation of the spinal cord of a chronic paralyzed subject restored bladder function for up to two weeks after treatment. Two of five patients reportedly no longer used catheters.

BRAIN MACHINE INTERFACE

Restoring function with an on/off switch: Engineers are moving faster than the biologists. Devices harness brain waves to control computers, move prosthetics, or even paralyzed arms. A quadriplegic woman, using her thoughts, piloted a fighter jet simulator. A man with a high cervical injury in LA, using thought to activate a prosthetic arm, grabbed a glass of beer and drank it. This area is moving very fast in many places, including Rancho Los Amigos, collaborating with USC and CalTech *(see vis.caltech.edu)*.

SUIT UP WITH AN EXOSKELETON

Robot suits are still a bit clumsy and bulky, but they're available in several area rehabs for training and exercise; there are some health benefits being reported. The FDA has approved the technology; you can get one for yourself now (in the $70,000 range, approved by the VA for reimbursement). *See rewalk.com, indego.com, eksobionics.com,* and *suitx.com*

GAIT TRAINING

Those with some sensory and motor function below the spinal cord lesion, so-called incomplete injuries, have potential to regain walking. Gait training, ambulation using braces or other devices, might be part of your therapy plans. While this training may not make you a full-time community walker, it may help facilitate minimal walking at home, and it's likely to be good exercise.

A physical therapist will make sure you have the strength and balance to stand, along with good range of motion and flexibility.

Gait training involves a lot of work. It can be slow and tedious, and not nearly as functional as moving about in a wheelchair. But it may lead to independence for some people.

Novice ambulators might start out in a sort of harness that holds part of their weight as they use parallel bars, or step with assistance, on a treadmill (locomotor training). There are a variety of braces available for gait train-

ing, depending on which joints need support. One type of brace called a KAFO (knee-ankle-foot orthotic) can enable a lot of paraplegics to get on their feet, even those with complete injuries. This requires a lot of effort and energy; the arms, with crutches, do most of the work.

FUNCTIONAL ELECTRIC STIM (FES)

Functional electrical stimulation is the direct activation of muscle using small electrical pulses. Implanted FES systems have been studied for many years in people with paralysis to facilitate ambulation, hand grasp, coughing, trunk control, bladder control, standing and transferring. An FES bladder stimulation system called Vocare was on the market in the U.S. until about 15 years ago; it is still available as the Finetech-Brindley Bladder Control System in Europe *(finetech-medical.co.uk)*.

To assess the full range of experiments and applications for functional electrical stimulation, visit the Cleveland FES Center; *fescenter.org*

The most widely applied use of FES is to facilitate exercise, using a type of bicycle called an ergometer. FES bikes apply computer generated, low-level electrical pulses through surface electrodes on the skin to muscles in the legs, arms and torso. This causes coordinated contractions, and thus movement, e.g., pedaling or arm cranking.

FES bikes provide a genuine, measurable physical workout, can build muscle mass, and remain the only real option for those with upper extremity injuries to get any sort of cardiovascular training.

FES bikes are available at many rehabs and clinics. They have been available for at-home use for 25 years or more but price has always been a barrier to getting more people riding. Fortunately, costs have fallen almost in half as the market has become more competitive. Restorative Therapies, established about 15 years ago, has seen a near monopoly for its RT-300 unit challenged by a newcomer, the MyoCycle, from Myolyn.

Restorative Therapies also offers FES for upper extremity ergometry and has recently introduced a supine cycle, to be used lying in bed; these have been tried in a few acute trauma centers, the idea being that very early FES activity can reduce the complications of bed rest.

RT also offers a trunk stimulation system for the abdominals and back muscles to build core strength for better posture, reaching, coughing and wheelchair propulsion. An RT add-on called Xcite allows stimulation off the bike for targeted muscle groups and task-specific sequences, such as posture or teeth brushing.

Myolyn was started in 2013 by two engineering PhDs in Florida. They developed the MyoCycle using stimulation techniques and control algorithms that they say result in a more powerful and efficient cycling workout. The MyoCycle (under $10,000) is cheaper than the RT-300 but is not as fully featured (e.g., fewer channels, no arm cycling add-on).

Insurance plans generally don't pay for FES bikes (they often assert that FES is beneficial as exercise only) but a case can be made for medical necessity. There is evidence in the medical literature that FES cycling may improve circulation and bone density, reduce spasms, and may even lead to functional recovery.

A doctor's prescription is necessary for FES; those with severe bone loss may not be good candidates. Work with the FES vendors for reimbursement. Really want one? Tenacity pays. *See restorative-therapies.com, or myolyn.com*

RESEARCH RESOURCES

The spinal cord is enormously complicated. And if it get damaged? In theory, at least, we might be able to fix it. Here are some resources if you want to stay abreast of regeneration and SCI restoration of function.

