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# iving with SCI—Peers Show the Way

Come readers may recall this scenario, others will have to imagine it...

You are lying in a hospital bed and your doctors have just told you that you suffered a spinal cord injury. You may never walk again, and you are learning about the other, unexpected, bodily functions that don't work the way they are supposed to. As the days go by, you get a crash course about what it means to be paralyzed. Despite the mountain of information therapists and nurses provide, you still have a thousand questions about what it's really like to live with a spinal cord injury. Can life possibly go on? And, if so, what does it look like?

This is where SCI peer mentors come in. Peer mentors are individuals with experience living with SCI who visit newly injured patients in the hospital. Unlike anyone else likely to visit you, an SCI peer is the one person who really has been where you are.

"When a peer visits, the patient meets someone with SCI who has been out of the hospital for a

while, living their life, doing things that they enjoy, and doing the same things that everybody has to do," says Chris Garbaccio, who coordinates the peer mentor program for the Northwest Regional Spinal Cord Injury System (NWRSCIS). Since SCI is relatively rare, most people have never met anyone with SCI before their injury."I believe that the actual advice a peer gives is often secondary to simply showing the patient that 'yes, life does go on after your injury, and I'm here to prove it."

Peer visiting at the University of Washington (UW) took place informally for several years until a 2003 grant from the Christopher and Dana Reeve Foundation (CDRF) allowed the UW to create a formal program to train and maintain a team of peer mentors serving newly injured SCI patients at Harborview and the UW Medical Center. After the CDRF grant ended, the program continued with National Institute for Disability and Rehabilitation Research (NIDRR) funding.

"We know from clinical experience and research conducted on other populations that meeting with a peer has many benefits," says Jeanne Hoffman, PhD, UW rehab psychologist in charge of the Peer Mentor program. "Being told by physicians and therapists that a good life is still possible after SCI doesn't have the credibility of hearing it from someone who is living it."

Furthermore, insurance restrictions have made the inpatient rehab stay shorter than ever before, and patients are justifiably nervous about leaving the safety of the hospital and coping on their own. Getting support and "survival tips" from another person with SCI who lives out in the community is invaluable.

Currently there are approximately 40 men and women with different types of SCI (tetraplegia vs. paraplegia, complete vs. incomplete, wheel chair users (power vs. manual) vs. ambulators) who have expressed an interest in being a peer and who have completed training. Individuals who become peers have been referred by rehabilitation staff or have expressed a desire to meet with other individuals because of the positive experience they had meeting with a peer early on after injury.

Peers are trained to leave the discussion open ended in order to best meet whatever needs the patient has at that moment. Some patients will ask very detailed questions about wheelchairs or driving or caregivers, others may just want to hear the peer's story of how they got from rehab to where they are today.

Garbaccio works with hospital staff to match newly injured SCI inpatients with trained peer mentors of the same sex and similar injury level, age, and life circumstances. While no two spinal cord injuries are exactly alike, even at the same injury level, efforts are made to match individuals as closely as possible and find a peer who might be most helpful.

Patients are offered the opportunity to meet with a peer while they are in inpatient rehabilitation. Although many are interested or even eager to meet another person with an SCI, "some people feel too overwhelmed and can't see how a peer could help them," says Garbaccio. "Others are resistant because they are not ready to accept that this has happened to them, and meeting someone can make it very real. Of course, that is fine. We want it to be a positive experience."

Aditya Ganapathiraju, who has C5 tetraplegia, was reluctant to meet others with SCI when he was first injured."I remember feeling like I did not want to be

# Riding the Rails: Testing out Sound Transit's Light Rail in a Wheelchair By Aditya Ganapathiraju

Seattle was recently rated #I among the "Top 20 Most Livable U.S. Cities for Wheelchair Users" by the Christopher & Dana Reeve Foundation, which included criteria such as climate, access to rehabilitation, fitness and recreation, accessibility of housing, and the big one: wheelchair-accessible transportation. (For the record, I have a C5/6 incomplete spinal cord injury and use a power wheelchair.)

As a frequent mass transit user, I decided to check out Link Light Rail, the newest addition to Sound Transit, the region's public transportation system. Link offers service from Westlake in downtown Seattle to SeaTac Airport, about 15 miles south.

