

Life in Action

Adapt // Connect // Achieve

Healthcare

Post-Rehab Therapy
The Affordable Care Act
Elective Surgery for Function



Travel
Honeymoon Cruise

Advocacy
Journey to VetsFirst

MS Life
To Breed or Not to Breed?

Dating/Relating
The Caregiver Conundrum



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of NSCIA, a program of
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Life in Action is the membership publication of National Spinal Cord Injury Association, a program of United Spinal Association. Our mission is to improve the quality of life of all Americans living with spinal cord injuries and disorders (SCI/D).

Membership Benefit Highlights

Member benefits are continually being updated, so stay tuned for more. Current highlights include:

- **Life in Action**, our member publication. Look for some changes in the next issue: We'll be emphasizing advocacy more in the print publication — including ways for you to become more involved — and offering you new ways to tap into general SCI/D information. (In 2014, most general SCI/D info will move from *Life in Action* to webinars, www.spinalcord.org or our sister publication, *New Mobility*.)
- **Member pricing on New Mobility**, our award-winning **monthly** magazine for wheelchair users who want to live "life beyond wheels." Known for its in-depth coverage of SCI/D health, travel, products, recreation, relationships — and everything else you need to live an active lifestyle — *New Mobility* is now available to members for just \$14.95/year. Call toll-free 800.404.2898, ext. 7260, and mention that you are a member. *Note: There are always some free articles on newmobility.com; check out the archives to see if a subscription is right for you.*
- **Connections to Chapters and Peer Support**. Whether you joined our community as a member of National Spinal Cord Injury Association or of United Spinal Association, you now have access to more than 210 NSCIA chapters and support groups nationwide. For a list of chapters and support groups, visit www.spinalcord.org or call 800.962.9629 for the latest additions.
- **Discount at Able to Travel**, our in-house travel agency, where you'll work with a travel agent knowledgeable about the access issues that can arise during a trip. Members pay only \$35 per person.
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Individual membership is free and open to people with spinal cord injuries or disorders, family members, caregivers and professionals. Learn more or join at www.spinalcord.org, or call 800.962.9629.

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Web. <<http://stnw.nhtsa.gov/cars/rules/adaptive/>>.

Editor's Note



LOOKING AHEAD

Ian Ruder

On the cover of our third issue, back in 2011, we featured a man using an exoskeleton to walk following a spinal cord injury. Inside we told you that as sci-fi as it may have seemed, the technology was coming and held huge potential for the SCI community.

Now, just two years later, exoskeletons are rapidly becoming a big part of the nation's leading rehab programs. Additionally, exciting approaches like locomotor training have moved into the mainstream and are helping many people regain function in ways most of us only dreamed of 15 years ago.

All of this is to say that rehab and how we handle SCI is changing at light speed. At the same time, the Affordable Care Act has brought a number of key healthcare-related issues to the forefront of discussion. In this, our 15th issue, we're focusing on healthcare. It would take a much better prognosticator than myself to confidently tell you where all of these developments are leading, but what I can assure you is that *Life in Action* will continue to cover these the topics that matter to you as we transition to our new format starting with our next issue.

You will likely notice a number of significant changes as we look to provide more behind-the-scenes insight into NSCIA and United Spinal, and more tangible ways you can get involved, whether through local support groups, chapters or national advocacy. We're excited about the changes, and we hope you will be too. Please take a minute to let me know what you think. Send me an email at iruder@unitedspinal.org or call me at 718.803.3782, ext. 7224.

Cover photo courtesy of Walk the Line

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Photo courtesy of Walk the Line

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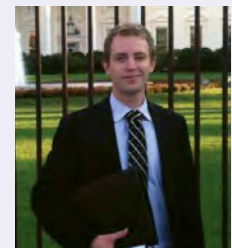
Jennifer French has a C6-7 SCI and is a user of the implanted stand-and-transfer system developed by the Cleveland FES Center. She is the cofounder of Neurotech Network, a nonprofit organization.



Shawn Dean is an attorney, blogger, and co-founder of the MNSCIA. He lives in Minneapolis and works in corporate compliance. He is a C6-7 quadriplegic.



Jane Wierbicky, RN, BSN, is a Nurse Information Specialist with NSCIA. For over 25 years she has worked exclusively in the field of spinal cord injury/dysfunction.



Christopher Neiweem is the director of veterans policy at VetsFirst, charged with advocating for federal policies that help disabled veterans reintegrate into their community and achieve independence.

Letters



Unique Bond

Thank you for sharing Scott and Melanie's story in your October 2013 article "A Different Type of Friend." The article represents not only their individual story, but the stories of many of Helping Hands' recipients and service monkeys across the country that share this unique bond.

We want your readers to know that we place all of our service monkeys (including lifetime support) with recipients at no charge and we are actively seeking appli-

cants to be matched with monkeys that will graduate from our program in 2014.

People that are interested in applying should visit www.monkeyhelpers.org to review our eligibility requirements, watch videos about our training program and inspiring recipient stories, and read our frequently asked questions.

We would love to welcome 8 to 12 new recipients to the Helping Hands family next year!

*Megan Talbert, Executive Director
Helping Hands: Monkey Helpers*

COMING WITH THE JANUARY/FEBRUARY ISSUE

In order to keep individual membership free, *Life in Action* will be changing formats in 2014. Beginning with the January/February issue, LIA will change from its current magazine-style format to a newsletter format that will average 24 pages. You'll still get complete coverage of NSCIA and United Spinal advocacy, news and events. You'll still have easy access to chapters and peer support groups, as well as profiles of members and chapters making a difference. However, most general SCI/D content will move to either the NSCIA website or to our sister publication, *New Mobility* (visit www.newmobility.com for a taste of this award-winning monthly wheelchair lifestyle magazine).

Please keep in touch with us as we proceed with this transition. What are your thoughts? What would you like to see, either in print or online?

We look forward to your participation in our growing organization!



Peer Perspective

Q: A year after my injury, I am struggling with finding the right balance between living my life and doing the rehab and exercise to keep myself in line for a potential cure down the line. How do others deal with this?

[Tennessee Member] Jessica Harthcock Responds

I like to think of rehab as working out; exercising to stay physically fit and making improvements along the way. I was an athlete before I was injured in 2004. Many able bodied people work out every single day to stay healthy and physically fit. Since we have a disability, this becomes increasingly important for us. Not only does active rehabilitation help you maintain the health and function

you do have, but it also helps you avoid risks of secondary health complications such as pressure sores, blood clots and decreased bone density. Staying active is the best thing you can do for your health, and the first step toward maximizing your potential of recovery.

Everyone's balance looks different. When

I was in college, I spent several years doing extensive rehab several hours a day, often five days a week. I was really happy with this balance. I still attended college and made time for friends and family. Today, that balance would not work for me. I recently graduated with my master's degree from Vanderbilt University and started my own company. My work/rehab/play life balance is very different. Depending on where you're at in your life, balance changes. Everyone has a different balance. At the end of the day, only you can decide what balance makes you happy and healthy.

Jessica Harthcock founded utilizehealth.co to match people with neurological disabilities with specialized therapies and equipment to help them maximize function.



United Spinal in Action

Peer Mentor Program Goes National

Our Peer Mentor Training Program is going national! Support from peers or those who have overcome the challenges of living with a spinal cord injury can be an important component in person's recovery. Mentors help people living with SCI re-evaluate their life/career goals and tackle day-to-day challenges, particularly those related to self-management of health care and social interactions.

The goal of United Spinal's Peer Mentor Training Program is to show prospective mentors the best ways to help newly injured individuals discover paths to greater health, independence and well-being.

To achieve this, United Spinal is collaborating with hospitals, rehab facilities, community-based organizations and our chapters and support groups across the country to offer training sessions to people interested in mentoring and making a difference in the lives of their peers.

On November 16, United Spinal hosted its very first training in Raleigh, N.C., in conjunction with one of our member chapters — the North Carolina Spinal Cord Injury Association. The 4-hour training was led by Lindsey Elliott, MSW, a social worker at United Spinal. During her time with the organization, Elliott has brought new strength and hope to many people living with SCI and their family members.

"It's an amazing experience for me to work with individuals with SCI who not only have successfully reintegrated back into their communities but have expressed a willingness to become mentors to others," says Elliott.

The training — which included role-playing and group discussions — focused on how to develop critical mentoring skills such as self-management, goal-setting and problem-solving skills, and effective communication. Participants were also offered tips on establishing an effective peer mentoring program from scratch.

"When I got injured in 2003, there was no support group and no NCSCIA," says participant Libby Braswell. "I just felt lost and longed to have someone to talk to that knew what I was going through. I think this program is a momentous step forward and will be very beneficial for the peer, mentors, and all involved." She says it was beneficial to be in a training session with an array of people from different walks of life. "I got a lot from the role playing and the comments of others," she adds. "It helps to see a different perspective other than your own. The group discussions helped me to see how



others may handle a situation different than I."

Elliott says the training program impacts many lives in different ways. "Its most important influence is the unparalleled first-hand knowledge and guidance that newly injured individuals are able to receive from their role-model mentors," she says. "I am very excited to have launched this program and look forward to doing many more trainings in the future."

United Spinal's next training session will take place in Charlotte on December 14.

For more information about starting your own mentoring program, please contact Lindsey Elliott, MSW, at lelliott@spinalcord.org.

Webinar Series Primed for Success in 2014

United Spinal Association is planning a stellar line-up of 2014 webinars, hosted by NSCIA, our membership division, that is sure to spark your interest.

There will be something for everyone as we look to broaden our participant base with a variety of contemporary and engaging disability topics. Here's a quick run-down of what you can expect next year:

- Motion therapy technology
- Access to implanted prosthesis
- Options after rehab, what's next?
- Resources for parents of children with disabilities
- Durable medical equipment & healthcare
- Personal assistance 101
- Service animals
- State of the art research & stem cell therapies
- Successful home modifications
- Disability employment

Presently, our webinars are rating higher than the national average in attendance. We're delighted with the growth these past few years and are eager to see where the series will go from here.

The ingredients for success have been helpful feedback and suggestions from webinar attendees and a fantastic team of dedicated staff members who get together regularly to kick around ideas for future topics and themes. And last but not least are our captivating and knowledgeable presenters.

You can check out our archived webinars online (www.spinalcord.org/webinar-archive/) and browse a ton of previous presentations that offer a wealth of helpful information.