Unite 2 Fight Paralysis, a research advocacy organization, "the voice of the cure," produces an annual symposium, Working 2 Walk, as well as an informative podcast and frequent news updates; *u2fp.org*

Wings for Life is a Europe-based nonprofit with an office in LA and a very robust SCI research portfolio, much of it based in U.S. labs. Operates the annual Wings for Life World Run, with major support from Red Bull; *wingsforlife.com*

CareCure is a long-running Internet forum that keeps up with SCI research; *carecure.net*

Reeve-Irvine Research Center at UC Irvine is active in SCI research; *reeve.uci.edu*

UC San Diego features a prominent SCI regeneration and stem cell research program; *neurosciences.ucsd.edu/centers/neural-repair*

Miami Project to Cure Paralysis is a large science effort to promote SCI recovery; *themiamiproject.org*

For more on stem cell research, see the **California Institute on Regenerative Medicine**, the state stem cell funding agency; *cirm.ca.gov*

Christopher & Dana Reeve Foundation supports SCI research, including the Big Idea stim trial; Reeve also offers a very handy lay-person friendly book on the basics of SCI cure, "Don't Call it a Miracle," by Kate Willett. Free. *christopherreeve.org*

The NeuroRecovery Network is a multi-site Reeve effort; the California location is NextStep Fitness in Lawndale, *nextstepfitness.org*; *see also christopherreeve.org/nrn*

Shoot for a Cure raises funds for the Canadian Spinal Research Organization, the American Spinal Research Organization, and Stop-Concussions Foundation, supporting investments in neurorecovery, neuroprotection, standardization of treatment, early interventions that reduce secondary damage; *shootforacure.org*

W.M. Keck Center for Collaborative Neuroscience at Rutgers in New Jersey, established by scientist physician Wise Young, is currently preparing to stage a clinical trial for people with chronic complete SCI testing umbilical blood stem cells, in combination with very rigorous physical therapy and lithium; Young reported that a 28-patient China trial showed some sensory and functional recovery, e.g. ambulation with a walker, some bowel and bladder improvement. U.S. trials are planned; *keck.rutgers.edu*

Craig H. Neilsen Foundation, headquartered in Encino, is the largest private funder of spinal cord injury research, rehabilitation, clinical training and program support in the United States and Canada, in the range of $20 million per year. Grants are made to nonprofits. The foundation's work is funded from the estate of Craig H. Neilsen, who built a billion dollar casino business while dealing with cervical spinal cord injury. Explore the range and depth of CHN grant-giving at *chnfoundation.org*

TAKE YOUR KNOCKS, PICK UP THE PIECES, AND GO ON

Here's advice from Craig Neilsen, who created a gaming industry giant while living with quadriplegia, on moving forward: "You have to find your inspiration for going on. For some it's seeing someone worse off and thinking, well, it could be worse – at least I didn't die. For others it's hearing the voice of someone you love, promising to remain by your side. In my case, I got mad, and I think that helped me. Nobody cuts you any slack, and the fact that you just about killed yourself is no reason for any accommodation. I was forced to get active and get some things accomplished, because I had my family depending on me. It was not the easiest thing to do. You can decide that you don't want to live your life, and a lot of people do that. But I think most people – when push comes to shove – take their hard knocks and then pick up the pieces and go on."

KEEPING HOPE: FAITH IN SCIENCE

by Suzy Kim, M.D.

When I started medical school, I never could have imagined I would be a doctor dependent on a wheelchair. Wheelchairs are for patients, not for doctors. I was in my third year of med school when I hit a sand bar while bodysurfing. And let's be honest, I had no idea about spinal cord injury. Neither did my family or friends and

unfortunately, many physicians who would be responsible for my medical care. Did I miss the lecture on how to be paralyzed? No. There wasn't one. And there was very little information anywhere about SCI and how best to treat it.

So, today, as I reflect on my own "First 90 Days" of living with a spinal cord injury, I'm grateful I didn't end up in a skilled nursing facility, or a nursing home, as a 25-year-old. Knowing what I know now as a practicing physiatrist with board certification in SCI, I appreciate the care I received at Rancho Los Amigos in Los Angeles, one of 14 designated Model Systems SCI Centers in the U.S.

In my practice I see many individuals with newly acquired SCI who initially did not receive specialized SCI medical care or meaningful rehabilitation. The reality is that insurance and reimbursement dictate your health care. That means we in the SCI community have to advocate for ourselves and seek out the best care we can. As a medical provider, I continue to educate my colleagues and payor sources about the value of specialized SCI medicine. All individuals with SCI deserve a full quality of life with the hope of functional and neurologic recovery.

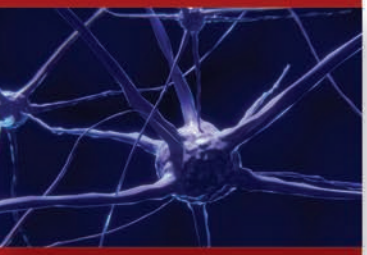
When I was injured, there was very little talk of possible recovery. But my injury came two years after Christopher Reeve had his accident; he brought the idea of SCI cure to the mainstream, and helped raise awareness about new therapies. Reeve encouraged a sense of hope in me that I maintain in high gratitude to this day.

I am eternally optimistic; I place my faith in medicine and science, the very same reasons I chose a career as a doctor in the first place.

Suzy Kim, M.D., is Medical Director for St. Jude Centers for Rehabilitation and Wellness in Brea, CA, and Team Physician for the U.S. Paralympic Teams.

Working 2 Walk

Our conference is a collaborative gathering that prioritizes the voice of the Spinal Cord Injury (SCI) Community. We bring together research scientists, clinicians, and community advocates, along with investors and industry leaders to exchange information and strategies for achieving recovery from SCI.