You can access Light Rail from any of the downtown tunnel stations used by Metro buses. I entered the Pine Street Station from 4th Avenue. There are elevator entrances to the transit tunnel on both sides of the street—however, one of the elevators didn't work; this, along with the delightful smell, convinced me to go to the other side. The elevator button was up high and hard to reach, but I managed to push it and arrive at the mezzanine floor, where you can buy Light-Rail tickets at two automated ticket booths or the customer service center.

You **must** purchase your fare before getting on the train, with either a prepaid ORCA card or tickets purchased at the station. Ticket personnel make regular sweeps through the train, so don't get

caught without a ticket. With a Regional Reduced Fare Permit card the fare ranges from \$.75 to \$1.25 from downtown to SeaTac. (See side bar for details.)

Take another elevator down to the main platform labeled "Light Rail to SeaTac Airport." Trains come about every 15 minutes. There is a small two-inch gap between the platform and the train which power chairs can traverse with ease, but manual wheelchair users will need to exercise caution and may end up having to wheelie over the gap.

Each train car has four sections where the benches fold up for wheelchairs. There are no tie-downs or straps to secure your chair, so manual chair users will definitely want to set their brakes before the train starts moving, which happens quickly. One woman forgot her belongings and realized only after the door closed. Banging on the doors didn't stop the train from departing.

Sporting an all-electric power system, the Japanese-manufactured trains accelerate smoothly to a top speed of 55 mph. At cruising speed, however, the ride got shaky, and I had trouble taking notes on my iPod touch. (I concluded that you would definitely spill your martini—if alcohol were allowed on the train — but your covered coffee mug would be fine.)

I arrived at SeaTac Airport 35 minutes after leaving Westlake. Even with all the station stops in between, this time is comparable to driving a car, and faster if traffic is bad (which is most of the time in Seattle).

If you think you'll need additional time to exit the train, you can press the ominous red "EMERGENCY INTERCOM" button located in the wheelchair area. Since I had seen how briefly the doors stayed open, I pressed this button before the SeaTac stop so I would have enough time to get off. To my embarrassment, the conductor's voice boomed over the intercom: "You pressed the red button! What's your emergency!" I responded

#### **Ticket and Access Info**

- How to obtain a Regional Reduced Fare Permit: http://www.soundtransit.org/Riding-Sound-Transit/Fares-and-Passes.xml
- ADA accessibility: http://www. soundtransit.org/Riding-Sound-Transit/ Accessibility-and-ADA.xml
- Regional Reduced Fair Permit application form (to be signed by your physician): http://metro. kingcounty.gov/tops/accessible/ RRFP-app.pdf
- About Sound Transit: http://www. soundtransit.org/Riding-Sound-Transit/ Schedules-and-Facilities.xml

sheepishly that there was no emergency, but I needed extra time to get off the train. He loudly reminded me that SeaTac was the last stop and I wouldn't need extra time. Cringing, I resolved never to press the dreaded "EMERGENCY INTERCOM" button again.

After getting off the train, you still need to traverse about a half-mile of flat, covered walkway and an elevator ride to reach the airport terminals. In a power chair this little segment took a few minutes; in a manual chair the trip might be a bit tiring. If you plan to haul your own luggage, give yourself extra time.

All in all, Sound Transit's Light Rail offers a relatively quick ride to the airport and may be your best bet if you want to travel quickly to and from the Sounders (soccer) game, enjoy some Friday night revelry downtown and make it back without driving, or just visit some friends south of Seattle.

Aditya Ganapathiraju, a research assistant in rehabilitation medicine at the UW, responsibly enjoys his martinis before boarding public transportation. He has a C5 level injury, but swears he feels like a C7 on good days. And like the late John Callahan, he too celebrates "the lighter side of being paralyzed for life."



# Northwest Women Wheelers' Network: An Interview with Co-Founder Anne Bostwick\*

What is the Northwest Women Wheelers' Network (NWWWN), and how did it get started?

A:The NWWWN is a social and support network for women who use wheelchairs. Five years ago, I found myself at a Spinal Cord Injury Forum (at the University of Washington) about women's issues. Tammy Wilbur (a friend with SCI) was also there, and about midway through the evening we looked at the roomful of women in wheelchairs, looked at each other, and you could practically see the light bulb over our heads. At the end of the forum, we began gathering names and emails and our little support group was born.

