MRSCICS Matters

# Fall 2016

Welcome to the summer issue of MRSCICS Matters, the newsletter of the Midwest Regional Spinal Cord Injury Care System (MRSCICS). This newsletter is designed to keep you in-the-know about spinal cord injury (SCI)-related information and updates on SCI Model Systems activities. In this issue you'll read about "Pain after Spinal Cord Injury", the new LIFE Center Resource Roundup, and opportunities to participate in other SCI focused research studies. Enjoy!

## Pain After Spinal Cord Injury

### The problem of pain after SCI

Pain is a serious problem for many people with spinal cord injuries (SCI). Pain after SCI can occur in parts of the body where there is normal sensation (feeling) as well as areas that have little or no feeling. The pain is real and can have a negative effect on quality of life. A person in severe pain may have difficulty carrying out daily activities or participating in enjoyable pastimes.

The majority of people with SCI report that they have chronic pain. Chronic pain is pain that does not go away and lasts months to years. The cause of the pain may be unknown but is most often related to nerve damage from the SCI or musculoskeletal problems that arise in dealing with an SCI. The pain can come and go. Chronic pain is difficult to eliminate completely but often can be managed or reduced enough so that it doesn't overwhelm your life.

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## *Activity Modification for Musculoskeletal Pain*

### Exercise

- Almost everyone can benefit from a fitness program that includes resistance training of the muscles that stabilize the shoulder. Training helps prevent shoulder pain as well as treat overuse pain. Strong muscles are less likely to be injured. Talk with your doctor or therapist about starting a program of resistance exercises that emphasizes muscles that are neglected during everyday activities, such as during transfers and wheelchair propulsion.

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## Are You Due For a National SCI Database Follow-Up Interview?

Are you approaching your 1, 5, 10, 15, 20, 25, 30, 35, or 40 year anniversary of injury? You may be due for your next follow-up interview. Don't want to wait for us to contact you? Please call or email **Kelsey Stipp** at 312-238-1405 or **kstipp@ric.org** to schedule your interview. Your interview can be completed by phone, mail, or in-person.

**LIFE Center Roundup**
Learn about quality, free SCI-related resources available to you.
*(page 5)*

**More Research Opportunities**
Find out about other research opportunities.
*(flyers and page 8)*

**The National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR)** is a national leader in sponsoring research. NIDILRR is located in Washington, D.C., and is part of the Administration for Community Living at the U.S. Department of Health and Human Services.

NIDILRR National Institute on Disability, Independent Living, and Rehabilitation Research

# Pain After Spinal Cord Injury (continued from p.1)

Chronic pain can cause or worsen psychological problems such as depression, anxiety and stress. This does not mean the pain is "all in your head," but rather that pain and distress can make each other worse.

Even though pain after SCI can be complicated and difficult to treat, there are many treatments available that can help. Understanding your pain, working with your doctor, and being open to a variety of treatments will help you manage your pain and improve your quality of life. Many people with chronic pain problems after SCI have found relief using techniques described here.


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If pain starts years after injury, it may be due to a new medical problem, such as a syrinx, a fluid-filled cavity that forms in the spinal cord. It is rare but may require surgery. Therefore, it is important to contact a doctor if you notice any new loss of sensation, especially in areas around the level of your injury, and any muscle weakness that doesn't improve with rest.

## Types of pain

A person with SCI can have many different types of pain in different locations, including areas where there is not usually any feeling. Understanding what type of pain you have is key to choosing the right treatment. Therefore, your doctor will ask you to describe your pain in a variety of ways, including its locations, severity, how long you have had it, what makes it worse or better, and so on. Your doctor also may ask you to undergo tests such as an x-ray or magnetic resonance imaging (MRI).

## Neuropathic pain

Neuropathic or "neurogenic" pain is caused by abnormal communication between the nerves that are damaged in your spinal cord injury and the brain, where nerve signals that inform your brain how your body feels are interpreted. The brain "misunderstands" or amplifies the intensity of the signals from around the area of your injury. This can cause you to experience pain coming from areas of your body below your level of injury. This is why a person can feel neuropathic pain in an area that otherwise has no feeling. People often use words such as *burning, stabbing* or *tingling* to describe neuropathic pain, but neuropathic pain varies from person to person. It is often difficult to treat, and frequently a combination of treatments are used.

## Musculoskeletal pain

Musculoskeletal pain is caused by problems in the muscles, joints, or bones. It is a common problem for everyone as they age, including those with SCI.

Musculoskeletal pain can be caused by injury, over- use or strain, arthritic changes, or wear and tear of the joints, often from wheelchair use including inadequate support for sitting and transfers. It usually gets worse with movement and better with rest.

- Upper limb (shoulder, elbow and hand) pain is often caused by overuse of the muscles transferring, and doing pressure relief maneuvers, and from pushing a wheelchair. It can occur months or years after injury. People with higher level injuries who use computers or joy- sticks for many activities (reading, communicating, environmental controls) may develop pain in the hand, arm, or shoulder from overuse. Upper limb pain can make it difficult to transfer safely and perform other activities of daily living.

- Back and neck pain are common problems. In people with paraplegia who have had surgery to fuse their spine, increased motion that occurs just above

and just below the fusion can lead to back pain. People with tetraplegia (quadriplegia) may also have back pain, especially if they are able to walk but still have weakness. People who use chin- or mouth-operated joysticks may sometimes develop neck pain.