If you have any ideas for future webinar topics, please contact Marlene Perkins at mperkins@unitedspinal.org or 718.803.3782, ext. 7330.

United Spinal Partners with AbleRoad

United Spinal is pleased to announce its partnership with AbleRoad, a new web and mobile app that connects people with accessible businesses.

Able Road lets wheelchair users and other people with disabilities rate and review the accessibility of a variety of businesses — from restaurants and hotels to supermarkets and nightclubs. If you have ever used Yelp, the Able Road app will feel very familiar. You can submit reviews based on four different criteria: mobility, hearing, sight and cognitive.

To learn more and start sharing reviews, visit www.ableroad.com or download on iTunes or Google Play. (For more on AbleRoad, read Member News on page 14.)

Advocacy: Journey to VetsFirst

Veterans Day each year is an opportunity for Americans to give pause and pay respect to the men and women who have served in the armed forces to defend the country. It is a celebrated holiday for all, but means more to veterans personally. Veterans celebrate this day as the rest of Americans do, but with a deep reflection on days during their service that have come to pass and the service members who had an impact on their life.

I enlisted in the U.S. Army Reserve following the 9/11 terrorist attacks when I was 19 — just a year out of high school. During a time when I wanted to do something in life and did not know what that was, this tragic event called me into service. I left for Basic Combat Training and Military Police School at Fort Leonard Wood, Mo., in summer 2002. The next four months were hard, and at times I wondered at night how I had ended up in those barracks, far away from home. The bunkmates I had, however, always encouraged me to “cheer up” on bad days when six hours of broken up sleep after a 15-hour training day didn’t seem to be enough. I would return that support to my fellow recruits when they needed it and before we knew it, we had graduated and become soldiers.

In February of 2003, I was deployed to southern Iraq to serve as a military police prison guard, tasked with patrolling roads and detaining enemy prisoners of war.

Though I had different faces in my unit than those at basic training, we served each other in the same way as we had during boot camp. We provided each other optimistic encouragement at times of sadness or isolation. Veterans often experience nostalgia when serving far away from family and friends. These experiences can be difficult, but they also provide an opportunity to create friendships for life.

These friendships and the encouragement I received in the military granted me the spirit needed to go on to use the Post-9/11 GI Bill, and earn a master’s degree from the University of Illinois at Springfield. I found the desire to work in Washington, D.C., during college, to advocate for veterans and those people that would follow a path of a career after military service. This Veterans Day, I spent the day with a fellow soldier from my boot camp platoon. It was a celebration, and a chance to reflect back on our time together in the military.

These experiences are shared across generations of veterans. VetsFirst Committee Chair Terry Moakley’s service in the military during the Vietnam era led him to push for increased rights for disabled veterans



Christopher Neiweem, Director of Veterans Policy for VetsFirst

following his return to the community after acquiring a spinal cord injury while serving stateside on active duty. In the late 1970s he fought to make public transit accessible and he has since worked to build coalitions of veterans and advocate on a federal level.

The path to advocacy I have taken was similar to Mr. Moakley’s. I have also used my experience in the military to identify the needs in our veteran population and then bring solutions to national and state policy

makers. This past summer, I appeared before the U.S. Senate Appropriations Subcommittee on Defense, informing the committee of better ways to help service members make informed decisions about their educational benefits. This September, I was hired as VetsFirst’s Director of Veterans Policy.

When we remember the service of our veterans I encourage you to ask a veteran — one you do or do not know — to talk more about the service members that influenced their journey while wearing the U.S. uniform. Each and every story is unique, sometimes humorous, and always inspiring.

— CHRISTOPHER NEIWEEM

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Research Participants Wanted!

Researchers at the University of Wisconsin—Madison are conducting a study about the way persons with spinal cord injuries evaluate themselves and their abilities (such as their self-esteem) and how this influences the satisfaction that they have with various aspects of their lives.

You are eligible to participate if you are an individual over the age of 18 who has had a spinal cord injury for at least one year. Participation will consist of completing an online survey consisting of several brief questionnaires which will take about one hour.

Please go to the following website to participate:
<http://tinyurl.com/spinalcordinjurysurvey>

If you have any difficulty with the link please contact Susan Miller Smedema, Ph.D., CRC at ssmedema@wisc.edu and she will be happy to assist you.

Thank you in advance for your participation in this important study. Findings from this study will help rehabilitation and health professionals develop effective services to help people with spinal cord injuries achieve the highest level of life satisfaction possible.



The first **300** participants will receive a
\$15 Target Gift Card
upon completion of the survey!



Note to Members

The price of the wonderful technological advancements that connect us so readily with one another, our country and the world might be that they also engender the expectation of instant answers, instant gratification and a diminished attention span, particularly in our younger counterparts.

To ensure that our organization

remains vital and relevant, and that we are reaching the people we need to reach with our programs and services, we recently conducted an online survey of our community. First and foremost, we asked survey participants to choose from a list five or more activities which they felt should be priorities and encompass the mission of an organization like United Spinal Association/NSCIA. A similar version of the survey was also administered to senior staff and to the members of our board of directors.

While we will be analyzing and reporting survey results in an appropriate venue, I wanted to share the good news that the priorities identified by survey respondents aligned with the priorities identified by the board of directors. This bodes well for our organization. It lets us know we are in touch with our community. And, just as importantly, it is an indication that the board of directors is a good cross-section and represents our members well in terms of their interests and expectations.

The majority of survey respon-



**GOOD NEWS!
WE GET YOU**

Paul J. Tobin
President and CEO

dents were individuals over 40 with SCI/D. This naturally makes us wonder whether we are reaching younger peers. Doing so might mean bolstering our social media presence and getting our information out in other formats. Everything must be looked at, re-evaluated, reconfigured and reinvented if necessary to keep up with changing

times and expectations. This is an added task to our day-to-day and one that we will be taking very seriously — all in the interest of meeting your needs and carrying out our organization's mission of helping to improve the lives of people with SCI/D.

One of the revealing parts of the survey is the desire of our membership to have access to local and community based programs. Of the more than 700 survey respondents, over 80 percent are already members of National Spinal Cord Injury Association. More surprising, however, was the revelation that only about 20 percent of those members are affiliated with a chapter. We have been working with local leaders from around the country to build a larger chapter network; as of this publication, we now have 42 chapters nationwide, with more in the pipeline. Please look at the chapter roster (www.spinalcord.org/chapters/directory) and find a chapter near you. If there isn't one, then please consider starting one. Email NLibassi@unitedspinal.org to find out more.

FOR PEOPLE WHO WANT TO GO PLACES



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Does a dentist in your neighborhood have an accessible exam room?



How's the line of sight at a theater in Sacramento?



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Chapter Check-In

Editor's Note: This month we're introducing Chapter Check In. Each issue we'll check in with a chapter to share what has worked and what hasn't, so other chapters can benefit from their experience.

Minnesota

The Minnesota Spinal Cord Injury Association (MNSCIA) has recently done a few very successful things to increase awareness of resources, education and advocacy to improve the lives of Minnesotans with spinal cord injuries. With September being Spinal Cord Injury Awareness Month there was no better time to do that.

The first thing that we did was kick off a state-wide project designed to raise awareness of the needs of people with SCI by asking cities across Minnesota to officially proclaim the month of September Spinal Cord Injury Awareness Month. One of our board members and a number of volunteers worked with mayors and city councils across Minnesota to write these proclamations. The result was that more than two dozen cities wrote such proclamations. MNSCIA board members and associated volunteers were invited to numerous city council meetings, where formal proclamation presentations were made to us. They were great experiences that grabbed local community attention.

We plan on doing the proclamation project annually, with the ultimate goal of getting every city in Minnesota to write similar proclamations. The lesson that we learned this year was to start the process earlier. We did not start reaching out to cities across Minnesota until July, which was possibly too short notice for many cities. Consequently, next year we plan to start reaching out to cities in March.

On September 21, members of the MNSCIA gathered with medical professionals from across Minnesota when we hosted lunch at the "Bridging Together: Advanced Spinal Cord Injury Conference." We

introduced our organization and communicated our desire to be a collaborative SCI advocacy group and resource partner with all organizations and professionals present, emphasizing our ability to fill resource gaps. We then drew attention to our proclamation project. One of our board members read the Minneapolis proclamation to the group, and copies of proclamations we received from various cities were prominently displayed on each table for everyone to peruse and discuss.

With MNSCIA members at each table we used lunch to have candid dialogue with nurses, therapists, and doctors about our theme, "Authentic Answers to Unspoken Questions." We explained what it is like to live with SCI. Conversation topics varied from table to table, touching on events of daily living, muscle spasticity, pain management, doctor bedside manner, SCI research and networking opportunities. It was great for the doctors, nurses and therapists to see people with spinal cord injuries outside of a medical setting. I think it helped the professionals see those of us

with SCI as whole people and not just patients.

According to the feedback we received, the event was a resounding success. For example, a registered nurse in attendance lauded the event for essentially serving as a role reversal with the MNSCIA members becoming the "experts" and the medical professionals being on the learning end — and he discovered that he had plenty to learn about SCI.

Both of these ventures did wonders to not only bring about further awareness of SCI in Minnesota, but also to spread the word about the great things that the MNSCIA plans to contribute to the Minnesota SCI community going forward. The momentum that we have seized since then has been invaluable to the further development of our organization.

— Shawn Dean,

MNSCIA Co-Founder and Vice-President

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MNSCIA members display the city of Edina's proclamation.



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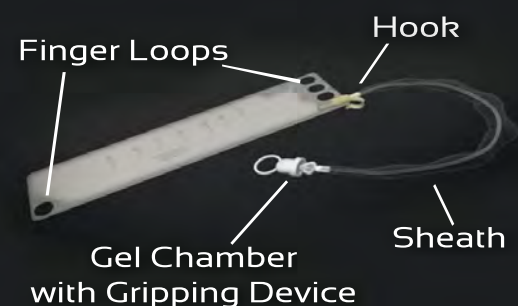
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Members in Action

[Florida Member] JR Harding: Gas for All

For the last five years, an ordinance aimed at improving access at gas stations for drivers with disabilities has been making its way around Florida counties.

To help drivers who have difficulty reaching the pump or pumping their own gas, the ordinance proposes requiring all stations to post a telephone number that drivers could call if they needed assistance. When Florida member JR Harding heard the ordinance was coming to his county he decided it simply wasn't enough.