My husband put together an email listserv with the 15 or so names we had gathered. From there, we used our network to "recruit" more women into our group, and little by little we grew into a group of nearly 60.

Whenever we're out and about and we spot another woman in a chair, we connect with her and usually gain a new member. We also get referrals from health care providers and others who know about our group. We're careful to screen new members (to make sure they really are women wheelchair users), we never share our

email list with anyone, and there's never any spam or junk mail. I am the list administrator.

The listserv is great because anyone in the group can send out an email with questions or comments, and we get some pretty lively discussions going. We also have an online forum that is open just to registered members.

Q:Who are NWWWN's members?

A: It's a hugely diverse group of great women from all "wheels" of life. Ages range from early 20s to 70s. We've got single mothers, married women, single women, women who work full time, part time, retired or not at all. Most of our members have spinal cord injuries but we have members with MS, spina bifida, muscular dystrophy and other disabilities.

O: In addition to the listserv, what are the NWWWN's other activities?

A: For the last four years we've had a picnic in the summer and a holiday party in December. Other than that we don't have regular meetings, but instead have casual gatherings that

start out like parties and end up providing support. We've partnered with Outdoors for All and had outdoor gatherings with cycling and kayaking, too.

O: How has the NWWWN evolved in the last five years, and what do you see in its future?

A: Like the women in our group, it just gets better with age. I've never met so many interesting women. We even have a small political action committee that was recently involved with the disability parking issue at the Seattle Center. If the group gets large enough, who knows? I could see us doing charitable



The NWWWN organizes a summer picnic for its members every year. This photo is from the 2009 picnic.

works and having even more gatherings and outings.

We started this group because the spinal cord injury community has traditionally been focused on men and men's issues, and there was a real need for a women's support group. At last year's picnic I was almost moved to tears to hear a couple of new members say they'd never been around other women in wheelchairs before. At that point I knew we'd really done something wonderful.

If you're a woman who uses a wheelchair for mobility and you're interested in joining our Northwest Women Wheeler's Network, send an email to info@nwwwn.org with a brief bio and we'll sign you up.We look forward to hearing from you and

\*Anne Bostwick has had T10/11 incomplete paraplegia since 1996 and says "I am an avowed "beadaholic" and am happily retired and live on Puget Sound's "Eastside" with my husband and our three wonderful "therapy puppies." Anne co-founded the NWWWN with Tammy Wilber.

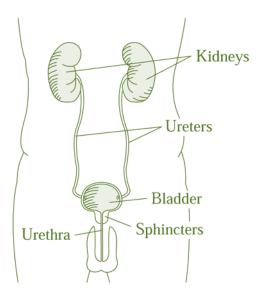
# forum report

The SCI Forum is an evening presentation and discussion series on topics of interest to persons with spinal cord injury and their family members, friends, caregivers and health care providers, held monthly at the University of Washington Medical Center. To learn about upcoming SCI Forums, read reports of past forums, or view forum videos, consult our Web site at <a href="http://sci.washington.edu/info/forums">http://sci.washington.edu/info/forums</a>. Contact Cynthia Salzman (email: csalzman@uw.edu; phone: 206-685-3999) if you wish to be added to the SCI Forum mailing list.

# Management of Urinary Complications Caused by SCI: Part 1

SCI Forum presentation by Stephen Burns, MD, SCI Service, VA Puget Sound Health Care System, and associate professor, Department of Rehabilitation Medicine, University of Washington, on October 13, 2009, at the University of Washington Medical Center.

Before 1940, most people with spinal cord injuries died from urinary tract infections (UTIs) in the first few months after injury. After the introduction of antibiotics in the 1940's, people started surviving longer, but kidney complications continued to be a problem and kidney failure became the leading cause of death. With current management practices and periodic testing, things have improved greatly, and now fewer than 3% of people with SCI die from kidney failure.



#### How the urinary system works

In normal urination, the bladder is either filling or emptying. The bladder is relaxed as it fills with urine, and the sphincter stays closed during this time so the urine doesn't leak out. When it's time to empty, the bladder contracts and the sphincter relaxes so the urine can flow out. Most of the time the bladder is relaxed and filling as urine is made. The bladder and sphincter muscles are automatically coordinated to contract and relax at the correct time. These are reflex patterns "wired" into the brainstem and spinal cord.

