SCI and Chronic Pain
Self-Management Techniques

By Dawn Ehde, PhD, Professor of Rehabilitation Medicine and Rehabilitation Psychologist at Harborview Medical Center.

This is part 2 of a two-part report on pain. Part 1 appeared in the Spring 2015 issue of the newsletter. Read Part 1 and watch the complete video at sci.washington.edu/chronic_pain.

Most pain in SCI is chronic, meaning that it is long-lasting and fairly continuous. That makes the person who is dealing with it every day the expert on it.

What is self-management? Teresa Brady from the Centers for Disease Control defined it as follows: "Self-management simply means what people do on a day-to-day basis to feel better and pursue the life they desire."

In self-management the important question is not "How or why did I get the pain?" but rather "What can I do to manage my pain so that I can get on with my life?" The main goal of self-management is helping people get back to participating in life and doing the things they want to be doing despite the pain.

While medical and rehab interventions are certainly important in managing pain, research has shown repeatedly for more than 50 years that pain is much more than just a medical problem. It affects and is affected by all aspects of a person's life, including feelings, relationships, and behaviors. It is best understood as a biopsychosocial phenomenon, meaning physical, emotional and social factors all play a role in the way you experience pain.

CONTINUED ON PAGE 3

What our readers told us

Thank you to the 109 readers who completed our reader survey sent with the spring 2015 issue of this newsletter. We were pleased to hear that respondents felt they learned new information from the newsletters and the information has helped improve their health and quality of life.

Readers' top concerns

Far and away the biggest concern among our readers was pain, followed by bladder and bowel problems and staying healthy and independent while aging. We will use this and other consumer feedback to help us plan future research and educational activities.

YES, we have a website! And videos!

Many readers said they did not know we had a website or online videos (more than 50!). We also have our own YouTube and Vimeo channels. Visit us online and find out what you’ve been missing! (See web addresses at the bottom of this page.)

We often hear that our videos and written materials provide vitally important, reliable information that can’t be found elsewhere. Many of our subscribers who live far away from SCI rehab centers say they share this information with their primary care providers, who may not be familiar with the unique health issues of people with spinal cord injuries.

Website: http://sci.washington.edu  ♦ Videos: http://sci.washington.edu/videos
Tips from the *Wheel World*

...wisdom and ideas for making life with SCI a little better, from individuals living with spinal cord injuries.

*This installment came from Lan Remme, who is a member of our SCI Consumer Advisory Board and has C6 complete tetraplegia.*

Remote-Controlled Door for the Home

Installing a remote-controlled door opener in my front door proved to be the simplest, most practical accommodation I have added to my home since I began wheeling four years ago.

I contacted the company Open Sesame (www.opensesamedoor.com/) for a bid, expecting to hear I would have to pawn my wheelchair to afford one and live around installation and disruption for a few days.

To my pleasant surprise, the price was $2,000 and the installation time around two hours. The hardware was installed by Adaptive Installations (www.adaptiveinstallation.com/). They were efficient and polite while warning my wife Laura to keep an eye on me lest I start sneaking out of the house at night. They did return once for an adjustment.

I open the door using a remote control that I keep on a lanyard for easy access. When I click the opener, the door swings wide and allows ample ten seconds for me to exit or enter. The time it stays open can be adjusted.

The door opener operates whether the door is locked or unlocked.

Because of my limited dexterity, I used to experience substantial stress closing and locking my door behind me when exiting and again when manually unlocking the door for re-entry. Sometimes I dropped my key and had to ask a neighbor or passerby to pick it up for me. I used rubber tubing to close the door behind me. Now I can preset the door handle lock and use the door opener to exit and close the door.

This definitely enhances my independence and makes life easier. And compared to other accommodations like ramps and lifts, the price is right and the installation simple.

*Photo upper left: Lan Remme, who has C6 tetraplegia, presses the remote door opener to open his front door. Photo lower left: Door opener installed on the top of Lan’s front door. Photo right: Front door swings open after Lan pushes his remote.*
Self-management skills

There are some very concrete practical self-management skills that can help you manage chronic pain.