"In a cold day in hell was I going to let that happen, because I don't think the responsibility should be on the customer to have a telephone," he says. "Frankly, nobody else calls anybody, and during emergencies telephones won't work."

Harding, a C5 quad who drives a full size Ford E250 van, took the issue to the Leon County Board of Commissioners.

"I explained to them that this was not the appropriate course of action. It wasn't equitable and quite frankly it didn't meet the needs of everybody," he says.

He proposed requiring larger stations to install an easily accessible button which drivers could press to let the attendant(s) know they needed assistance. Harding had used similar system while driving on the Florida turnpike.

"It was very pleasing for me, as someone who travels a lot, to be able to stop at these stations and hit the button and have a service station staff that was sensitive



A year of advocacy and working with his county commissioners and the local SCI community paid off for Florida member JR Harding, with the nation's first ordinance requiring gas stations to install accessible call buttons.

and knowledgeable ... I would actually go out of my way to stop at those stations," he says.

On Oct. 29, after over a year of working with the commissioners and rallying local support, Harding's hard work paid off when the commissioners unanimously passed an ordinance requiring stations that serve 10 or more cars install a call button within 90 days — the first such ordinance in the country. The victory was sweet for Harding.

"I've been successful in a variety of arenas, but I've never in my entire 22 years of driving been able to get gas independently," he says. "The day that I will be cut free of my wife and my personal aide is quite unimaginable, and I'm still breathless in anticipation of this."

That day might not have come without Harding's tenacity and savvy, according to Commissioner John Dailey.

"[JR] pushes hard, he pushes the community hard and he makes everyone aware of ADA issues that you might not normally think of, but he does it in a way that is very respectful and he does it in a way that truly sheds light on the situations," says Dailey. "He is very effective."

Harding is now working with state representatives to try to attain similar legislation at the state level. He hopes the new ordinance will energize gas access advocates in other states and be the beginning of a bigger movement.

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"Each show reminds me of what a dynamic and passionate community I am a part of because of my disability, and I continue to be inspired by the people I meet and the experiences we all share." Kris R.

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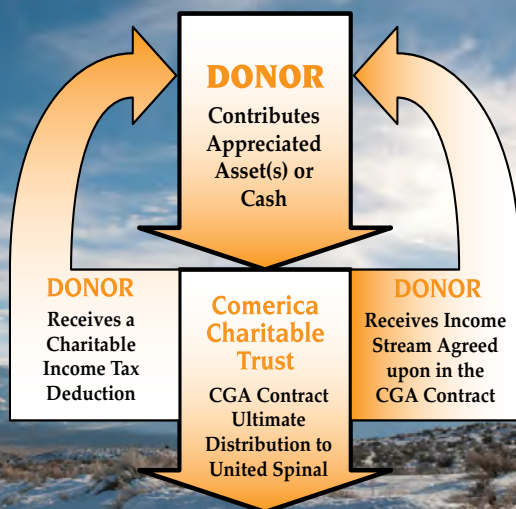
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Member News

Access App Only the Beginning

Massachusetts member Kevin McGuire has had his hand on the pulse of the disability community since he was paralyzed in a 1968 accident. He worked on accessibility issues for two prominent senators, he founded his own consulting firm dealing with accessibility compliance and he even showed famous actors like Tom Cruise and Ethan Hawke how to portray wheelchair users in *Born on the 4th of July* and *Gattaca*. Since the rise of the Internet, McGuire has envisioned building a disability and accessibility site. Before the bubble burst at the end of the 1990s, many others tried to build such a site with little success.

"I just sort of sat back and watched people fail and tried to learn from those that worked," McGuire says. "When iVillage sold to GE for 650 million in 2006, I thought you know, you need to revisit this idea and maybe now is the time to do it."

After more than six years of research and pounding the pavement, this fall, McGuire officially launched AbleRoad.com. He hopes the site will succeed where

others failed, and in doing so help improve the lives of the millions of Americans with disabilities. Available on the web or as an app for iOS and Android, in its current form, AbleRoad gives users the ability to rate the accessibility of businesses, locations and other entities using the same interface as the popular app Yelp. That's just the beginning, if McGuire has his way.

"My vision is bigger, or greater than what other people were thinking. I'm not looking at sort of a portal, I really want to build a brand," says McGuire. More than just accessibility ratings, McGuire wants to create a destination where people with disabilities would congregate and share information, resources and more — think Yelp meet's Angie's List meets Facebook.



AbleRoad could turn into a destination for much more than access info.

AbleRoad did a soft launch back in January and officially launched in late October. McGuire and his AbleRoad team have used the constructive feedback submitted by users and partners, including United Spinal Association, to tweak and improve the app's functionality. For more information, visit the site at AbleRoad.com or download the apps in the Google Play or Apple iTunes stores.



Family Matters

SIMPLY DAD

Raemon Davis

"God, you've taken so much away from me already, please don't take my children."

This is a journal entry that my husband, Robert Davis, wrote two months after an injury that left him a T6 paraplegic at 24. He was thinking about his new life as a para and what his future might hold. Having someone to love and have his children meant everything to him. Today, we can't help but recall this time in Robert's life and smile through our extreme exhaustion! Let me explain.

I met Robert about three years after his accident and after the entry above. I knew I was going to marry Robert 20 minutes into the blind date one of my sisters set up for us. He was so very smart and incredibly handsome with wit and charm to boot. He must have thought I was OK too, since we were married a year and a half later.

Here's the exhaustion part ... we now have five children. Atlas is 16, Birch is 15, Evariste is 13, Augustus is 11 and Mercella is 7; yep, four boys and one girl. After 17 years of marriage, we are still happily shocked, blessed, amazed and yes, exhausted. The official statistics say paraplegics have a 6 percent chance of conceiving. We blew that statistic out of the water!

Our kids are kind, lovely, smart, funny, maddening, talented, argumentative, persistent, beautiful, aggravating and every other adjective you can think of to describe a child. They keep us grounded, and Robert keeps us all reaching for more and achieving our goals. The kids are growing up watching their dad ride up to 550 miles across the Colorado Rocky Mountains on his handcycle, or mono-ski down the slopes of Crested Butte like a pro, or use a compound bow for hunting, or fishing from his kayak. Apart from sports, Robert is an attorney licensed to practice in Louisiana, Texas and Colorado. He gives his time to multiple nonprofit organizations that help all people with disabilities. This list goes on and on, but to our kids, this is simply their dad.

All of our children came to the realization that their dad didn't walk like the other Dad's around the same age. The perspective from a child who has a parent with a disability is rarely heard, so I asked each one of our children what is the worst thing and what is



Evariste, 13: 'The best thing is getting to pass everyone in line at the Empire State Building when we went to New York. The worst thing is ... not really that much!'

the best thing about having a dad in a wheelchair.

Atlas, 16: The best thing is that we get to experience unique things like when I road my bike with him during this past year's Ride the Rockies. The worst thing is when buildings aren't built truly accessible for people in wheelchairs.

Birch, 15: The worst thing is that he can't do normal stuff as easily as other people can — like throw a football as far. The best thing is that he can counter that negative by the positive of being the good person he is and figuring out a way.

Evariste, 13: The best thing is getting to pass everyone in line at the Empire State Building when we went to New York. The worst thing is ... not really that much!

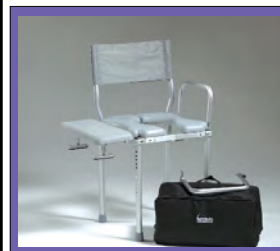
Augustus, 11: The good thing about him being in a wheelchair is the really good parking spots we get, and the worst thing is that it takes him a long time to get out of the car sometimes.

Mercella, 7: The worst thing is that he can't run and he can't walk. The best thing is that I can ride on his lap.

When we are watching our boys play football until 10 p.m. on a school night, or bringing our daughter to dancing twice a week, or finding a soccer coach before tryouts or staying up till 2 a.m. helping with a project, we remember that one day we will sleep again, and we try not to take one moment for granted. They are our hearts and our souls, and because of having a dad like Robert, they are learning tolerance, kindness, perseverance and equality.

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Need to Know: The Affordable Care Act

By Paul J. Tobin with Josie Byzek

There has been a tremendous amount of information distributed about Obamacare, which has caused considerable angst among people who may be eligible. We will try to put some of the myths and misconceptions to rest in the hope that you find some of the answers you seek about such an important topic.

If you presently have health insurance — either public or private — and that coverage will be in place in 2014 AND it meets minimum coverage requirements, then there's nothing you have to do to comply with the Patient Protection and Affordable Care Act (ACA). You'll be able to keep your insurance, uninterrupted.

That's because the ACA, also known as Obamacare, doesn't — and isn't intended to — replace private health insurance. Instead, the act is about expanding the existing health insurance net to include as many people as possible. It aims to do this by expanding public and private insurance coverage, and reducing the costs of health care for individuals and the government. It provides a number

of mechanisms — including mandates, subsidies and insurance marketplaces — to increase coverage and affordability.

If you do not currently have health insurance, then it's highly recommended that you shop at healthcare.gov to find one that's best for you. As you explore this site, you'll find that some plans available through the healthcare market are very affordable, but they only offer minimum coverage. So a bronze plan will cover 60 percent of costs, a silver plan 70 percent, a gold plan 80 percent and a platinum plan 90 percent.

Your access to wheelchairs and related medical equipment, assistive technologies, prescription drugs and medical supplies is highly dependent upon which health insurance carrier and which health insurance plan you choose. Pay close attention to what is covered under "Rehabilitative and Habilitative Devices and Services" under each plan and what medical equipment, prescription drugs and medical supplies are available. It is very possible that a platinum plan (the highest level) is actually cheaper than the bronze plan (the entry level), when you take into

account the purchase of a wheelchair and/or medical supplies that you use regularly.

The Basics

- Everyone must have insurance by March 31, or risk paying a fine. If you are already on Medicare, Medicaid or any other government-funded health care, nothing will change for you. If you have no insurance, or if you are self-employed and paying a whole lot for insurance, you are encouraged to log onto the health care exchange at www.healthcare.gov. Although this website was plagued with problems when it first went live in October, most now report they are able to log on, compare plans, and buy one that works for them. And, thanks to tax subsidies that are immediately applied, most people are reporting these plans are significantly cheaper than what had been available to them in the past.