Scientific Advisory Board (SAB)

Many smaller foundations want to fund promising research, but lack the scientific expertise to vet their funding decisions. The U2FP Scientific Advisory Board is here to fill this gap. Our SAB helps SCI foundations direct dollars to research that is Relevant to Chronic Injury, Replicable, Translatable and Innovative. To date, the U2FP SAB has reviewed grants totaling over $9M.

Cure Advocacy Network (CAN)

With almost $12M in legislative funding as a result of lobbying efforts by CAN Activists from within the SCI Community - the tide is turning. We're making our voices heard, and demanding to have a say in the research efforts that will affect us. We've passed Spinal Cord Injury Research Bills in Pennsylvania, Minnesota, Ohio and Washington states. We are currently working with a group of committed activists in Wisconsin where we have introduced a $10M SCI research funding Bill.

U2FP CureCast Podcast

Our podcast attempts to distill the complexities around the research economy. Our Executive Director, Matthew Rodreick and Contributing Writer, Kate Willette (author of "Don't Call It A Miracle: The Movement To Cure Spinal Cord Injury") conduct interviews with scientists, advocates and others in order to help unpack the science and deepen the dialogue with the SCI Community.

Team U2FP

Team U2FP is a way for runners and wheelers who want to participate in the movement to cure paralysis. All of our racers get free registration, a Team U2FP T-shirt, and a personal fundraising page optimized for social media sharing. Join our team in one of our featured races, or in any race in which you are participating.

unite@u2fp.org www.u2fp.org 888-564-2228

SCI: FIRST 90 DAYS

RESOURCES

- RECREATION, SPORTS, ACTIVE LIVING
- EDUCATION, WORK & FUNDING STRATEGIES

SPORTS, RECREATION, ACTIVE LIVING

There is no limit to the activities one can pursue from a wheelchair. All the cool recreational options in SoCal can be made accessible. Tennis and handcycling are excellent activities with your walking friends. If you want to go big, there are role models aplenty; some of the most celebrated wheelchair athletes in the world live and train in SoCal. Most cities and college campuses in California have a recreation program, and all are inclusive of people with disabilities (PWD). No excuse not to get out, get active.

Beyond just being fun, activity is especially important for PWD, who are more inactive anyway. A little fitness goes a long way toward combating conditions secondary to spinal cord injury, such as cardio health, insulin resistance, fatigue, skin problems, joint issues or spasticity. Physical activity improves health and stamina, therefore directly affects your level of independence, your participation in the community, and the way you operate in the world.

There is evidence that exercise and activity also help you stay smart, reducing the risk of cognitive decline.

The U.S. Department of Health and Human Services recommends PWD get at least 150 minutes a week of moderate-intensity, or 75 minutes a week of vigorous-intensity aerobic activity, plus muscle strengthening at least twice a week.

How to find support to stay fit? See the list of specialized fitness centers on p. 87. Although the ADA requires all public fitness clubs to be accessible, some are accommodating, some not so much.

There are good connections online, such as the National Center on Health, Physical Activity and Disability (NCHPAD), a resource center on health promotion for people with disability. NCHPAD offers many videos on fitness, exercise and health; see also a publication called "Life on Wheels," a toolkit from NCHPAD to help those new to SCI "navigate this new life and break down all the barriers and myths you might face along the way." *nchpad.org*

RESOURCES

Home workout? Look up "wheelchair fitness" at YouTube.com. There are quite a few seated aerobic videos to use in the comfort and privacy of your living room.

NATIONAL PROGRAMS

Disabled Sports USA (DSUSA) founded in 1967, has over 120 chapters in more than 40 states; Over 50 different sports offered nationally. *disabledsportsusa.org*

Cooperative Wilderness Handicapped Outdoor Group (C.W. HOG), formed in 1981 by Idaho State University, offers year-round activities including martial arts, swimming, weight training, handcycling, river rafting, waterskiing, and wilderness trips. Pocatello. *isu.edu/outdoor/test*

National Ability Center, founded in 1985 in Park City, offers year-round sports and recreational opportunities. Robust winter ski and snowboard programs, plus skating, archery, boating, equestrian program, climbing wall, water skiing, wakeboarding, kayaking, canoeing and paddle boarding, etc; *discovernac.org*

Splore pioneered the concept of inclusive outdoor adventure, going back to 1977. "Splore trips leave participants with an expanded sense of what they can accomplish both individually and as a family." Splore recently joined with the National Ability Center, *discovernac.org*

Sports Abilities is a guide to resources in all states for adaptive sports organizations and equipment; *sportsabilities.com*

No Barriers is a national nonprofit that uses sports and adventure to break through barriers and tap into participants' full potential. The pledge: "I am promising to harness adversity, break through my personal barriers and create a life of purpose and impact." Their flagship program is the annual No Barriers Summit, a 4-day event held with over 40 adaptive activities, speakers, entertainers plus all the latest mobility gear. *nobarriersusa.org*

World T.E.A.M. Sports promotes inclusive sporting events. For example, Adventure TEAM Challenge Colorado is a two-day race with five-person teams, two members with a disability (one in wheelchair) along with three nondisabled team members. The race combines orienteering, hiking, mountain biking, rock climbing, rappelling, zip-line, and white water rafting. *For more see worldteamsports.org search 'events.'*