Set a goal

One of the most important things in taking back your life when living with pain is to set a goal. Steps for setting goals:

- State your goal.
- Make sure your goal is both manageable and realistic.
  - On a scale from 1 to 10, how confident are you that you can reach your goal?
  - A rating between 0–6 means that the goal is too hard and needs to be broken down into smaller pieces.
  - A rating of 7 to 10 means it’s a good fit.
- List steps that will help you reach your goal.
- Evaluate results. Did you reach your goal?

Another goal-setting approach is to make a statement specifying what you will do, how often, which days, what barriers you anticipate and how you will deal with them. This ensures that your goal is tangible and doable.

Activation

One of the most important ways to treat both pain and emotional suffering is “activation” or getting active. Getting active may include:

- Increasing physical activity.
- Increasing activities that are enjoyable, meaningful, or pleasurable.
- Increasing participation in activities consistent with your values and goals.

Activation works best if activities are:

- “Anti-depressant” and “anti-pain” (i.e., reinforcing, valued, enjoyable). Rather than do a “chore” that you don’t enjoy, choose something enjoyable—it is more likely to distract you from your pain.
- Scheduled, rather than waiting until you “feel better or feel like it.” Schedule it and follow through like you would a doctor’s appointment, and don’t cancel even if you don’t feel like it at the time.
- Increased gradually and systematically—“paced.”
  - Avoid doing too much when you do feel good.
  - Don’t go out for a whole day if you’ve been staying home for weeks due to pain; just go out for an hour or two.
  - Overdoing can set you back, and you can get in a cycle of crashing after overdoing, then feeling tired, cranky, discouraged and less active.
  - Set time limits on new or increased activities.
  - Plan the activity to allow rest or relaxation interspersed with the activity.
  - Part of specific, measurable and attainable goals.

Relaxation skills.

We know when the brain is in a more relaxed state the body tends to hurt less. And relaxation is helpful for coping in general. There are many different techniques for relaxation.

Progressive muscle relaxation

This method involves systematically tensing and relaxing the muscle groups in your body that you can move, one group at a time. The idea is to give you an awareness of tension in your body and what it feels like to release that tension.

Breathing

Even simpler, you can use your breathing as a form of relaxation. I’ve even done breathing relaxation with people on ventilators, which involves counting breaths and using this as a path toward relaxation. This can often be used in conjunction with imagery—thinking about a place that you associate with relaxation and feeling good while you are doing relaxation exercises.

Relaxation Practice is Key

- Practice regularly; even 30 seconds of practice is worthwhile and better than none.
- Develop relaxation into a habit. You are learning a new skill. You need to use it often to benefit from it.
- Practice relaxation even when you’re not stressed or in pain.
- Use relaxation audio recordings. Find links to different audio recordings at http://sci.washington.edu/manage.
- Mobile apps for relaxation: Breathe to Relax is a free app that will talk you through how to practice breathing relaxation.

Yoga

Yoga can provide a combination of breathing, relaxation and positive imagery skills. There are many different types; look for one that accommodates people of all abilities and levels of experience. Your rehab provider and therapists may be able to suggest a class geared toward individuals with disabilities.

Hypnosis

Hypnosis for managing pain (called hypnotic analgesia) in SCI is backed by scientific evidence. Several studies here in the Uni-
versity of Washington Department of Rehabilitation Medicine have found that hypnosis is very helpful in reducing pain in about a third of people with SCI pain. About another third say it helps some, and a third say it doesn’t really help very much. You won’t know if you’re going to be someone who benefits from it unless you give it a try.

What is hypnosis?

Hypnosis is a state of focused attention and use of imagery to get you into a very relaxed state. While in that state you listen to positive suggestions (from a therapist or audiotape) for decreasing unpleasant experiences and increasing comfortable experiences.