- Pre-existing clauses are gone — no longer can any insurance company turn a potential customer down because of a spinal cord injury/disease. Also, since everyone must buy into the system or pay a

fine, there will be enough healthy people in the system to offset costs of those whose disabilities require more care.

This reform alone will dramatically expand employment opportunities for people with SCI/D. People with SCI are no longer tied to whichever insurance carrier was in place at the time of their injuries or the onset of our spinal cord disorders, and many will no longer be forced to remain on SSI or SSDI for fear of losing health benefits. In short, the opportunity to find a job, or move from one employer to the next is now easier for people who have the desire and capacity to work.

- Health insurers can no longer limit or deny benefits to children under 19 due to a pre-existing condition. That's right, insurance companies were previously able to deny coverage to the children of otherwise insured parents, because of a congenital SCI/D.

- If a plan covers children, then individuals under age 26 can be included on their parents' plan. In many cases this is true even if they're married, not living with their parents, attending school, not financially dependent on their parents, and eligible to enroll in their employer's plan. It's no secret we need as many young, healthy people enrolled in health insurance as possible, and this is one way to make that happen.

- Lifetime caps on coverage for most benefits end. Let's face it, we're expensive and many of us reach that \$1 million lifetime cap pretty quickly. Additionally, annual dollar limits on coverage will be phased out by 2014.

- Your insurance carrier can no longer arbitrarily withdraw insurance coverage due to mistakes on insurance applications. This was a frequent occurrence for people with SCI/D, or a history of SCI/D, if they didn't fully disclose their medical history. Considering how involved many of our disabilities are, these types of mistakes were common. Now we don't have to worry about losing our health insurance because of an oversight.

- Insurance companies must now publicly justify any unreasonable increases in premiums. In the past, insurance companies could encourage people to "volun-

The Affordable Care Act and Medicare

People who are already on Medicare or Medicaid do not need to apply for the health care exchanges since they are already covered by insurance. This isn't exactly good news for everyone, as Sandra Lambert discovered. Lambert is 61, on SSDI for post-polio, and would love to purchase Medi-Gap insurance, but can't because she uses a wheelchair.

"Nothing has changed for me," says Lambert, a writer from Gainesville, Fla. But no one could — or would — tell her that officially until the new law rolled out. "I've been putting off some medical procedures and getting a new wheelchair hoping that I'd be eligible, and nothing has changed at all."

In Florida, a person under the age of 65 can purchase Medi-Gap, but not if the person uses a wheelchair. Lambert says Aetna has a plan she could purchase, "But it's \$3,000-\$4,000 a year, so basically it's not real," she says. "It makes me mad. It's a terrible thing."

So Medi-Gap hasn't changed, but here are a few ways the Affordable Care Act does impact Medicare and DME:

- There is a 2.3 percent excise tax on medical devices, including wheelchairs. The government is coy about this, saying, essentially, "Well, it's a tax on the manufacturer, not a tax on the consumer," but increased costs on manu-

facturers tend to be passed on to the end user.

- People on Medicare no longer have an option to buy equipment, but instead must rent it.

- Competitive bidding for DME is written into the law, and that is expected to dramatically decrease the number of suppliers. This could seriously curtail the ability of people to choose who they want to do business with, and limit them to the options offered by a government-appointed supplier.

"In Medicare's world, it seems like competitive bidding is working," says Ann Eubank, vice president of community initiatives at United Spinal Association and the force behind UsersFirst. "But that's because people don't know what's going to happen until they order their next CPAP machine or wheelchair or repair." They might learn they can't use the same supplier, or the new supplier is so far away from where they live that they're stranded without their wheels for far too long. And, on top of it, they might not realize that Medicare's to blame for changing how people buy equipment and get it serviced. "People don't know the lingo or who to complain to," says Eubank. "So I say whatever sucks about your wheelchair or supplier, write it down and let us know."

— JOSIE BYZEK

tarily” dump their coverage by making the plan unaffordable.

- Also, insurance companies must now spend at least 80 percent of premium dollars on actual health care and if they don’t, they must issue a rebate. This is one way to try to keep them honest.

- Changes to Medicare’s prescription drug coverage will reduce the out-of-pocket cost impacts of the “doughnut hole” gap. Some of this has already begun happening, as subsidies to help pay for generic drugs were put in place in 2011. This year, more subsidies will be phased in to help pay for brand-name drugs. By 2020, the gap will shrink from 100 percent to 25 percent.

- If you currently have coverage through the federal Pre-Existing Condition Insurance Plan (PCIP), be aware that this plan will end Dec. 31, 2013. You must enroll in a new health plan by Dec. 15, 2013 to ensure pre-existing condition coverage that starts Jan. 1, 2014. PCIP was a temporary program put in place to provide immediate relief for people who could not otherwise obtain health insurance, but now that the exchange is up and running, PCIP is being phased out.

To Learn More

- “Health Law Helper,” Consumer Reports; www.healthlawhelper.org

- “Health Reform and People with Disabilities,” American Association of People with Disabilities; www.aapd.com/resources/fact-sheets/health-reform-people-with-disabilities.html

- “The Affordable Care Act Kicks In: Important Facts for People with MS and Their Families,” National MS Society;

www.nationalmssociety.org/government-affairs-and-advocacy/health-care-reform-resources/index.aspx

Quick Links Via Healthcare.gov

The Health Insurance Marketplace, Affordable Care Act can be found at Healthcare.gov and this is the site where you can shop for insurance. It’s an easy process and people are encouraged to explore before they make a final purchase. Following are some links within Healthcare.gov that provide useful additional information:

- “Get Covered: A one-page guide to the Health Insurance Marketplace,” www.healthcare.gov/get-covered-a-1-page-guide-to-the-health-insurance-marketplace/
- “How do I get help enrolling in the marketplace?,” www.healthcare.gov/how-do-i-get-help-enrolling-in-the-marketplace. This link can connect you to “health care navigators,” trained professionals in your local area who can help you figure out the best plan for your situation.
- “What if I have PCIP Coverage?,” www.healthcare.gov/what-if-i-have-pcip-coverage/.

No computer? No problem. You may call the Health Insurance Marketplace at 800.318.2596.

How Does It Work?

Enrollment for plans purchased through the healthcare marketplace began Oct. 1 and runs through March 31, 2014, but coverage begins in every state on Jan. 1, 2014. How the program is run may depend upon where you live, as states can choose one of three options:

- build either a fully state-based marketplace
- enter into a state-federal partnership marketplace
- or default into a federally-facilitated marketplace

The latter two options, which

involve the federal health insurance marketplace, have been the focus of the majority of the news reports.

The Affordable Care Act directs the Secretary of Health and Human Services to establish and operate a federally-facilitated marketplace in any state that is not able or willing to establish a state-based marketplace. States entering into a state-federal partnership marketplace may administer plan management functions, in-person consumer assistance functions, or both, and HHS will perform the remaining marketplace functions.



Rehab is Over ... Now What?

By Jen French

Your time in rehab is over. After spending several weeks in intense rehabilitation therapy following a spinal cord injury, brain injury or another acquired disability, it can feel like ending a love-hate relationship. Even for those with degenerative diseases like multiple sclerosis or ALS, where do you go from here? In the booming \$18 billion health and fitness industry, wheelchair users tend to be left behind. The irony is that this is the population that needs more access.

According to the Center for Disease Control, adults with disabilities have a 58 percent higher incidence of obesity than our able-bodied counterparts. Couple that statistic with high incidences of cardiovascular disease, pulmonary disorders, diabetes and the array of secondary conditions like osteoporosis and pressure sores, and this population seems ripe for the health and wellness market. Unfortunately, it is not so easy to access.

Research conducted by Drs. Rachel Cowan, Kim Anderson and Mark Nash found that nearly 64 percent of those surveyed do not have access to a trained therapist to oversee their exercise regimen. More than half reported their physician had advised them to exercise, but less than a quarter had received specific instructions from their doctor regarding the kind of exercise to engage in or how often. Doctors know that exercise and fitness may lead to functional gains in daily activities. There seems to be a need for supplemental therapy and fitness programs, and there is obviously a demand. How does that gap get filled?

One key is to understand the difference between rehabilitation therapy and fitness; both include exercise but with different goals. Rehabilitation has a focus on areas such as recovery and compensation, whereas a fitness plan focuses on conditioning, prevention and performance. There are a host of extended therapy, enhanced fitness and wellness programs popping up around the country. Some are offered by rehabilitation hospitals and clinics, some are stand-alone programs and still others are offered through public access parks and recreation programs.



Photo courtesy of Walk the Line



Photo courtesy of Walk the Line

Clinical Programs

More and more rehabilitation facilities are offering extended therapy programs. This can give you access to trained professionals, including physical and occupational therapists and nutritionists. They can also offer access to expensive rehabilitation equipment, such as functional electrical stimulation cycling, locomotor training and repetitive motion robotics. These are programs like the PEAK program at Craig Hospital in Denver, Colo., or the Neuro-Recovery Center at Brooks Rehabilitation Hospital in Jacksonville, Fla. These programs tend to be highly structured with goal setting and establishing expectations early in the process of customizing an exercise plan with you. Programs are typically not covered under insurance but payment is available in a “gym membership” payment plan.

Stand-Alone Programs

Much like clinical programs, these programs offer similar services without being affiliated with a rehabilitation facility. You still have access to equipment, but the staff typically consists of personal trainers and exercise physiologists. These include programs like Journey Forward in Canton, Mass., and SCI-FIT in Sacramento, Calif. Reputable programs will establish goals, set realistic expectations and help you create an exercise plan. Some programs offer a membership fee while others require an up-front payment.

Public Access and Private Gym Programs

Private gyms and wellness centers are starting to of-

fer programs and equipment for people with disabilities. For instance, some YMCA facilities offer FES cycling while others offer roll-up exercise equipment. Parks and recreation departments around the country are now offering fitness centers, aquatics and outdoor fitness zones. Since these are public access, they need to meet the limited requirements under the ADA. These programs are not structured and are not monitored by trained professionals. They do give you access to fitness for a much lower cost.

Before beginning any exercise program, you should consult with your physician and make sure you ask some key questions like:

What should I expect from a typical program?

Is it a rehabilitation program or a fitness program?

Will there be a trained professional monitoring my program? If so, what are his/her qualifications?

What type of equipment will I have access to?

What is the length of the program?

How much will this cost me?