ADAPTIVE SPORTS AND REC ACTIVITIES IN SOCAL

Angel City Sports produces the Angel City Games, an annual competitive showcase for athletes with disabilities, held at UCLA. ACS also offers adaptive sport clinics for archery, swimming, soccer, wheelchair tennis, track and field, volleyball, golf and more; *angelcitysports.org*

RESOURCES

Body Building: hit the weights; *wheelchairbodybuilding.com*

Gaming: most video games are accessible, even to those with no hand function, with the right gear. *See accessiblegamer.com*, *ablegamers.org*, *oneswitch.org.uk*, *broadenedhorizons.com*

Golf: You can do it sitting down. There are hundreds of golf courses in SoCal, of course, and while they are required to accommodate players with disabilities, not all links will be accessible. Keep this in mind: A golf course that provides golf carts to its customers but does not provide a single rider golf cart is discriminating against persons who cannot walk, in violation of the ADA. Best to call the pro shop and tell them what you want to do. Check out Solo Rider, they make an all access cart. *solorider.com*

Hunting and Fishing: There are plenty of options for anglers and hunters. No hands, no problem. Get a sip n puff trigger rig with chin controls. For adaptive gear, including rifle mounts, *see adaptiveoutdoorsman.com*; *changedbynatureoutdoors.org*

Infinite Flow is a nonprofit wheelchair dance company based in LA. IF offers professional performances plus many community activities, classes and inclusive dance events. *infiniteflowdance.org*

Junior Wheelchair Sports Camp, from Cottage Rehab in Santa Barbara, an annual event for kids 6 to 19 years old; includes rugby, basketball, tennis, handcycling, volleyball, swimming, kayaking, SCUBA diving, tennis, climbing wall, roller sled hockey, lacrosse and more; *cottagehealth.org*

Lacrosse: Why not? Based in San Diego. *wheelchairlacrosse.com*

Land Meets Sea Sports Camp is three days of adaptive fun on water (jet ski!) and land (tennis!), produced in Long Beach by Casa Colina Outdoor Adventures program and Triumph Foundation. 909-596-7733, ext. 4131; *casacolina.org*.

Kayaking: Wheels To Water provides adaptive kayaking, for free. Central coast-based founder Andy Janicki, who has a cervical spinal cord injury, says folks with even extreme disabilities can paddle along, same as anyone else. "This serves as an equalizer rarely experienced in everyday life," he says. *wheelstowater.com*

Paralympics, when you're ready to take on the world's best, summer or winter. *teamusa.org/us-paralympics*

PossAbilities is a free community outreach in San Bernardino County, from Loma Linda University Health, Activities include road cycling, swimming, triathlons, basketball, quad rugby, baseball, flag football, racing events; *teampossabilities.org*

Sailing: there are several SoCal programs to get PWD on the water. The United States Sail-

RESOURCES

ing Center, Long Beach, and Challenged America, San Diego, are two of the best; *ussclb.org*; *challengedamerica.org*

San Diego Therapeutic Recreation Services offers lots of adaptive activities, including handcycling, bowling, archery, golf, outings, social events. *sandiego.gov/park-and-recreation*

SCUBA: if you can breathe you can dive. Learn how from Handicapped Scuba Association, based in San Clemente since 1981; *hsascuba.com*

Skydiving: there are many facilities that tandem jump, some will accommodate PWD, including people with no arm or hand function. For example, *see skydiveperris.com*

Sled Hockey is fast and fun, a popular and dynamic Paralympic sport. There's a team in Riverside supported by the LA Kings. Contact LAKingsSledHockey@gmail.com

Spinal Injury Games are held annually at Rancho Los Amigos. Activities include powerchair relay, tennis, football, rock climbing, rugby, handcycling, racing and basketball. *ranchofoundation.org/sig.html*

Surfing is cool, almost anybody can do it, with help from friends. LA-based Life Rolls On offers events along the SoCal shore. *liferollson.org*

Tennis: Big in California, you can play every day of the year. This is a great year-round activity and one of the best sports to integrate wheelchairs and walkies (you get two bounces if you're sitting!). Connect via the US Tennis Association, *visit usta.com search 'wheelchair'*.

Triumph Foundation provides adaptive sports, fitness, recreation, and outdoor adventure opportunities. Activities include handcycling, adapted shooting; snow and water skiing trips; baseball, and plenty more. Triumph hosts a Wheelchair Sports Festival in Santa Clarita every spring. They know where to send you for whatever activity strikes your fancy. *See triumph-foundation.org*

UCLA Adaptive Recreation features many adaptive activities in the LA area. *See recreation.ucla.edu/adaptiveprograms*

Unrecables: The LA chapter of Disabled Sports USA, offers ski trips to Mammoth. In the off-season try whitewater rafting, camping, water skiing, Hollywood Bowl outings, concerts and parties; *unrecables.com*

United States Adaptive Recreation Center offers skiing and water sports at Big Bear Lake; *usarc.org*

WCMX: Gravity can be your friend. Drop in for some extreme wheeling. Check out Aaron Fotheringham, the undisputed duke of chair-flipping and WCMX; *aaronfotheringham.com*