The process goes something like this:

- **Induction:**
  - Induce relaxed state by focusing attention on a single stimuli (such as the therapist’s voice).

- **Suggestion:**
  - Altered pain experience
  - Decreased unpleasantness
  - Sensory substitution (e.g., “warm” instead of “burning”)

Mindfulness

Mindfulness is simply being aware of the present moment and having a nonjudgmental attitude toward your present thoughts and feelings. This method can help people relax and be less bothered by chronic pain. There are many mindfulness resources and trainings available, including the Mindfulness-Based Stress Reduction Programs at the Center for Mindfulness in Medicine, Health Care, and Society (www.umassmed.edu/cfm).

Depression and Pain

Major Depressive Disorder (MDD) is much more common among individuals who have chronic pain, including SCI pain.

Often pain and depression occur together, and evidence suggests that pain precedes depression more often than the reverse.

It is very important that you know the symptoms of depression: feeling down and blue most of the time; having low energy; not wanting to get out and do things or be with others. Check with your health care provider if you think you might be depressed, because depression can make pain worse, and there are effective treatments for depression.

Other pain treatments

Self-management also includes asking for help from mental health professionals trained in specific behavioral and psychological techniques.

Cognitive-Behavioral Therapy (CBT)

CBT is based on a cognitive behavioral theory of pain, in which thoughts and behavioral responses to pain influence adjustment and functioning.

Acceptance and Commitment Therapy (ACT)

A mindfulness approach focused on allowing and accepting some pain some of the time and not fighting pain all the time or letting pain rule your life.

Acceptance can lead to:

- Decreased pain intensity, psychological distress, physical disability, and attention to pain.
- Increased physical functioning, general mental well-being, motivation, and engagement with daily activities.

Resources

**Pain Self-Help Books**


**Online Programs**


*painAction* has several online self-management programs, including one for neuropathic pain, at http://www.painaction.com.
4th Annual Spinal Cord Injury Wellness Summit

The UW South Campus Center buzzed with activity inside and out last spring at the 2015 SCI Wellness Summit as 200 wheelchair users, family members, friends, and health care providers roamed between demonstrations and activities to learn about adaptive recreation programs. Attendees could sign up to try out adaptive tennis, cycling, yoga and painting; watch demonstrations of rugby and basketball; and browse displays about everything from accessible camping to adaptive photography, swimming, fishing and more. Equipment vendors showed off their latest models, and local non-profit recreational organizations enticed visitors to try something new.

Three speakers opened the event with presentations highlighting recreational activities and the scientific evidence behind the benefits of participation. These talks included: Keynote speaker Aaron Bunnell, MD, UW assistant professor of Rehabilitation Medicine and a person with a spinal cord injury, speaking on the benefits of recreation after injury; Beth Reite, OT, on adaptive yoga; and Harriet Ott, OT, on aquatic therapy. Continuing education credits were given to therapists who attended these presentations.

The SCI Wellness Summit was a collaboration of the Northwest Regional SCI System and the SCI Transitions and Wellness Program, in the UW Department of Rehabilitation Medicine.

Thank you to our underwriters and many volunteers for making this event possible.

Underwriting support came from these companies: Numotion, Restorative Therapies, Rocklyn Medical Supply, Coloplast, Hollister, Bellevue Healthcare, Invacare Corporation, Permobil, ABC Medical, and Dependable Medical Equipment.

Join our mailing list to learn about the next SCI Wellness Summit and other activities. Go to sci.washington.edu/subscribe, send an email to nwrscis@uw.edu or call 206-685-3999.
**LOCOMOTOR TRAINING**

- Safety and efficacy of at-home robotic locomotion therapy in individuals with chronic incomplete spinal cord injury: a prospective, pre-post intervention, proof-of-concept study.
  