The good thing is access to exercise and fitness programs is expanding; the bad thing is how difficult it can be to find them. Unfortunately, there is no central registry of programs or website to access programs near you. How do you find programs like this? Spinal Cord Central has a listing of some programs (see resource sidebar); that and the National Center on Health, Physical Activity and Disability are good places to start. Ask your physiatrist about local programs and check with your local parks and recreation department about fitness opportunities for people with disabilities.



Photo courtesy of Walk the Line

Kimberly Baker, C4-5-6, says she has gained much “strength, independence and self reliance” during three years of therapy at Walk the Line.

If you live in a rural area, you may need to start a home-based program. Meet with a physical therapist and specifically request exercises and a home-based plan for your needs. Specifically request a low equipment program and one that is capable of being done at home. Remember to ask how to exercise not only the limbs where you have voluntary movement, but also those that are paralyzed. Also, don't forget cardiovascular exercise. If it is a home-based program that you are seeking, remember that you need to be the motivator.

Whichever program you chose, the key is to make a choice and a commitment. Like any exercise program, able-bodied or disabled, you can't make progress without a commitment. Make a plan and stick with it; you will achieve better results.

Contributing authors: Kim Anderson, Jennifer McParland, Candy Tefertiller, Jane Wierbicky.

Resources

Extended Therapy Programs

- Beyond Therapy-Atlanta, GA: www.beyond-therapy.org
- Brooks Rehab Neuro-Recovery Center, Jacksonville, FL: www.brookshealth.org/programsservice/neuro-recovery
- C.O.R.E.-Northridge, CA: corecenters.info
- Journey Forward – Canton, MA: www.journey-forward.org
- Neurorecovery Network – Several Locations: www.christopherreeve.org
- NeuroXcel – North Palm Beach, FL: www.neuroxcel.com
- Next Step Fitness – Lawndale, CA: www.nextstepfitness.org
- PEAK Center – Englewood, CO: www.craighospital.org
- Precision Rehabilitation – Long Beach, CA: precisionrehabilitation.com
- Project Walk – Several Locations: www.projectwalk.org
- SCI-FIT, Sacramento, CA: www.sci-fit.org
- SHARE Program – Minneapolis, MN: www.couragecenter.org
- The Recovery Project - Two Locations in MI: www.therecoveryproject.net
- Walk The Line – Southfield, MI: walkthelinetoscirecovery.com

Additional Resources

- National Center on Health, Physical Activity and Disability Directories: www.ncpad.org/directoriesIndex
- Neurotech Network, Exercise Weak or Paralyzed Muscles: www.neurotechnetwork.org/educate_exercise.htm

Wheelchair Exercises

- www.disabled-world.com/fitness/exercise/wheelchair-exercises.php



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Elective Surgeries for Hand Function

By Ian Ruder

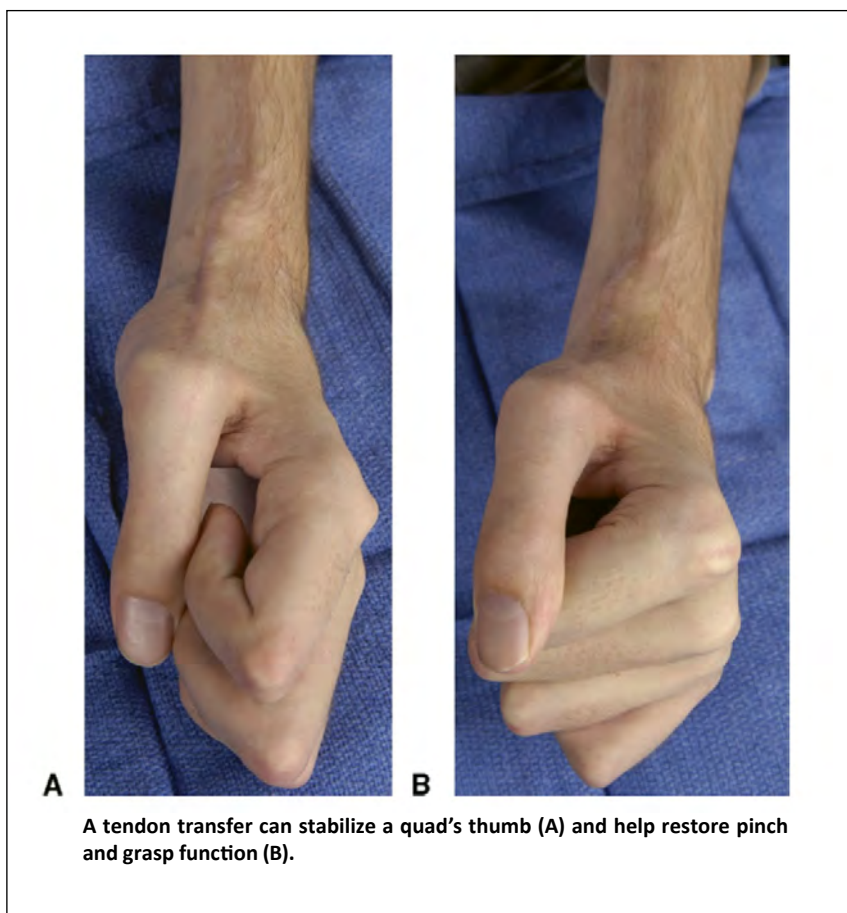
If you are one of the thousands of people with limited hand and arm function as the result of a cervical spinal cord injury, would you be surprised to know that there is a proven road to increased function and independence that doesn't involve a cure?

For over 40 years, orthopedic surgeons have been helping individuals with SCI regain pinch, grasp, finger flexion, triceps use and more by transferring tendons to connect enervated muscles (below the level of injury) with muscles patients can control. As surgeons have refined the procedures and studied the outcomes, immobilization times have decreased and results have improved. Most surgeons report nearly universal happiness with the outcomes and promise no noticeable impact, should a cure arrive. Yet only a small percentage of those eligible for the surgery take advantage of it, and many quads don't even know it is an option, raising the question: why?

Drs. Scott Kozin and Dan Zlotolow, orthopedic surgeons at the Philadelphia Shriners Hospital and published experts on tendon transfers, say the answer is complicated and are working to address its many roots.

"It's an uphill battle for us," says Zlotolow. "There's a bias among physicians in particular, who don't see the results of these surgeries so they don't believe in them and think it's just a bunch of surgeons operating willy-nilly — they don't really see that there is any benefit to them. They generally tend to discourage patients from having anything done. ... It's very frustrating."

Additionally, Zlotolow says the surgeries are "underused" because of the relatively small number of surgical centers where doctors specialize in transfers and because of fears that transfers could impede an eventual cure. His response to concerns about the impact on a cure has the polished sound of a line that has been delivered many times. "Tendon transfers do not get in the way of a cure," he says. "The day we have a cure is the day you will be cured, whether you've had tendon transfer or not. You can think of the tendon transfers as a way to make you as functional



as possible until the cure comes."

As little as 10-15 years ago, lengthy immobilization times and rehab periods also discouraged potential beneficiaries, but new techniques and a better understanding of how best to rehab tendon transfers have all but eliminated those excuses.

A biceps-to-triceps transfer to give a C5 or C6 quad the ability to extend his/her elbow and use the biceps to function like triceps formerly required up to six weeks in a motion-restricted cast before rehab could begin. Now recipients are mobilized as quickly as one-week post-surgery. For wrist and grip transfers, immobilization can be as little as one day. "We've got pretty good data that shows that biceps-triceps does better with less post-operative immobilization and is not as hard to relearn," says Kozin.

Kozin and Zlotolow described their target audience as "the person who has a little bit of function in their arm, but not enough to be independent."

"Because most of the time, if you have a little bit of function in your arm we can get you independent," says Zlotolow.

As an example, he described how tendon transfers might benefit a C7 quad with some grasp, a weak pinch

and decent triceps. "You can take that person and give them a strong pinch and a stronger grasp, and usually you can give them opposition [control of the thumb]," he explains. "The difference between somebody who has no pinch and no grasp and you give them pinch and grasp — that's huge."

Both doctors said transfers can benefit someone as low as C8, but acknowledged that the farther down the injury, the less the benefit.

Kozin encouraged interested quads to reach out directly to a surgeon who is known for doing transfers or an SCI center that can help connect you with one. While there may not be a multitude of surgeons specializing in tendon transfers, Zlotolow believes the patient-pleasing surgery has attracted a uniquely loyal brand of doctor. "People who do this surgery do it because they really care about it," he says. "Nobody does it just to make money. People who are doing it are very committed to people who have spinal cord injuries." Shriners Hospitals in Philadelphia, Chicago and Sacramento, Calif., all offer transfer options for minors, and the doctors there can help connect adults too.

Nerve Transfers

If tendon transfers aren't your thing, but you're still interested in options to regain arm and hand function, Dr. Justin Brown thinks he may have the ticket. Dr. Brown, the Director of the Neurosurgery Peripheral Nerve Program and Co-Director of the Center for Neurophysiology and Restorative Neurology for the UC San Diego Health System, is one of the leading advocates and practitioners of nerve transfers for people with SCI.

Surgeons have transferred nerves to help people with nerve injuries for many years, but only in the last four to five years have they begun connecting nerves to restore function below the level of injury for people with spinal cord injury. Conceptually, imagine tendon transfers with nerves replacing tendons. The potential benefits can surpass tendon transfers according to Brown.

"For a muscle tendon to move you can only gain one movement on the other side, so if you take a wrist extensor and you put it into finger flexors, you're going to tie it into all the finger flexors and they're all going to pull as a single unit," he explains. "When you do the corresponding nerve transfer, you plug the nerve into the recipient nerve and there is the potential in some folks to have independent movement of individual fingers."

A shorter, simpler operation and the absence of immobilization post-op are among other reasons Brown is excited about the transfers potential for SCI, though he noted that recipients must wait up to a year for the transferred nerve to grow and connect before seeing results.

Once connected, one of those individuals should be able to put you in contact with someone with a similar level of injury who has had whatever transfer you are interested in. "We've found that personal connections are the most effective way to educate and help people learn [about potential benefits]," says Kozin.

Resources

- For more detailed information on tendon transfers and what is involved, check out this helpful overview prepared by the American Society for Surgery of the Hand: www.asssh.org/Public/HandConditions/Pages/Tendon-TransferSurgery.aspx.