RESOURCES

Wheelchair Rugby, also known as quad rugby or, appropriately, murderball, is rough, fun and fast, and very well represented in California. Check out the Northridge Knights or the Sharp Edge. For more about the game, contact USA Wheelchair Rugby, *usawr.org*, or the Quad Rugby Association, *usqra.org*. The sport is played at the Paralympics; *paralympic.org/wheelchair-rugby*

RECREATION GEAR SOURCE

Don Krebs used to be a competitive water skier. He broke his neck, C5-7 doing the sport. Back then, in the 1980s, after he couldn't find a ski, he started Access to Recreation so folks would not have to work as hard to find the gear they needed to stay active. Don's company, now called AccessTR, carries tons of cool adaptive recreation and exercise equipment: fishing and hunting equipment, adapted golf clubs, swimming pool lifts, wheelchair gloves and cuffs, and bowling, devices to help with embroidery, knitting and card playing, and practical aides such as wheelchair ramps and book holders. "If there is something you need that we do not offer please either call or email and we will try to find it for you." Says Don, who's based in the LA area, "*AccessTR.com* not only has the most recreation and exercise equipment anywhere but we also have it at the best prices." 1-800-634-4351, *accesstr.com*

TRIUMPH-FOUNDATION.ORG

FUNDING STRATEGIES

Finding the money to pay for SCI expenses can be difficult. Friends and family will always help, if they can. In the networked world, there are cool new options for engaging your connections to chip in, listed below.

There are some grants available to individuals, though these are usually not large amounts of money.

Even if you're not tapping your network for help, friends and family want to stay connected. To form an engaging online network, see below.

CROWDFUNDING

It's very common these days to raise money through your own networks with crowdfunding campaigns. You get to keep all the money raised, but reports indicate that most campaigns do not reach their goal. The ones that do hit their goal get money from 50 or 60 donors – that's a pretty big network, so your friends and family base will have to get the word out as widely as possible.

GoFundMe is a popular, trusted, user-friendly online fundraising platform that dominates the field. GoFundMe now incorporates former Crowdrise, YouCaring and Give Forward crowdfunding customers. GoFundMe campaigns are easy to set up and manage. Tap into your network. Charges credit card fees of 2.9% plus $.30 per transaction; *gofundme.com*

TAX ADVANTAGED CROWDFUNDING

Here is an excellent alternative funding source that raises money through community campaigns but manages the funds and thus creates a tax deduction advantage for donors:

HelpHopeLive is a nonprofit that supports community-based fundraising for people with unmet medical expenses due to cell and organ transplants or catastrophic injuries and illnesses. HelpHopeLive coordinators work with patients and families to establish a volunteer network and a campaign. HHL helps with fundraising details and media support. The big difference between HHL and

other online funding agencies is that donations are tax deductible to the donor and not counted as income or assets to the recipient, which may be an important detail with regard to public benefit eligibility. HelpHopeLive holds the money raised through campaigns and pays for needs as they arise; the agency takes a 5% fee. *helphopelive*.org

GRANTING AGENCIES

Amy Van Dyken Foundation, aka Amy's Army, is a nonprofit formed by the six-time Gold Medal Olympic swimmer to assist people with spinal cord injuries. A Wheels for Kids initiative helps younger wheelers get fitted with the right gear. *amyvandyken.org*

BikerDown is a small non-profit that assists motorcycle accident survivors with emotional support, medical equipment, financial advice; *bikerdown.org*

Blood Brothers Foundation provides financial support to SCI folks for vehicle modifications. 303-882-7469; *bloodbrothersfoundation.org*

Bryon Riesch Paralysis Foundation supports SCI research and provides assistance to people with neurological disorders; Bryon Riesch was spinal cord injured in 1998. Based in Wisconsin. *brpf.org*

Challenged Athletes Foundation provides grants and support for active lifestyles through physical fitness and competitive sports; says CAF, "involvement in sports at any level increases self-esteem, encourages independence and enhances quality of life." In 2018 CAF made 2,806 individual grants in 40 countries for 95 sports, a total of $4.3 million. *challengedathletes.org*

Chanda Plan offers funding for preventative and wellness services. *iamtheplan.org*

Dreams of Recovery Foundation (Cindy Donald) offers people with SCI funds for therapeutic exercise; *dreamsofrecovery.org*

Gridiron Heroes provides support to people with SCI injured playing high school football; *gridironheroes.org*

High Fives Foundation, started in 2009 by para Roy Tuscany, supports mountain action sports athletes with prevention awareness, resources and grants for living expenses, adaptive equipment, and "stoke" (positive energy, outlook, attitude). Based in Truckee. *See highfivesfoundation.org*

Joni and Friends is a disability Christian ministry based in Agoura that offers scholarships and grant support for equipment, rehab or special treatments; *joniandfriends.org*

Kelly Brush Foundation Active Fund provides adaptive sports equipment to people living with spinal cord injuries; KBF has funded handcycles, monoskis, sport chairs, racing chairs, hockey sleds, and more. Kelly Brush was

injured in a skiing accident in 2006; *kellybrushfoundation.org*

Modest Needs provides short-term financial assistance to individuals and families in temporary crisis who are ineligible for most conventional social assistance. 844-667-3776, *modestneeds.org*

Ramp Less Traveled provides scholarships and mentoring for people with spinal cord injuries in the pursuit of higher education. Founded by Jay Ruckelshaus, C4/5, Rhodes scholar; *ramplesstraveled.org*