  This study tested 5 prototypes of a robotic locomotion training device (MoreGait) for unsupervised home-based therapy. Twenty-five (5 tetraplegia, 20 paraplegia) participants with chronic sensorimotor incomplete SCI (7 ASIA Impairment Scale (AIS) C, 18 AIS D) completed a training program of 45 minutes per day, at least 4 days per week, for 8 weeks. After therapy, 9 of 25 participants improved with respect to the dependency on walking aids. For all individuals, the short-distance walking velocity measured by the 10-Meter-Walk Test showed significant improvements compared to baseline. Only one device-related adverse event (pressure sore on the big toe) occurred in over 800 training sessions. The magnitude of functional improvements achieved by MoreGait in individuals with incomplete SCI is well within the range of complex locomotion robots used in hospitals. Thus, unsupervised MoreGait training is a possible option to continue training aimed at recovery of locomotor function beyond in-patient rehabilitation.


- Facilitatory effects of anti-spastic medication on robotic locomotor training in people with chronic incomplete spinal cord injury.
  
  This study investigated whether an anti-spasticity medication can enhance the effects of robotic locomotor treadmill training (LTT) to improve gait in people with incomplete SCI. Individuals with chronic incomplete SCI participated a 4-week program of either LTT alone (26 participants) or LTT combined with Tizanidine (TizLTT), an anti-spasticity medication (22 participants). Gait, speed, endurance, strength, active range of motion (AROM) and peak velocity (Vp) of ankle dorsiflex- and plantar-flexor muscles were recorded. Walking speed and dorsiflexion maximum strength improved in both groups, with no differences between groups. However, a higher proportion of subjects in the TizLTT group achieved the minimal important difference (MID) for walking speed (40%) compared with LTT alone (13%). Those that achieved the MID for walking speed were significantly higher functioning at baseline than those that did not in the TizLTT group, and the change in walking speed was associated with the change in dorsiflexion peak velocity using the MID for clinical scores analysis. Therefore, Tizanidine appears to enhance the effects of LTT on gait function in individuals with chronic SCI that are higher functioning at baseline. This may be due to restoration of inhibitory mechanisms by Tizanidine, resulting in greater stretch in the plantarflexor muscles during the LTT.

  Duffell LD, Brown GL, Mirbagheri MM.

**RESPIRATORY HEALTH**

- Effects of air stacking on pulmonary function and peak cough flow in patients with cervical spinal cord injury.
  
  This study evaluated the effects of air stacking (taking in a breath of air; and then without exhaling taking in another breath of air; multiple times prior to breathing out) on pulmonary function and peak cough flow. Twenty-six patients with cervical SCI were randomized into experimental (n = 14) and control (n = 12) groups. The control group performed incentive spirometry (a device used to measure how deeply a person breathes in), and the experimental group performed 20 repetitions of air stacking exercise twice a day. Both groups trained 5 days a week for 6 weeks. Forced vital capacity (FVC) and peak cough flow (PCF) increased significantly in the experimental group compared to controls. All within-group variables in the experimental group differed significantly at 6 weeks compared to baseline, while in the control group only FVC differed significantly at 6 weeks compared to baseline.

  Air stacking exercise significantly improved pulmonary function and PCF in patients with a cervical spinal cord injury.

  Jeong JH, Yoo WG.

- Abdominal Functional Electrical Stimulation to Assist Ventilator Weaning in Acute Tetraplegia: A Cohort Study.
  
  The aim of this study was to investigate the feasibility of using Abdominal Functional Electrical Stimulation (AFES) to improve respiratory function and assist ventilator weaning in acute tetraplegia. AFES was applied for between 20 and 40 minutes per day, five times per week on four alternate weeks, with 10 acute ventilator dependent participants with tetraplegia. Each participant was matched retrospectively with a ventilator dependent tetraplegic control, based on injury level, age and sex. Tidal Volume (VT) and Vital Capacity (VC) were measured weekly, with weaning progress compared to the controls. Stimulated VT was significantly greater than unstimulated VT, and VC increased throughout the study. Intervention participants weaned from mechanical ventilation on average 11 days faster than their matched controls. These results show that AFES is clinically feasible for these patients and may improve respiratory function and enable faster weaning from mechanical ventilation.