After SCI, these reflex patterns no longer work, and two basic problems can occur:

- I. Filling problems (incontinence or leaking) occur when the bladder is overactive and contracts too much or at the wrong time, or the sphincter doesn't contract enough to keep the urine from leaking out.
- 2. Emptying problems (retention) occur when the bladder doesn't contract enough or the sphincter won't relax.

#### **Urinary Tests**

These tests help your physician determine what kind of urinary problem you are having:

- A postvoid residual test shows how much urine remains in the bladder after voiding (emptying). This can be done using a catheter or by ultrasound.
- A group of tests called urodynamics tells us more precisely what the nerves and bladder are doing during filling and emptying. These tests require the bladder to be slowly filled with fluid through a small catheter, while the activity of different muscles is measured. Urodynamics help answer these types of questions:
  - Is the bladder relaxing enough to allow it to fill up with urine?
  - Is the sphincter opening at the right time?

# Choosing the best method of bladder drainage

The goal in choosing a method of bladder drainage is to find the simplest, most convenient and least expensive method that will keep you dry, avoid serious complications and treatment side effects, and preserve your kidneys for your entire life.

#### No catheter in the bladder

Some people have enough nerve preservation to be able to void (urinate) under their own control, sometimes in combination with medications to calm an overactive bladder muscle.

#### Bladder emptying for males: Open the sphincter

If your bladder is able to contract but the sphincter does not open, there are a few methods for keeping the sphincter open so urine can flow freely from the bladder into a condom catheter. (If your bladder does not contract, the urine won't drain out, and you are at risk for infection.)

- **Sphincterotomy**: Surgically cut and open the sphincter. Scarring can occur over time, and the surgery may need to be repeated. It can also worsen erectile dysfunction.
- **Botox** injected into the sphincter. This needs to be repeated every three to nine months, and as it wears off there is an increased chance for urinary retention.
- **Urethral stent** (small steel tube) placed in the sphincter. Disadvantages are that the stent can move around or tissue may grow into it and block the flow or urine, requiring corrective surgery.

Condom catheters are not without problems. They can be hard to keep in place, and some patients will need to have a penile prosthesis put in so there is enough penis for the condom to attach to. And even though the condom catheter does not involve a tube going into the bladder, it does not seem to result in fewer UTIs than indwelling or Foley catheters.

#### Intermittent Catheterization

With this method, you insert a catheter into the bladder and empty it completely (often called "cathing") every four to six hours. The goal is to "cath"

forum report

frequently enough to keep urine volumes in the bladder lower than 500 ml. You must closely monitor your fluid intake, usually around 2 liters per day, otherwise you might be cathing too frequently to make this practical.

Intermittent Catheterization (ICP) is the preferred method for patients who have enough hand function (usually C7 level, but sometimes C6 if a motor-incomplete injury) to perform it independently and who can remember to cath on schedule. It is the closest thing to the normal bladder function, where the bladder fills continuously for a period of time and then empties all at once. This method reduces the risk for infections because there is less time for any bacteria left in the bladder to reproduce enough to cause symptoms. However, ICP does have complications, including narrowing of the urethra from passing the catheter through frequently.

ICP is not usually a good method for someone who is unable to perform it independently. Having someone else cath you increases your risk for infections and also reduces your independence, since you need someone with you to perform the ICP.

Anticholinergic medications, such as oxybutynin (Ditropan) or tolterodine (Detrol), may be necessary to inhibit bladder contraction.

#### **Indwelling Catheter**

An indwelling catheter is a common bladder-emptying method for those who cannot perform ICP. A tube is inserted into the bladder, and a balloon on the end holds it in place. It remains in the bladder and drains constantly into a container, such as a leg bag. There are two types of indwelling catheter:

- Foley catheter: the tube is inserted through the urethra.
- Suprapubic catheter: the tube goes through a hole in your abdomen.

#### **Advantages:**

- It will usually empty the bladder and keep you dry regardless of what kind of bladder or sphincter problems you have.
- Even those with higher level injuries can be completely independent—once you're set up, you can use an electric leg bag opener to empty out urine and not need assistance from anybody all day long.