Road 2 Recovery Foundation helps injured professional motocross/supercross riders with financial assistance; *road2recovery.com*

SCORE offers grants for young people injured in sporting events or athletic recreation; *scorefund.org*

Swim With Mike, named for Mike Nyeholt, paralyzed in 1981, believes that getting back to education is getting back to life. Provides scholarships to athletes with disabilities; *swimwithmike.org*

ThreeSixtyFive Foundation is an Indiana charity that offers grants for people in their first year post injury; *threesixtyfivefoundation.org*

Travis Roy Foundation offers a grant program to people with SCI for gear, etc. Roy was injured in 1995, 11 seconds into his first college hockey game for Boston University; *visit travisroyfoundation.org*

Wheels With Wings is an SCI support group in upstate New York. Grants to individuals are available; *wheelswithwings.org*

Will2Walk Foundation funds fitness memberships, supplies, education, etc.; *will2walk.org*

Walking With Anthony supports SCI research and education, and provides financial assistance; *see walkingwithanthony.org*

KEEP YOUR NETWORK INFORMED

It's good to keep friends and family informed while you are dealing with SCI trauma, rehab and recovery. You can set up a Facebook page, or use Twitter, or perhaps one of these no-cost online sharing platforms:

Carepages is a popular Internet community to share the stories of people dealing with life-changing health events; *carepages.com*

Caring Bridge is a sharing site to "amplify the love, hope and compassion in the world," says the company. No fees, no ads ; *caringbridge.org*

Lotsahelpinghands is a place to coordinate the good intentions of others. Here families can post requests to a calendar function and ask for help with such things as meals, rides, shopping, errands, etc.; *visit lotsahelpinghands.com*

RESOURCES

PostHope makes it easy to follow your health and recovery status. The platform also offers a no-fee crowdfunding platform; *posthope.org*

OTHER FUNDING

California Victim Compensation Program (CalVCP) may help if your injury was the result of violent crime, which includes assault and violence but also drunk driving. Maximum payout is $70,000; *vcgcb.ca.gov*

CalFresh is the state food stamp program. Eligibility depends on income and family size. You do not have to be on welfare to qualify for CalFresh benefits. To get more details *visit calfresh.ca.gov*

HIGHER EDUCATION

If going to college is in your plans, don't stop now. There are national organizations, as well as programs at the various colleges and universities in SoCal, to help you figure out where to go, and perhaps, what to study. Students with disabilities usually qualify for extra help, including modifications to testing times, early registration for classes, assistive technology, and accessible dorms and classrooms.

There are dozens of colleges and universities in the area. It's best to scour the course offerings and visit the schools that seem best. All community colleges in California have disability service offices, and every campus in both the California state system and University of California system offer disability services.

COLLEGE RESOURCES

Career Opportunities for Students with Disabilities (COSD) gives college students or recent graduates tools and knowledge to secure a career; *cosdonline.org*

The National Center for College Students with Disabilities (NCCSD) is a federally-funded project under the U.S. Department of Education. Provides technical assistance and information to anyone needing information about disability and higher education; *nccsdonline.org*

DREAM (Disability Rights, Education Activism, and Mentoring) supported by NCCSD, offers mentoring and services to higher education students. "We explicitly include people who have traditionally been marginalized or under-represented in the disability or higher education communities," says Dream; *visit dreamcollegedisability.org*

Association on Higher Education And Disability (AHEAD) is a professional membership organization for those involved in services to meet the needs of people with disabilities in areas of higher education; *ahead.org*

Vocational Rehab: the state of California can help qualified students with career assessment and counseling, job search and interview skills, independent living skills, education and training and assistive technology; in some

cases VR will provide a vehicle, unless there is an "equally reasonable and less expensive method, such as public transportation or special transit." *dor.ca.gov*

SCHOLARSHIPS

Funds are available for higher education for students with disabilities. Here are a few scholarships that are open across all states:

Swim With Mike, named for Mike Nyeholt, paralyzed in 1981, believes that getting back to education is getting back to life. Provides scholarships to athletes with disabilities; *swimwithmike.org*

AmeriGlide Achiever Scholarship awards $2,500 to a wheelchair user. *ameriglide.com/Scholarship*

Frederick J. Krause Scholarship on Health and Disability awards $1,000 to students with a disability pursuing studies in public health. *aahd.us search 'scholarship'.*

Bryon Riesch Paralysis Foundation awards $2,000 to $4,000 for post high school education. Priority for spinal cord injuries and diseases resulting in paralysis. *brpf.org search 'scholarship'.*

Lime Network, a nonprofit resource for university students and professionals with disabilities, manages two scholarships, one in partnership with Google, one with PwC (PriceWaterhouseCooper) business services. Google offers $5,000 a year for students interested in tech careers; PwC offers $4,000 for students in accounting, economics, etc *limeconnect.com search 'scholarship'*

Microsoft disAbility Scholarship awards $5,000 per year, renewable up to $20,000 for students "with a passion for technology." The scholarship is paid by Microsoft by way of the Seattle Foundation; *see seattlefoundation.org/scholarships*

WORK AND BENEFITS

It's not always easy getting work: the latest numbers from the U.S. Department of Labor note that only one in five people with disabilities has a job, compared to two of three in the general population. Some don't work because they can't. Others because they'd lose their benefits, so why should they? True, the system has long been rigged against people who earn money and who also get Social Security benefits; make too much, you lose your health care. The Social Security Administration has made some attempts to reduce these built-in disincentives to getting a job.