  McCaughey EJ, Berry HR, McLean AN, et al.

- A Canada-wide survey of chronic respiratory disease and spinal cord injury.
  
  The objective of this study was to evaluate the association between chronic respiratory diseases (asthma and chronic obstructive pulmonary disease) and SCI in a large representative sample. Data were compiled from more than 60,000 individuals from the 2010 cycle of the cross-sectional Canadian Community Health Survey (CCHS). After adjusting for age, sex, and smoking status, SCI was associated with significant increased odds of asthma and chronic obstructive pulmonary disease. These heightened odds highlight the need for targeted interventions and prevention strategies for respiratory health among individuals with SCI.

  Grogg JJ, Winner FM, Kramer JK, Borisoff JF.

**BOWEL MANAGEMENT**

- Outcomes of neurogenic bowel management in individuals living with a spinal cord injury for at least 10 years.
  
  In this Dutch study, 258 individuals with long-term SCI (at least 10 years) participated in a medical assessment, physical examination, interview and self-report questionnaire. Thirty-five percent used digital evacuation and 31% used mini enemas. Transanal irrigation (TAI) and surgical interventions were used by 11% and 8%, respectively. Participants using surgical bowel management had been injured significantly longer than those using TAI. Hemorrhoids (39%) and constipation (25%) were the most common problems. Severe neurogenic bowel dysfunction was present in 36% of all participants and in 40% of those using a conservative method. However, only 14% were (very) dissatisfied with their current bowel management. Dissatisfaction with bowel management was significantly associated with constipation and severe neurogenic bowel dysfunction.

CONTINUED FROM PREVIOUS PAGE

SCI TRENDS


The objective of this study was to assess trends in national incidence, cause, health care utilization, and in-hospital mortality in acute traumatic SCI from 1993 to 2012. Survey data from the US Nationwide Inpatient Sample databases for 1993-2012 identified 63,109 patients with acute SCI. Over the study period, the incidence rate of acute traumatic SCI remained relatively stable but, reflecting an increasing population, the total number of cases increased. The overall incidence rate of SCI in the male population aged 16 to 44 years substantially declined over time. Public education, improved motor vehicle safety features, stricter safety belt laws, and drunk driving laws and their enforcement may have contributed to this overall decline in SCI rates in these age groups. The largest increase in incidence was observed in older patients, largely due to an increase in falls, and in-hospital mortality remained high, especially among elderly persons.


MENTAL HEALTH

■ Novel risk factors associated with current suicidal ideation and lifetime suicide attempts in individuals with spinal cord injury.

Suicide risk after SCI is 3 or more times greater than in the general population. Understanding the risk factors for suicide specific to individuals with SCI can help guide prevention efforts. For this study, 2,533 participants with SCI from six U.S. SCI rehab centers were recruited and screened for depression. Of these, 179 (7.4%) reported a lifetime suicide attempt (SA) and 323 (13.3%) reported any suicidal ideation (SI) in the past 2 weeks. SA was associated with less education, younger age at injury, depression and current or past treatment of depression, and having bipolar disorder or schizophrenia. SI was associated with more years since injury and a history of SA. Further work needs to be done to identify ways to assess and treat suicide risk in this population.


FERTILITY & REPRODUCTION

■ Successful pregnancies and healthy live births using frozen-thawed sperm retrieved by a new modified Hotchkiss procedure in males with retrograde ejaculation: first case series.

This study analyzed the effectiveness of using a new protocol, including a modified Hotchkiss technique (MHT), for sperm retrieval and cryopreservation in 10 individuals with retrograde ejaculation (RE). Eight of these subjects had spinal cord injuries. The novel protocol is based on an asynchronous management, involving systematic freezing of spermatozoa recovered from the bladder. The ten couples underwent 26 intracytoplasmic sperm injection (ICSI) cycles: nine clinical pregnancies were achieved in six couples, including eight after fresh embryo transfer and one after thawed embryo transfer, resulting in seven live births. This is the largest series of births achieved using spermatozoa retrieved from post-ejaculatory urine by the new MHT and shows that the new MHT allowed for successful sperm cryopreservation, leading to the efficient and easier management of couples with RE.