#### **Disadvantages:**

- Having a catheter sitting in the urethra all the time can cause urethral erosion, which is often a reason for switching to a suprapubic tube.
- The suprapubic tube requires surgery, and sometimes the bladder neck needs to be closed to prevent leaking.
- There is a catheter coming out of your body and a bag of urine with you all the time. Some people just don't want that.
- Increased risk of bladder cancer and bladder stones.
  - More infections than with ICP.

#### What's different about females?

Because women have no penis, collecting urine is more difficult. There is no good external collection device, like a condom catheter, for women. Women doing ICP have more problems with incontinence than men because the female urethra is short and more likely to leak urine.

Women get different complications from having an indwelling Foley catheter for a long time. The urethra can become dilated (larger), which results in more leakage. Switching to a larger catheter just dilates the urethra more, causing more incontinence. For this reason, a suprapubic tube is a good option for a woman who otherwise would be using a Foley catheter.

#### What is the best method for you?

#### **Considerations**:

- Do you have the hand function to do ICP independently?
- How much mobility is required?
   For example, does the method require transferring to a toilet?
- How much of your day is going to be devoted to bladder management?
- What are the risks if you don't follow the program? Are you likely to comply?
- Do you live in a remote location with no follow-up around, or are you close to specialized medical care?
- What's the likelihood that you would benefit from one of the more complicated, more time-intensive techniques?

#### Other surgical options

Sometimes additional surgeries are required to manage urinary problems:

- Bladder augmentation, which uses a piece of the bowel to enlarge the bladder, may be a good option for someone doing ICP whose bladder doesn't hold enough urine in spite of medications
- **Urinary diversion** (diverting the urine away from the urethra)
  - **Urostomy**, which uses a piece of bowel to create a connecting tube from the bladder to the outside of the body (like a colostomy does for stool). Urine drains out and collects into a bag fastened to the opening (called a stoma).
  - Catheterizable stoma (Mitrofanoff) creates a thin tube from a piece of bowel that connects the bladder to the abdomen where a person can insert the catheter to drain the bladder.

# Botulinum toxin injection to the bladder

If oral medicines (anticholinergics) are unable to relax the bladder muscle enough for a person to do ICP, Botox injections to the bladder muscle can accomplish this. Botox is effective for about six to nine months. When it begins wearing off, you start having incontinence and need it done again.

"Management of Urinary Problems Caused by SCI: Part 2" will appear in the Winter 2011 issue of the newsletter.

Read the full report and watch the video of "Management of Urinary Problems Caused by Spinal Cord Injury" online at http://sci. washington.edu/info/forums/reports/urinary\_problems.asp.

See all 24 of our SCI Forum videos available for viewing online at http://sci.washington.edu/info/forums/forum\_videos.asp

# literature review

The articles previewed below were selected from a recent screening of the National Library of Medicine database for articles on spinal cord injury. In the judgment of the editors, they include potentially useful information on the diagnosis or management of spinal cord injury. You may obtain copies of the complete articles through your local medical library or from UW Health Sciences Library Document Delivery Service (call 206-543-3436 for fee schedule).

#### **AUTONOMIC DYSREFLEXIA**

■ Boosting in athletes with high-level spinal cord injury: knowledge, incidence and attitudes of athletes in paralympic sport.

Autonomic dysreflexia (AD) is unique to individuals with SCI at T6 or above and can be voluntarily induced. Although AD improves wheelchair racing performance in some athletes, it also increases blood pressure, which could be dangerous. The International Paralympic Committee considers AD doping and banned its use. A survey of athletes at the Beijing Paralympic Games found that of 99 participants, 54.5% had previously heard of AD while 39.4% had not, and 16.7% (all males) had used AD to enhance performance. Participants reported that AD was useful for middle (78.6%) and long distance racing (71.4%), marathon (64.3%) and wheelchair rugby (64.3%). They also reported AD was somewhat dangerous (48.9%), dangerous (21.3%) or very dangerous (25.5%) to health. Results were not influenced by age, injury level or injury duration. Findings indicate the need for education to enhance the AD knowledge of professionals, coaches and trainers working with SCI individuals.

Bhambhani Y, Mactavish J, Warren S, et al.