One recent program is called Ticket to Work *(choosework.net)*. It's necessary to sign up with an Employment Network (EN) or state voc rehab office, which works with you to set a career goal, make a plan, then line up any services you need, such as training, career counseling, vocational rehabilitation, job placement, or ongoing support services necessary to achieve your goal. Beneficiaries also can use work incentives to maximize their income until they begin to learn enough to support

themselves. The key to the Ticket is that you can go to work without automatically losing disability benefits; you can set aside money and continue to receive healthcare benefits. Also, you are protected from having a medical disability review.

You can pick any EN. In SoCal these include the Workforce Development Board, City of LA *(wiblacity.org)*, or Goodwill Industries *(pathpoint.org)*, and several other private contractors. *See choosework.net* for a search tool by region or city.

The PASS (Plan to Achieve Self-Support) is another federal work incentive plan that allows you to be employed, set aside income, and keep your Social Security healthcare. Income in a PASS does not reduce your SSI benefit. An approved PASS, based on a specific, written work plan, lets you use your income or other things you own to help you reach work goals, such as going to school, transportation, assistive gear, or special training. Search PASS at the main Social Security site, *ssa.gov; also see passonline.org*

ABLE Accounts, which came into play in 2016, are tax-advantaged savings accounts for PWD and their families. These accounts allow holders to bank up to $15,000 a year (to a max of $100,000 total) to be used for any expense related to living with a disability. That includes housing, transportation, personal assistance, assistive technology, and any other health care not covered by Medi-Cal or Medicare.

To get an ABLE account you have to have been under age 26 at the onset of your disability. You are automatically eligible if you are already getting SSI and/or SSDI.

The funds in an ABLE account will not affect the $2,000 a year income rule – you won't lose benefits eligibility with this savings program.

A very important advantage for ABLE account holders is that funds can be invested, and that any investment income is not taxable. Earnings in a CalABLE account receive federal and California state tax-free treatment. Withdrawals for qualified expenses are also tax-free.

For more on the national ABLE program *see ablenrc.org*

WORK RESOURCES

Job Accommodation Network (JAN) is a free service that provides information about employability, work accommodations, and the ADA; *see askjan.org*

Office of Disability Employment Policy (ODEP) is a federal agency that boosts job opportunities for adults and youth with disabilities while eliminating barriers to employment; *see dol.gov/odep*

Vocational Rehab: this state-supported program can help qualified individuals with career assessment and counseling, job search and interview skills, independent living skills, education and training and assistive

technology; in some cases VR will repair or provide modifications to your vehicle so you can get to work.

The California Department of Rehabilitation is the largest vocational rehabilitation and independent living program in the country. The agency offers services to train, rehabilitate, and connect you with jobs. Says DOR, "We believe in the talent and potential of individuals with disabilities. We invest in the future through creativity, ingenuity, and innovation."

There are many regional Voc Rehab offices in the state. This is also an agency that helps with Ticket to Work planning. Call 916-324-1313; *see dor.ca.gov*

INDEPENDENT LIVING CENTERS

Independent living centers provide services for housing, disability rights, ADA compliance, Social Security, benefits, transportation, attendant care, etc. Independent living is a philosophy: This from the **National Council on Independent Living** *(ncil.org)*:

"Independent Living philosophy emphasizes consumer control, the idea that people with disabilities are the best experts on their own needs, having crucial and valuable perspective to contribute and deserving of equal opportunity to decide how to live, work, and take part in their communities, particularly in reference to services that powerfully affect their day-to-day lives and access to independence."

SOCAL ILCS

California Foundation for Independent Living Centers is a non-profit whose members include the ILCs listed below. CFILC supports several programs related to accessible technology for all, including AbilityTools, FreedomTech, and CaliforniaReuse; *cfilc.org*

Access to Independence (a2i), San Diego, Escondido; *accesstoindependence.org*

Communities Actively Living Independent and Free (CALIF), Los Angeles; *califilc.webs.com*

Community Access Center (CAC), Riverside, Desert Hot Springs, Menifee; *ilcac.org*

Disabled Resource Center (DRC), Long Beach; *drcinc.org*

Independent Living Center of Kern County (ILCKC), Bakersfield; *ilcofkerncounty.org*

Independent Living Center of Southern California (ILCSC), Van Nuys, Lancaster; *ilcsc.org*

Independent Living Resource Center (ILRC), Santa Barbara, Atascadero, Santa Maria, Ventura; *ilrc-trico.org*

Rolling Start, Inc., San Bernardino, Hesperia; *RollingStart.com*

Service Center for Independent Life (SCIL), Claremont; scil-ilc.org

Southern CA Rehabilitation Services (SCRS), Alhambra, Downey; *scrs-ilc.org*

Disability Community Resource Center (Formerly Westside CIL), Los Angeles, Santa Monica; *wcil.org*