- The three Shriners hospitals that specialize in spinal cord injury are located in Sacramento, Philadelphia and Chicago, for eligibility questions call 800.237.5055.

- To find out more about nerve transfers, call the Peripheral Nerve Center at UC San Diego Health System, 858.246.0674.

CCF IRB# 11-823
Approval Date: 9/9/2013
Expiration Date: 9/8/2014

A rehabilitation study at the Cleveland Clinic is seeking patients with spinal cord injury. The purpose is to investigate whether a novel program of the therapeutic exercises helps function of the weak arms/hands. To be considered, patients must be between 18-70 years old, have a spinal cord injury that occurred more than 6 months ago, and have no other neurological or cognitive deficits. For more information or to schedule a short presentation, please contact Myranda Long or Corin Bonnett at 216-445-6728 or Dr. Ela Plow at 216-445-4589.

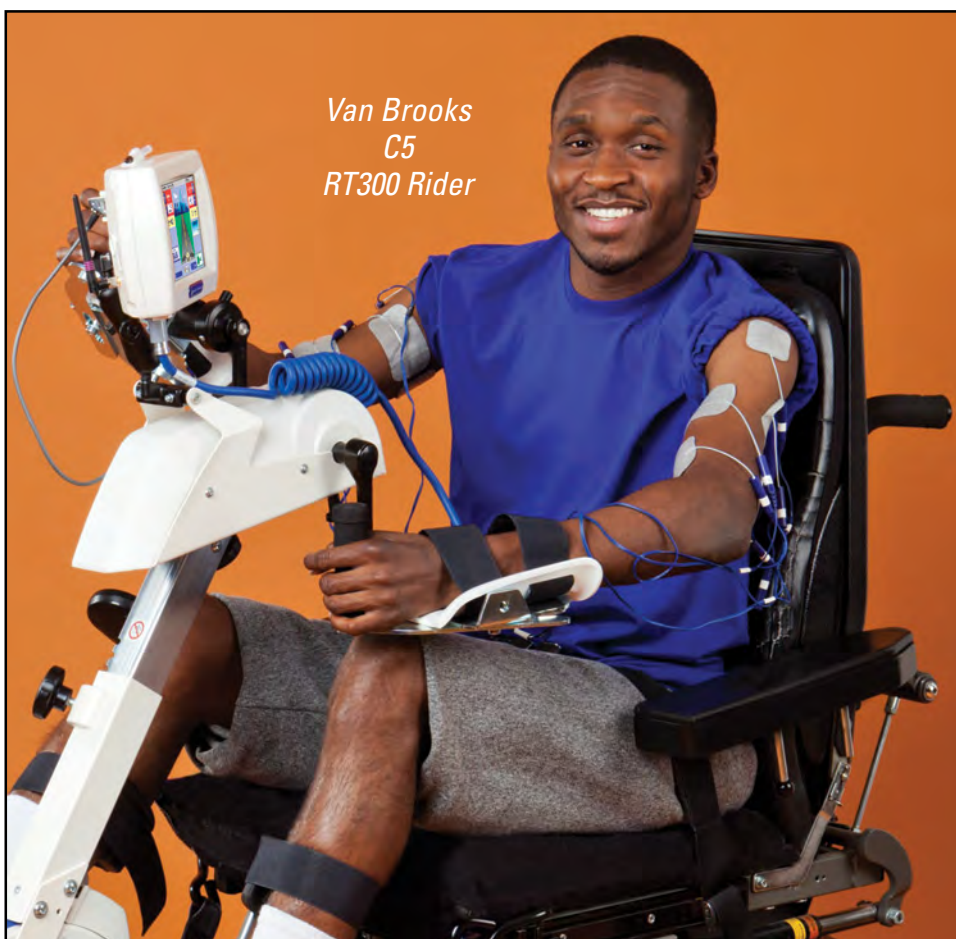
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Ask Anything

By Jane Wierbicky, RN, BSN

After 23 years in a wheelchair, this last few months I've noticed slow but steady changes in my sensation level and my general ability to do things muscle-wise. I don't feel too bad but find the decrease in function frustrating. A friend suggested I should get checked for syringomyelia, but I grew scared after doing some quick web research. What should I do?

age of people with spinal cord injury with roughly 3 percent to 8 percent of people with SCI experiencing neurological symptoms from PTS. PTS is known to occur in both people with tetraplegia and paraplegia, and in both complete and incomplete injuries.

Among people with spinal cord injury, the syrinx typically originates at a segment of the cord damaged by the original SCI. The syrinx can elongate and expand over time, compressing the surrounding nerve tissue. This damage to the nerve tissue can translate to progressive functional loss. As the fluid-filled cavity ascends in the cord, a loss of mobility and sensation can be experienced in areas that were intact after the spinal cord injury.

Sensory changes and complaints of pain are often among the first symptoms to appear. The ability to feel temperature such as hot or cold water or sense pain (such as to pin prick) may be impaired or lost in areas of the body where sensation was previously intact. Some describe hypersensitivity, experiencing pain in circumstances where they

normally would not (such as when being touched).

The pain generally occurs at the site of the original spinal cord injury and can radiate, often times into the neck and arms. Symptoms can come on gradually or rapidly and can occur months to decades following SCI. Symptoms may be nonspecific, minimal or occur on one side of the body in the early stages. Individual symptoms may vary depending on the location of the syrinx.

Anyone experiencing any of the above symptoms should contact their physician for an evaluation as soon as possible. Assessments of motor and sensory function should be completed. PTS is generally diagnosed by magnetic resonance imaging (MRI). A CAT scan can be useful to determine the extent of the syrinx in people with spinal hardware limiting MRI.

In some cases, PTS may stabilize over time; however, the treatment of PTS often requires surgery. It's extremely important to locate a neurosurgeon with expertise in the management of PTS.

Surgery is aimed at removing the scar tissue, untethering the cord, and restoring the space around the spinal cord and the normal flow of spinal fluid. Surgical options also include procedures to drain the syrinx. In some cases shunt placement is considered. Shunt placement involves the insertion of a small tube into the syrinx, and draining the accumulated fluid into another space where the fluid can be absorbed (such as the abdominal cavity). Shunts can become blocked over time, and a recurrence of symptoms may occur. It is not uncommon for syringomyelia to recur prompting further surgical procedures. Follow-up with a rehabilitation practitioner with PTS expertise is essential for long term monitoring and management of the syrinx to maintain neurological function.

For more information, visit www.newmobility.com/2009/03/untethering-the-invisible-knot/ and www.newmobility.com/2011/01/paramedic-syrinx-and-pain/

For assistance locating specialists with PTS expertise, please contact the NSCIA Resource Center at: www.spinalcord.org/resource-center/askus/index.php?pg=request or by calling 800.962.9629, M-F, 8:30 – 5:00 ET.

Symptoms

- Sensory changes (numbness, changes in ability to feel temperature)
- Pain, often described as burning, stinging, or shooting
- Changes in motor function (weakness, increased difficulty pushing chair or performing activities of daily living, for example)
- Changes in bowel or bladder function
- Sexual function changes
- Changes in spasticity (increase or decrease)
- Orthostatic hypotension (drop in blood pressure when moving to an upright position)
- Profuse sweating
- Horner's syndrome (differences in pupil size, decreased sweating on the affected side of the face)



Syringomyelia is a potentially disabling condition in which a fluid-filled cavity (syrinx) forms within the spinal cord. As we age, it's not uncommon for people to disregard some symptoms such as weakness as typical signs of aging. In the case of syringomyelia, this approach can delay diagnosis and lead to greater neurological decline. It's important to remain vigilant about your health status and immediately address any changes with your healthcare professionals.

At the most basic level, syringomyelia results from a buildup of cerebrospinal fluid (which normally surrounds and protects the brain and spinal cord) within the spinal cord, which can accumulate to form a syrinx — a fluid-filled cavity.

The two most common forms of syringomyelia are post-traumatic syringomyelia and Chiari I formation, a congenital malformation of a portion of the brain. Post-traumatic syringomyelia (PTS) can occur following a number of medical conditions including spinal cord injury. PTS affects a relatively small percent-

Access: Paradise Around the Corner

By JR Harding

There is nothing like soaking up the sun's warm rays on a pristine sandy beach. If you use a wheelchair, that statement takes on a whole new meaning because finding an accessible beach can be like searching for an elusive oasis.

Florida residents and others with disabilities need search no farther. William Joseph "Billy Joe" Rish Recreational Park is a 98 acre beach paradise located at Cape San Blas in the Florida Panhandle. This park has been developed specifically for people with disabilities and their families and shows how some vision and planning can magnify one of nature's treasures by expanding access. The current vision of the park is to allow people with disabilities and their families to enjoy an affordable, barrier-free outdoor recreational experience.

Originally envisioned by State Representative Rish in the early 1970s, the park has maintained its natural qualities through a county ordinance which mandates environmental protection and limits development to ensure pristine views on Cape San Blas. The park is owned by the state of Florida and operated by the Florida Agency for Persons with Disabilities (APD) with two full-time staff.

More than a Beach

One of the unique features Rish Park offers is access to St. Joe Bay and the Gulf of Mexico, which are renowned for scallops, wildlife and estuaries. The bay side of the park is currently being renovated to improve its accessibility, but the north side of the park will soon permit access to the bay through a boardwalk. Visitors with the appropriate fishing permit will be welcome to capture their limit of scallops in St. Joe Bay. At the same time, the south side of the park drops visitors into miles of sugar white beaches that are known for seasonal sea turtle nesting.

The park has two family cabins that can house up to seven people. They each contain a living room, kitchen, two bedrooms and two bathrooms, complete with a roll-in shower. The cabins are maintained in a rustic fashion and users must bring personal items such as sheets, towels and groceries.



Extensive boardwalks grant access to bays and beaches at Rish Park.

Rish Park can also house 107 people in the six dormitory-style group cabins. Visiting groups can utilize the industrial kitchen located in the main lodge. If the weather is unfavorable, the main lodge contains a large projector screen that allows groups to watch movies and play video games. Next to the main lodge is an Olympic-size, accessible swimming pool. Visitors can use the grills located by the pool while listening to music of their choice over a speaker system.

The current 2.1 miles of updated accessible boardwalk enables visitors to access the beach. Through the available beach wheelchairs and Mobi mats, wheelchair users can equally enjoy the beach with their fam-

ily. For visitors that prefer to ride in luxury, there are two Beach Scoots (golf carts with hand controls) available for use. Groups and visitors are encouraged to bring personal equipment like kayaks, pontoon boats, snorkeling gear and anything else that could be useful on your family or group vacation.