Disabil Rehabil. 2010 Aug 18

■ Incidence of symptomatic autonomic dysreflexia varies according to the bowel and bladder management techniques in patients with spinal cord injury.

A group of 571 patients with SCI at T6 or above were assessed for the incidence of symptomatic AD according to age, sex, ASIA Impairment Scale, injury level, and bowel and bladder management techniques at discharge. The highest incidence of symptomatic AD was diagnosed in subjects using reflex voiding and in those using manual removal of stool. By contrast, the lowest incidence of symptomatic AD was in those on continent voiding and continent defecation.

Furusawa K, Tokuhiro A, Sugiyama H, et al.

Spinal Cord. 2010 Aug 10.

#### **BLADDER MANAGEMENT**

■ Treatment of neurogenic male urinary incontinence related to intrinsic sphincter insufficiency with an artificial urinary sphincter: a French retrospective multicentre study.

In this retrospective study, 51 patients with urinary incontinence due to sphincter problems had an artificial urinary sphincter (AUS) inserted. Sixteen (31%) had spina bifida and 35 (69%) had SCI. Perfect continence was defined as a period of dryness of at least 4 hours between two self-intermittent catheterizations or spontaneous voiding; moderate incontinence as nocturnal leakage or need to wear protection once during the day or for stress leakage; and severe incontinence as uncontrollable leakage. Mean age at the procedure was 35 years (18-58). Of the patients in the study, 74% had perfect or moderate continence with a working AUS after a 10-year follow-up.

Kastler EC, Genevois S, Gamé X, et al.

BJU Int. 2010 Jul 13.

■ Bladder management after spinal cord injury in the United States 1972 to 2005.

Bladder management with an indwelling catheter for patients with SCI can cause urological complications such as stones, urinary infection, urethral strictures and bladder cancer. Bladder management method of 24,762 patients in the National Spinal Cord Injury Database was determined at discharge from rehabilitation and at each 5-year followup period for 30 years. Bladder management with a condom catheter

decreased steadily from a peak of 34.6% in 1972 to a low of 1.50% in 2001, whereas the use of clean intermittent catheterization increased from 12.6% in 1972 to a peak of 56.2% in 1991. Indwelling catheter use decreased from 33.1% in 1972 to 16.5% in 1991 but increased to 23.1% in 2001. Of 12,984 individuals with followup data, 71.1% of those originally using an indwelling catheter continued to use it at 30 years. Of those using clean intermittent catheterization and condom catheterization at discharge, only 20% and 34.6%, respectively, remained on the same management.

Cameron AP, Wallner LP, Tate DG, et al.

J Urol. 2010 Jul;184(1):213-7. Epub 2010 May 15.

#### **BODY FAT AND HEALTH**

■ Secondary complications and subjective well-being in individuals with chronic spinal cord injury: associations with self-reported adiposity.

A total of 531 men and 164 women who were enrolled in the Study of Health and Activity in People with Spinal Cord Injury (SHAPE-SCI) completed questionnaires about health complications, pain, satisfaction with life and depression during a telephone interview. Body mass index measurements were obtained from 73 of the SHAPE-SCI participants during home visits. Individuals who reported being overweight were more likely to have overuse injuries and fatigue, greater pain and depressive symptoms, and lower satisfaction with life than individuals who did not report being overweight. Future studies should examine whether losing body fat can improve symptoms and satisfaction with life.

Hetz SP, Latimer AE, Arbour-Nicitopoulos KP, Martin Ginis KA. Spinal Cord. 2010 Aug 24.

#### **BONE HEALTH**

Influence of season, ethnicity, and chronicity on vitamin D deficiency in traumatic spinal cord injury.

Inadequate levels of vitamin D increase the risk of osteoporosis, a common condition in people with SCI. Reduced sunlight and dark skin further contribute to low vitamin D levels. Ninety-six individuals with motor complete SCI (from C3-T10) were tested for 25-hydroxy vitamin D [vitamin D25(OH)] levels in summer and winter months. In summer, 65% of patients with acute SCI (2 to 6 months after injury) and 81% of patients with chronic SCI (more than one year after injury) were deficient in vitamin D. In winter, these percentages increased to 84% and 96%, respectively. Levels of vitamin D were lower in African Americans than whites. Because vitamin D deficiency is common in acute and chronic SCI, initial screening for serum vitamin D levels should be performed early in rehabilitation and regularly after that. Oleson CV, Patel PH, Wuermser LA.

| Spinal Cord Med. 2010;33(3):202-13

#### **CARDIOVASCULAR DISEASE**

■ Cardiovascular disease, SCI and exercise: unique risks and focused countermeasures.