CARDIOVASCULAR HEALTH


SCI results in unhealthy changes in body composition and metabolism that can lead to cardiovascular disease (CVD). Unsurprisingly, heart disease occurs earlier and more frequently in persons with SCI than in the general population. Effective treatment to reduce the risk of CVD depends on early and accurate diagnosis. This study used nuclear magnetic resonance (NMR) spectroscopy to provide more detailed information about the lipid profile that is known to be an independent risk factor for CVD. Fasting blood samples were obtained on 83 persons with chronic SCI and 62 able-bodied (AB) subjects. Fasting plasma insulin (FI), triglycerides (TG), and P number and size of VLDL (very low density lipoprotein), LDL, and HDL subclasses were determined. Prolonged sitting and restricted physical activity in individuals with SCI had the most profound effect on the HDL-C and its lipoprotein P subclasses, but not on LDL-C. Its P subclasses were also unfavorable affected but not to the same degree. The insight gained from combining lipoprotein cholesterol concentration with that of the lipoprotein particle number can permit a more accurate estimate of risk for CVD in this population and can more appropriately guide treatment with pharmaceutical and/or lifestyle modification.


■ Lower-extremity muscle atrophy and fat infiltration after chronic spinal cord injury.

Atrophy (wasting) and fatty-infiltration of lower-extremity muscles after SCI predisposes individuals to metabolic disease and related mortality. The purpose of this study was to determine the magnitude of atrophy and fatty-infiltration of lower-extremity muscles and related factors in a group of individuals with chronic SCI. Muscle cross-sectional area and density were calculated from peripheral quantitative computed tomography scans of the calf of 70 participants with chronic SCI (50 males, mean age 49 years, C2-T12,AIS A-D) and matched controls. Participants with motor-complete SCI had approximately 32% less muscle area and 43% lower muscle density compared to controls. Participants with motor-incomplete SCI had muscle area and density values that were 14% lower than controls. There are modifiable factors related to muscle size, body composition, and activity level that may offer therapeutic targets for preserving metabolic health after chronic SCI.


BONE HEALTH

■ Longitudinal study of bone loss in chronic spinal cord injury patients.

This prospective longitudinal study evaluated the changes in bone metabolism markers and bone mineral density over 3 years in 20 participants with SCI. It also assessed the relationship between bone mineral density, bone metabolism, and clinical data (i.e., immobilization due to surgery, neurological status, neurological level, and extent of lesion). Bone mineral density, and hormonal and biochemical markers were measured at 0, 6, 12, and 36 months. Femoral neck T score (which defines bone density) decreased significantly at 36 months. Parathyroid hormone and vitamin D were significantly elevated, while bone turnover markers were significantly decreased at 12 and 36 months. Bone mineral density of the femoral neck decreases significantly during the long-term follow-up of patients with SCI. This could be due to changes in hormonal and bone turnover markers.

Co-Motion Study
UW researchers are seeking individuals with traumatic SCI at C6 or below for a study examining the effectiveness of a 16-session physical activity program for improving health and fitness. To learn more and find out if you might be eligible to participate, call 206-221-4079.

PASS Study
Individuals with SCI who have been injured a year or more, are at least 18 years old, and have chronic pain may be eligible to participate in this UW study. Participation involves one lab visit to complete questionnaires and learn how to use an activity monitor, followed by 7 days of home monitoring. The purpose of this study is to understand the day-to-day experiences of people who have chronic pain and does not involve any treatment. Participants will be paid $100 for completing the study. For more information, please call 206-685-0945 or send an email to nwrscis@uw.edu.