The State's Commitment

Following the 2004-05 hurricane season, the state of Florida invested \$3.5 million to update Americans with Disabilities Act compliance issues and repair damage on the Gulf side of the park incurred during the storm season. The park is a tribute to the state's continued investment in accessible economic development and tourism.

In the future, visitors can expect Rish Park to be more dynamic and accessible due to a recent \$1.4 million appropriation. This revenue is specifically designated to enhance the north side of the park that has access to the St. Joe Bay. The accessible boardwalk from the beach all the way to the bay will be modernized to allow both freshwater and saltwater fishing. A floating dock will be included in the bayside renovation of the boardwalk. The dock will have all of the appropriate accessible features for adaptive sports and recreation.

APD is working to secure more funding for enhancements such as accessible nature trails, tree forts, campground, RV park, miniature golf course, multipurpose sports area for adaptive tennis and basketball, and additional family cabins.

Visitor Information

Rish Park is open all year and encourages both overnight stays and day visits. Reservations can be made by calling 850.482.9386 between 8 a.m. and 4:30 p.m. CST, Monday through Friday. An online application is available on the Rish Park website, www.rishpark.org.

Overnight guests pay \$15 per night per person. Groups of more than 60 people pay \$12 per person per night. The day visits are \$5 per person. Groups can rent the entire park for \$650 per night.

The physical address of the park is 6773 Cape San Blas Road, Port St. Joe, FL 32456.

Dating/Relating: The Caregiver Conundrum

Finding the right caregiver involves a rigorous interview process on its own, but when you finally settle on the best candidate, how do you forge a relationship? Sometimes taking that extra step to connect can make all the difference in what is often a forced 1:1 working arrangement. If someone is going to see the most intimate parts of your life, you might as well create some kind of friendly (yet professional) environment, right?

Take a former caregiver of mine — she was mid-50's, not as financially stable or fashion-savvy as me. We couldn't have been any more different, but she was sweet, reliable, and hardworking, and that's what mattered to me. However, my younger self found some pitfalls in our generation gap. I felt she would judge me if she ever saw a hickey on my neck from my boyfriend. I also wasn't sure how to explain that my bowel program was going to go REALLY well since I had a full weekend of drinking celebrations. Would she judge me simply on that? Or look at me differently? Plus, I'm pretty sure my brightly colored bras and lacey underwear caught her by surprise. To me, it wasn't shocking, but to her, it was quite the opposite of what she was used to seeing.

My solution was simple — be honest, joke about our differences, and get to know her as a person while she got to know me. The more we became comfortable with each other, the less awkward some of those situations became. Daily conversations about work life, friends and family, plans for the weekend, etc. all helped us ease into a solid work relationship. We could both go about our business, but also hold a conversation. And she was young once; I figured she would understand. I briefly mentioned to her about my booze-filled weekend and what to expect; we laughed about it and that was that. Crisis averted!

On the other hand, I had a younger RN helping me out, and she turned out to be a total flop. In my mind, I was psyched to have someone helping who was more my age. I assumed we'd be able to relate and chat about age-appropriate things while going about our routine. Sure, the conversation was



Zoë Amour

great, but she was a little too comfortable in our young, sort-of-friends vibe. I saw her always sending off texts during our scheduled visits and wanting to sit down and chat, not work and chat simultaneously. It made for a strained relationship. I eventually cut down the chatter and kindly asked her to help with A,B,C and D. I did the same thing day in and day out until she caught on ... or just got tired of hearing me repeat myself each visit.

Both experiences taught me a lot: YOU have to set the tone. A friendly demeanor is a must, and knowing when to pull back and not interfere with what your caregiver is there to do is just as crucial. You're not rude if you nicely interrupt a conversation for a second to ask for a towel. Being respectful about sharing too much is also key; you don't want to make your extra hand feel uncomfortable or become too carefree. However, share if you feel it does have something to do with your health and overall care routine since that is what really matters.

Every relationship may be different, so feel it out and ultimately do what you think is best for your situation. Being best friends doesn't exactly have to come with the job title, but having some level of open communication with your helping hand will make all the difference.



Axel Grande

Those of us who have attendants pretty much run a small business. We hire our help. We train them. They become our staff. We become their managers. In the end, we need to manage well to keep our own lives on track.

This can be complicated by the fact we often become close to our attendants. It's nearly impossible not to when we spend so much time one-on-one. That makes it all the more important

we make those relationships good ones and ensure that things run smoothly.

The first step to keeping things running smoothly is finding the right people. If you're going to be spending hours with somebody, make sure you'll get along! Treat the hiring process like a professional one. I always ask for references,

chat about the job requirements and see if we have a good vibe. Somebody doesn't even need experience with care work: Most of my staff had never done this before, but they've all worked out great. I even prefer hiring people without experience, just because folks work around my training rather than their experience.

You can even reach out to your friends. One of my attendants is a buddy that I met in college. We always joked around and hung out on the weekends, going to things like

street fairs and talent shows. Then one day, one of my shifts opened up, and I poked around to see if any of my buddies needed a job (I even put a note on Facebook). He said yes, then started doing my evening routines before adding one morning a week. When you get along like we do, the routines feel just like hanging out.

Still, even if you're working with friends, set some ground rules and expectations. I tell my attendants that they need to be on time, move quickly and be thorough. I point out the most important things, especially those that I can't check every day. If there's a slip up, it's important to have a conversation and make sure it doesn't happen again.

Here's a perfect example: Another guy helps me out three mornings a week, and he put my leg bag on backwards a month ago. As soon as I had to empty the bag, I reached down and realized I couldn't get the lever. I had to call him in the middle of the day — he came out to my work and was able to switch it around, but it was pretty stressful when it happened. After that, I did the boss thing and told him that was a big can't-do. We made a system to make sure it wouldn't happen again: a big sharpie smiley face on the front of the bag and an angry frown on the back.

It's also important to protect against the awkward. Some of us have attendants around for several hours at a time, and small talk can only work for so long. Talking about our personal lives can provide support but can also add stress or get in the way of keeping a relationship professional.

Try having a distraction to smooth things out and keep the routine rolling. I'm a bit of a news junkie, and always have podcasts playing — I even bring speakers into the bathroom during showers. The distractions help with awkward silences and give us things to talk about when we have some downtime.

Working with attendants is a balance. You need to make sure they do the job right, but you need to get along so your routine is enjoyable. So figure out how to keep engaged as a supervisor and friend, and you'll find the harmony you're looking for.

YOU NEED TO MAKE SURE THEY DO THE JOB RIGHT, BUT YOU NEED TO GET ALONG SO YOUR ROUTINE IS ENJOYABLE.

Travel: Cruising Around Accommodations

By Ian Ruder



After a beautiful courtship and an even more beautiful wedding, why would you leave anything to chance when planning your honeymoon?

That's what Emily and Frank Sciarretta thought when the time to book their honeymoon cruise came. The New York newlyweds, who both use power chairs, did pretty much everything they could do to make sure their week-long excursion to the Bahamas was as perfect as could be. They chose a new Norwegian ship — the Breakaway — for the latest in accessibility options. They went on a pre-tour to identify possible issues and gave Norwegian a detailed list of the accommodations they would need.

So you can imagine Emily's reaction upon arriving in their luxury suite to find that a bar by the toilet they had asked to be removed was still in place, the bed hadn't been lowered and the riser for the toilet didn't work right.

"I told them then, I'm leaving the ship and thank you for ruining my honeymoon," she says.

Luckily, the story didn't end there.

After much finagling with the concierge and a phone call to Norwegian's corporate offices, things started to turn around. It took a team of cruise mechanics four hours, but eventually they removed the bathroom bar so the Sciarrettas could transfer to the toilet. They fixed the bed and came up with a solution for the toilet riser. With all the accessibility issues in their room resolved, the Sciarrettas finally began to enjoy the luxury amenities they had envisioned.

"Once it all was taken care of, we had

"YOU'RE REALLY TREATED LIKE ROYALTY. THEY WENT ABOVE AND BEYOND TO TRY TO MAKE US AS COMFORTABLE AS POSSIBLE. THEY REALLY WORKED WITH US."

a great time on the cruise," says Frank.

"It was extraordinary, actually," adds Emily.

The Sciarrettas signed up for Norwegian's 7-day cruise from New York to the Bahamas, with a stop at Cape Canaveral and two stops in the Bahamas — at Great Stirrup Bay and Atlantis. The Breakaway, a beautiful new ship that holds nearly 4,000 passengers and features 29 restaurants, Broadway shows and much more — was recently awarded Best New Ship in the Cruise Critic Editors' Picks Awards. The ship has 42 wheelchair accessible cabins, including the one the Sciarrettas booked in the ship's luxury complex, The Haven.

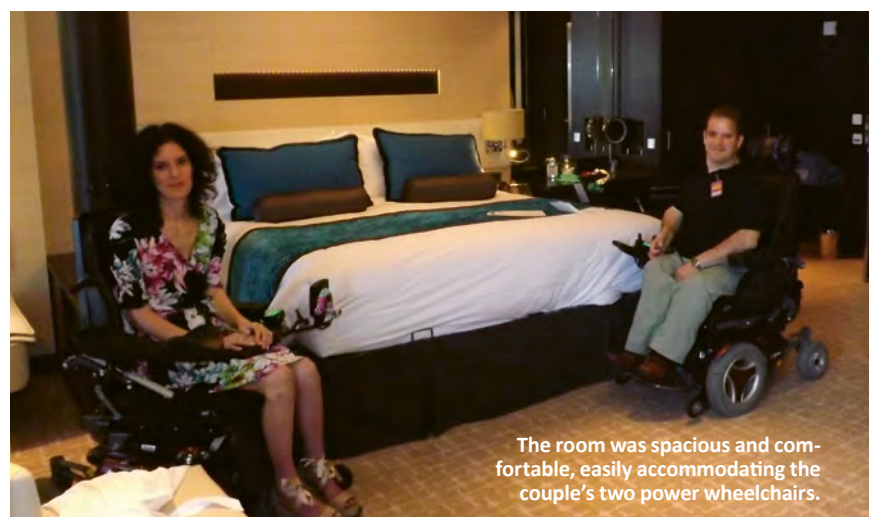
"The Haven is expensive but it's worth it," says Emily.