At least three cardiovascular disease risk factors (CVD) have unique profiles in the SCI population. Fasting dyslipidaemia is characterized in the SCI population by depressed HDL cholesterol and normal or low total cholesterol. After meals, persons with SCI have an exaggerated triglyceride rise and delayed clearance compared to non-disabled persons. Finally, vascular inflammation, indicated by C-reactive protein, is elevated in SCI. Fasting dyslipidaemia responds to 8 weeks of moder-

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## literature review

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ate intensity aerobic exercise performed 5 days weekly for 30 min daily. Post-prandial (after a meal) lipaemia treatment requires daily moderate or vigorous aerobic exercise, as the effect dissipates day by day. Cowan RE, Nash MS.

Disabil Rehabil. 2010 Jun 7.

#### **DENTAL CARE**

## ■ Factors that limit access to dental care for adults with spinal cord injury.

Use of dental services in 192 adults with SCI was compared to that of a sample from the general population. Although a similar proportion of both groups visited the dentist, those with SCI were less likely to go for a dental cleaning compared to the general population (54.6% vs. 69.4%). The three most commonly reported barriers to accessing dental care were cost (40.1%), physical barriers (22.9%), and dental fear (15.1%). Dentists should remodel their facilities to accommodate wheelchair users and have appropriate strategies for the management of dental fear among patients with SCI.

Yuen HK, Wolf BJ, Bandyopadhyay D, et al. Spec Care Dentist. 2010 Jul-Aug; 30(4):151-6.

#### PAIN

# ■ Chronic spinal cord injury pain: pharmacological and non-pharmacological treatments and treatment effectiveness. Of 279 persons with SCI who responded to a survey about pain, 215 (77.1%) reported having chronic SCI pain. Of these, 62.8% reported more than one pain type, of which neuropathic pain was most common (69.3%). Many of those with pain (63.8%) were receiving treatment but still had high levels of pain. The most common treatments were massage therapy/relaxation, anticonvulsants, and non-steroidal anti-inflammatory drugs (NSAIDs). The treatments most often thought to be effective were acupuncture/magnetising, cannabis/alcohol, physiotherapy and exercise, and massage therapy/relaxation. TENS/ultrasound and antidepressants were least often perceived as effective.

Heutink M, Post MW, Wollaars MM, van Asbeck FW. Disabil Rehabil. 2010 Aug 9.

#### **SEXUAL FUNCTION**

## ■ Sildenafil in women with sexual arousal disorder following spinal cord injury.

A group of 129 women with SCI were randomly divided into two groups and treated with either sildenafil or placebo for 12 weeks. Participants recorded their sexual activity and completed questionnaires about their sexual function, sexual quality of life, and sexual distress. Both the treatment and control groups had an increase in sexual activity during the study period, but there were no differences between the two groups in percentage of successful sexual activities or in their scores on the questionnaires. In conclusion, sildenafil was not beneficial in this population.

Alexander MS, Rosen RC, Steinberg S, et al. Spinal Cord. 2010 Aug 24.

# ■ Treatment for ejaculatory dysfunction in men with spinal cord injury: an 18-year single center experience.

Semen retrieval success rate and semen quality was assessed in 3,152 samples from 500 men with SCI. Nine percent could ejaculate by masturbation. Penile vibratory stimulation was successful in 86% of patients with a T10 or higher injury level. Electroejaculation was successful in most cases of failed penile vibratory stimulation. Sperm were obtained without surgical sperm retrieval in 97% of patients. Total motile sperm counts exceeded 5 million in 63% of cases. Sperm can be easily

obtained nonsurgically from most men with SCI, resulting in sufficient sperm for simple insemination procedures. Brackett NL, Ibrahim E, Iremashvili V, et al. | Urol. 2010 |un; 183(6):2304-8.