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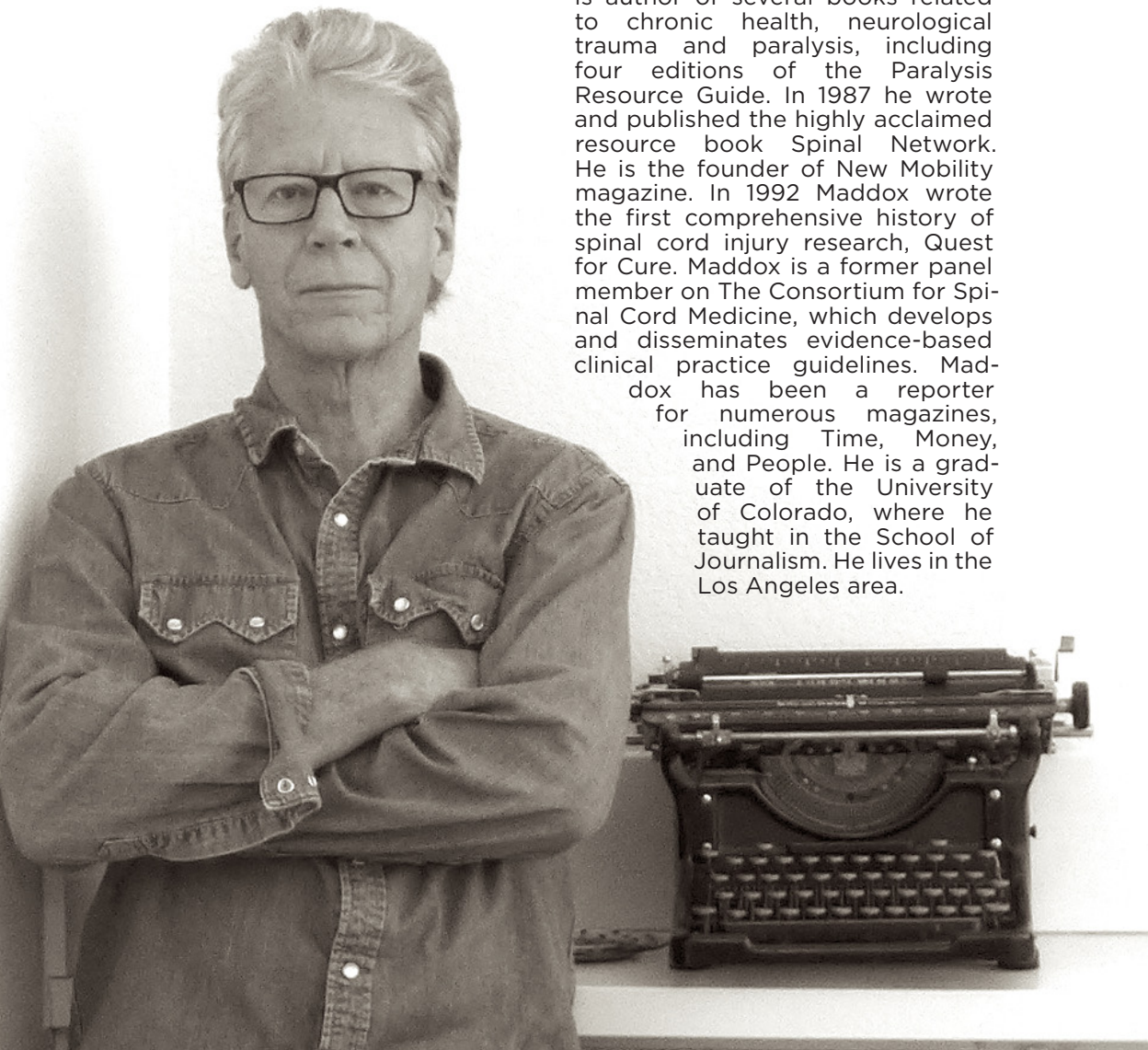
Sam Maddox is director of the Scientific Advisory Board for Unite 2 Fight Paralysis *(U2FP.org)*. He is a member of the Board of Directors for Wings for Life *(wingsforlife.com)* and is former Knowledge Manager for the Reeve Foundation Paralysis Resource Center *(christopherreeve.org)*. He is author of several books related to chronic health, neurological trauma and paralysis, including four editions of the Paralysis Resource Guide. In 1987 he wrote and published the highly acclaimed resource book Spinal Network. He is the founder of New Mobility magazine. In 1992 Maddox wrote the first comprehensive history of spinal cord injury research, Quest for Cure. Maddox is a former panel member on The Consortium for Spinal Cord Medicine, which develops and disseminates evidence-based clinical practice guidelines. Maddox has been a reporter for numerous magazines, including Time, Money, and People. He is a graduate of the University of Colorado, where he taught in the School of Journalism. He lives in the Los Angeles area.



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At Select Medical, helping our patients regain function and rebuild their lives is how we measure success.

Our national network of nearly 30 medical rehabilitation hospitals is committed to supporting residency and spinal cord research programs that provide new hope for the future of rehabilitation medicine and the patients it serves.

Through a partnership with Cedars-Sinai and UCLA Health, Select Medical created California Rehabilitation Institute, the largest hospital of its kind on the West Coast. With a physician-led, interdisciplinary care team, our reputation as the trusted leader in rehabilitation medicine, just like our patients, grows stronger every day.

CaliforniaRehabInstitute.com

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