"You don't wait in any lines," says Frank. "You don't make any reservations, you just tell the concierge what you want to do that night and they take care of it."

"You're really treated like royalty," adds Emily. "They went above and beyond to try to make us as comfortable as possible once they took care of those problems ... They really worked with us."

Aside from an awkwardly placed

continued on page 30



The room was spacious and comfortable, easily accommodating the couple's two power wheelchairs.

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BEST STRATEGIES

MS Groups and Pages on Facebook

Wish you could talk with someone who understands what you're going through with your MS? Here are a few Facebook pages where you can do just that. To find one of these, just do a simple search for its title on Facebook.

Multiple Sclerosis Forum is a closed group, meaning you have to ask to join, but people outside the group can't see what you post — so it's private. Also, the moderator is excellent at keeping the forum free from any spam or promotions.

Multiple Sclerosis Talk uses a Q-and-A format, where someone asks the moderator an MS-related question and the moderator posts it. Then, people who like the page can chime in with their own experiences or ideas. What's nice

about this public page is the gentleness of those who've had MS for a very long time toward those who are just coming to terms with words like "chronic" and "incurable."

MS Views and News sponsors **Stu's Views and MS News**, which in turn is one of the most informative email-based sources for anything having to do with MS. So, as you'd expect, this Facebook page is also a good source for relevant info about living with MS.

Trevis L. Gleason's Life with MS supports Gleason's award-winning blog at www.everydayhealth.com, and his blog is fantastic. This Facebook page has taken on a life of its own, with regular posters forming a community.

MED ALTERNATIVES

Fatigue: Perhaps It's Not MS

It's easy to blame MS if we're more fatigued than usual, but before you call your neurologist, talk to your primary care physician. Here are a few of the many causes of fatigue that have nothing to do with MS:

Both **hyper- and hypothyroidism** can cause fatigue. Many women, especially, have hypothyroidism, which can be corrected with a daily pill. It may take a while to get the correct dosage, but once it's established, there are no side effects. You simply feel better and more energetic, and may even have an easier time losing weight.

Sleep apnea is another common cause of fatigue.

People with sleep apnea briefly stop breathing while asleep, which can cause sleep deprivation and also increase the risk of high blood pressure, heart disease, obesity and diabetes. Treatment can include a weight loss program and possibly sleeping with a CPAP machine.

Eating habits play a role with fatigue as well. Even if you're skinny, if you're not eating properly — fruits, veggies, lean meats, whole grains, plenty of water — you can feel fatigued.

A vitamin or mineral imbalance, too, can rob you of energy. Especially if you're a middle-aged woman, if you're experiencing fatigue, your doctor may wish to take blood tests to determine if you need more iron in your diet or, very commonly, vitamin D or B. If you are experiencing a vitamin or mineral deficiency, just taking an over-the-counter multi-vitamin won't be enough to help. You may need prescription-level doses.

These are just a few common causes of fatigue, so before you blame MS, go to your doctor and get screened for other conditions. They're easier to treat than MS, and you may just "get lucky."



RESEARCH NEWS

Alternative Treatments Mapped

A Nordic study has successfully mapped out the use of alternative medicine by people with MS — including who is most likely to use alternative medicine, as well as why. There's not much surprising in the study, and many with MS will find it affirming.

"What we see is that people with MS do not usually use alternative treatments for treating symptoms, but as a preventative and strengthening element," says Lasse Skovgaard, industrial Ph.D. candidate from the Faculty of Health and Medical Sciences and the Danish Multiple Sclerosis Society, which helped coordinate the questionnaire-based study. A total of 3,800 people with MS in Denmark, Sweden, Norway, Finland and Iceland participated.

Skovgaard noted some critics think only naïve or uneducated people hoping for a miracle "fall" for alternative treatments, but this study shows the opposite to be true. "Our results indicate that it is primarily the well-educated segment that is subscribing to alternative treatments. And that using alternative treatments is part of a lifestyle choice," says Skovgaard.

Read more:

- www.news-medical.net/news/20130419/Researchers-map-use-of-alternative-treatment-among-multiple-sclerosis-patients.aspx
- www.sciencedaily.com/releases/2013/04/130419121114.htm

Study: CCSVI Does Not Cause MS

A new study published in *Lancet* is the most recent to find that chronic cerebrospinal venous insufficiency does not cause MS. This study looked at 177 people with MS and members of their family who don't have MS. The people with MS did not have a statistically different rate of narrowed veins than the people without MS.

"I think we can say that story is closed," said Dr. Anthony Traboulsee, a neurologist at the University of British Columbia and the lead researcher, about the theory that MS is caused by narrowed veins. Theoretically, these narrowed veins allowed iron deposits to build up in the brain, which caused MS symptoms.

However, the story may not be quite closed, as Traboulsee also says he supports a new study that will follow 100 Canadians with MS after they receive treatment for CCSVI. He says people who've undergone the treatment report that it helps alleviate their symptoms. "People might want to discount this as a placebo effect," he said. "I think that's being a bit patronizing to people and we need to do the proper research to fully address if there is any treatment benefit. And if we determine treatment benefit, then we have to figure out why."

MS Perspectives

When a couple decides to start trying for their first baby, it is usually a time filled with a dash of excitement and a pinch of wonder. But what happens when they know that an incurable neurological disease is already in the mix?

Starting a family is a decision that should never be taken lightly, and this was certainly true when my husband and I took the plunge. We had married young, but always planned to wait for 10 years before starting a family, just as his own parents had done. This would afford us the opportunity to work and travel first and put me at the age of 30 when we had our first baby.

Unfortunately, when I was 28, I was diagnosed with multiple sclerosis. Due to the highly unpredictable nature of the MS monster (as I call it), nobody can accurately forecast how an individual will be affected by it in the future and so planning a family is a task fraught with uncertainty. Along with all the usual worries about this new chapter in our lives, we bore the additional burden of knowing about the MS and yet having no idea about what that meant for the future. Would my symptoms get worse? Would I pass on the risk of developing the disease to our baby? How would we cope with all the implications that we couldn't even envisage?

When I was first diagnosed, I registered with the MS Society and went to a Newly Diagnosed session as recommended by my neurologist. The room was filled with people of various ages; the newly diagnosed and their partners or families sporting similar shell-shocked demeanors to our own. There was also a panel of volunteers with MS who shared their thoughts and experiences and answered questions from the new "recruits."

Strangely, I don't remember asking about having a baby, but I do remember asking about getting a puppy as I was planning to buy one for my husband for his 30th birthday. A tired-looking woman answered, "Do yourself a favor and don't get a dog. I have four kids and a couple of dogs, and while I love my animals, they just mean even more extra work for me." I know that the lady meant well, but I'm really



TO BREED OR NOT TO BREED? THAT IS THE QUESTION

By Vanessa Waller

glad we didn't follow her advice at the time. Our Rhodesian ridgeback, Scout, was with us for nine glorious years and provided immense happiness in our lives.

I do remember telling my neurologist about our plan to have a baby when I was 30 and asking for his advice. He told us that as there was no cure and no way to predict my particular future with the disease, the best thing we could



do was to continue on as we had already planned but immediately start one of the available treatments and surround ourselves with as much support as possible. Then when we were ready to start trying for a baby, suspend the treatment and see how it all went. For the next 18 months, my symptoms were quite mild with just a few relapses here and there so we followed the advice and started trying for a baby.

I fell pregnant almost immediately and as often happens during pregnancy with MS, all the symptoms completely disappeared. It was as though I didn't have the disease anymore. In September 2000, when I was 30, just like we'd planned, we had our darling son, Kai, who changed our lives in every possible positive, amazing way. We immediately fell head over heels in love with him and are still enthralled by the love, joy and utter completeness he has brought with him into our world.

About four to five months after giving birth, women with MS often experience a relapse and I was no exception. I had a substantial relapse which resulted in difficulty walking and the loss of sight in one eye. Fortunately I regained the function in that eye but soon lost it in the other. Luckily, the optic neuritis resolved itself. However, as our precious son naturally gained his ability to walk, I slowly lost mine. I continued to accumulate disability to the point that now, almost 13 years after being diagnosed, I use a wheelchair.

You might wonder whether or not we would change our decision to have a baby at all if we could go back in time and my answer is unequivocally "no." Our hearts simply overflow with the intense love for our son and I wouldn't exchange that nor the experience of being a mum for anything in the world. The MS monster is a skilled and wily thief that has already robbed me and my husband of so much; I am immeasurably glad that we didn't let it steal our chance to become parents too.

This article first appeared as a blog entry on Vanessa Waller's site about wheelchair travelling and her life with MS, www.wheelieplanet.com.

NSCIA Hospital Members

NSCIA thanks its growing list of hospital and organizational members, each of which has expressed their commitment to partner with us in our mission of improving the quality of life for people with SCI/D. Visit www.spinalcord.org for a full list of Hospital Members with links to their websites, and information on how your hospital can join NSCIA.

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OH, 937.208.8000

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405.951.2277

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206.221.7390

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lege of Wisconsin Spinal Cord
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414.805.3000

* * *

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Travel continued from page 25



The bathroom was big enough for them to both use it at the same time.

support beam, the room was spacious and comfortable, easily accommodating the couple's two power wheelchairs. The main door could be opened using a card, which made going in and out easier. The bathroom was big enough for them to both use it at the same time, and Emily couldn't stop raving about the "amazing" shower with six jets. On the down side, the bathroom door was very heavy and hard to open and the seaside deck wasn't large enough to turn a power chair around.

Outside the room, the Sciarrettas had little trouble navigating the ship's never-ending halls, destinations and events. They were disappointed to find some of the restaurants and stages lacked appropriate accessible seating, but they made do.

More disappointing were the cruise's three on-shore excursions. A broken down bus and a slew of scooter-users cut the Sciarrettas' time at Canaveral from six hours to two. Another port that the cruise line had promised to be accessible proved otherwise. Atlantis was mostly as billed, though the Sciarrettas had inadvertently signed up for a water park adventure that was clearly not accessible (their tickets were discounted later.)

"We were so excited to go [places] and we didn't even get to see the things we wanted to see," says Frank.

Still, by the time Emily took the stage with one of the bands on the cruise's final night, most of the bad experiences and memories had been replaced by good ones. The newlyweds are even considering booking another cruise.

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