#### **SPONTANEOUS RECOVERY**

## ■ Extent of spontaneous motor recovery after traumatic cervical sensorimotor complete spinal cord injury.

This study used datasets from the European multicenter study about SCI (EMSCI) and the Sygen randomized clinical trial to determine how much spontaneous motor recovery took place in the first year after cervical (C4-C7) sensorimotor complete spinal cord injury. American Spinal Injury Association Impairment Scale (AIS) grade and upper extremity motor score or motor level were examined. There were no overall differences between the EMSCI and Sygen datasets in motor recovery patterns. After I year, up to 70% of subjects spontaneously recovered at least one motor level, but only 30% recovered two or more motor levels. Regardless of initial cervical motor level, most individuals recover a similar number of motor points or motor levels. Careful tracking of cervical motor recovery outcomes may help to reliably detect subtle but meaningful treatment effects in experimental studies. Steeves JD, Kramer JK, Fawcett JW, et al. Spinal Cord. 2010 Aug 17.

#### **STEM CELLS**

### ■ First patient enters trial to test safety of stem cells in spinal injury

The first patient has been recruited to a Phase I clinical trial to assess the safety and tolerability of oligodendrocyte progenitor cells derived from human embryonic stem cells to treat complete spinal cord injury. This study is recruiting patients with T3-T10 complete (ASIA A) injuries within 14 days of injury from seven U.S. medical centers. The trial's primary end point is safety, measured by the frequency and severity of adverse events related to the injected stem cells, to the injection procedure, or to the concomitant immunosuppression administered during the first year after treatment. Neurological function will also be assessed as a secondary end point. The stem cells being used in the trials have been developed by the U.S. company Geron. Animal studies showed that the cells migrated throughout the lesion site and matured into functional oligodendrocytes that remyelinated axons and produced neurotrophic factors, resulting in improved locomotion in the treated animals. The ultimate goal for the use of these cells in humans is to repair spinal cord injuries by injecting the cells directly into the spinal cord lesion.

Susan Mayor BMJ 2010; 341:c5724

#### WHEELCHAIR ASSESSMENT

# ■ Are wheelchair-skills assessment and training relevant for long-standing wheelchair users? Two case reports.

A 60-year-old man with a 15-year history of T12 complete paraplegia fractured his femur due to a tip-over accident that occurred 2 days after a follow-up clinic visit at which no limitations in wheelchair-skill performance were identified. If a procedure had been in place to identify and correct his wheelchair-skill deficiencies, this injury might have been prevented. A 34-year-old woman with spina bifida, whose wheelchair use had gradually increased, was able to significantly improve her wheelchair abilities through training. The newly learned skills enhanced her community participation. These cases suggest that, even in long-standing wheelchair users, wheelchair skills should be routinely assessed and formal training offered when needed.

Mountain AD, Smith C, Kirby RL.

Disabil Rehabil Assist Technol. 2010 May;5(3):230-3.

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associated with anyone with a disability because I did not consider myself to be like 'them.'" he admits. Still, he did agree to meet a peer. Later, he recognized that the experience "was helpful because of the insights they offered and also their mere presence as people with SCI who were just getting on with their lives despite everything." He has been a UW peer mentor since 2006.

People are often motivated to become peers because of the help they received from peer mentors during their own inpatient stay. "My mentor showed me a lot of things about how to live as a quad," says Joe Meyer, who has C4 tetraplegia. "There are so many things I would still be struggling with if not for his sharing of experience. I became a peer mentor in the hopes that I could provide someone else with the same type of very helpful information that he had given me, and to reassure them that you can live and function successfully and happily as a quadriplegic."

Anne Bostwick, who was injured before the UW peer mentor program started, became a peer because "I wanted to provide a positive role model for newly injured women. We (women) are in the minority in the world of SCI."

Having a peer visit "lets the patient see that a productive and happy life is possible after SCI," Anne says. "I think it gives them hope, plus a sounding board with someone who can totally relate. Sometimes just listening is the most important part of mentoring. Most newly injured people are still in shock when you see them."

"Peer mentors make an powerful and positive impact on patients at a critical, vulnerable time," says Hoffman. "We are enormously grateful for their time and willingness to share such personal aspects of their lives."

If you have questions about peer mentoring, please contact the NWRSCIS peer program at 206-616-8568 or nwrscis@uw.edu.

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