- Muscle spasm pain happens when muscles and joints are strained from spasticity.

## Visceral pain

Visceral pain is located in the abdomen (stomach and digestive area) and is often described as cramping and/or dull and aching. It can be caused by a medical problem such as constipation, a kidney stone, ulcer, gall stone, or appendicitis. Since a person with SCI may not have the usual symptoms associated with these conditions, it is important to see a doctor who has had experience caring for SCI patients.

Pain that comes from a visceral problem is some- times felt in an area away from the source of the problem. This is called referred pain. One common example is shoulder pain that results from gallbladder disease.

## Managing pain after SCI

Since pain can have so many different causes, there is no single way to treat it. You and your doctor may need to try a combination of drugs, therapy, and other treatments, including behavioral psychological treatments, and this may take time to work out.

## Physical treatments and interventions

- Activity modification for musculoskeletal pain. Changes in your mobility equipment (wheelchair, sliding board), your wheelchair pushing and transfer techniques, and in the way you do pressure reliefs can significantly decrease muscles and joint pain. Exercises that strengthen and balance your joints can also help reduce musculoskeletal pain.
- Physical therapy is used to treat musculoskeletal pain. Stretching and range of motion exercises may help relieve pain associated with muscle tension. Exercises that strengthen weak muscles can restore balance in painful joints and reduce pain.
- Therapeutic massage may help relieve musculoskeletal pain due to muscle tightness and muscle imbalance.
- Acupuncture is used to treat musculoskeletal pain. Tiny needles are inserted into the skin at specific points on the body. Acupuncture is thought to work by stimulating the body's pain control system or by blocking the flow of pain.
- Transcutaneous electrical nerve stimulation (TENS) is sometimes used to treat musculoskeletal pain. Electrodes are placed on the surface of the skin and send low levels of electrical current into the body. The current blocks signals from the areas of nerve damage that are triggering a pain response.

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## Psychological treatments

We now know that people can learn to use psychological techniques to help them manage their pain better so it doesn't take over their lives. Psychologists trained in pain management can help with a variety of behavioral techniques proven to be effective in reducing the intensity and impact of pain.

- Relaxation techniques and/or biofeedback dedesigned to teach you how to reduce muscle pain tension and "mental tension" associated with pain can be helpful in self-management.
- Self-hypnosis training has proven helpful for reducing chronic pain in some individuals.
- Cognitive restructuring Learning how to think differently about your pain and its effects can lead to changes in brain activity and, in turn, the experience of pain.
- Individual psychotherapy designed to help identify desired goals and increase pleasure and meaning in daily life can help reduce pain. Therapy can also

help if there is a significant amount of anxiety associated with pain.

## Medications

There are many medications to treat pain. All of the medications listed below have shown some success in reducing pain, but none do so completely in every instance. All have possible side effects, some of which can be serious. Discuss all side effects with your doctor. Sometimes combinations of drugs work better than a single drug.

- Non-steroidal anti-inflammatory drugs (also known as NSAIDS) such as aspirin, ibuprofen (Motrin, Advil) and naproxen are most commonly used to treat musculoskeletal pain. Side effects may include stomach upset or bleeding.
- Antiseizure medications such as gabapentin (Neurontin) and Pregabalin (Lyrica) are used to treat neuropathic pain. Side effects include dizziness, sleepiness, and swelling.
- Antidepressants are used to treat neuropathic pain and depression. These medications include selective serotonin norepinephrine reuptake inhibitors (SSNRIs), such as venlafaxine (Effexor), and tricyclics, such as amitripltyline (Elavil). Side effects include dry mouth, sleepiness, dizziness, and (with SSNRIs) nausea.
- Narcotics (opiates) such as morphine, codeine, hydrocodone and oxycodone are not recommended for treatment of chronic or long standing neuropathic or musculoskeletal pain. These drugs have many side effects, including constipation, depression of breathing, and slowed thinking. They are habit forming and use often leads to dependency. Withdrawal symptoms can occur when stopped suddenly.
- Muscle relaxants and anti-spasticity medications medications such as diazepam (Valium), baclofen (Lioresal) and tizanidine (Zanaflex) are used to treat spasm-related and musculoskeletal pain. These may be taken by mouth or delivered directly to the spinal cord through an implanted pump (see "Intrathecal pumps" below). These drugs can cause sleepiness, confusion and other side effects.

- Topical local anesthetics such as lidocaine (Lidoderm) are used to treat pain that occurs when skin is touched lightly (called *allodynia*).

## Surgical Treatments

- Dorsal column stimulator is used to treat neuropathic pain due to nerve root damage. A high frequency, low intensity nerve stimulator is surgically placed in the spinal canal next to the spinal cord or nerve roots.
- Intrathecal pumps are used to treat neuropathic pain (using morphine) or muscle spasm-related pain (using baclofen). A pump containing morphine or baclofen is surgically placed under the skin in the abdomen. It delivers the medication directly to the spinal cord and nerve roots.
- Individual psychotherapy designed to help identify desired goals and increase pleasure and meaning in daily life can help reduce pain. Therapy can also help if there is a significant amount of anxiety associated.

## Prevention and self-care

- Get treatment for medical problems. Overall health can have a big effect on pain. Urinary tract infections, bowel problems, skin problems, sleep problems and spasticity can make pain worse or harder to treat. Keeping yourself as healthy as possible can help reduce pain.

- Try to get as much exercise as possible. Getting regular physical activity can reduce pain as well as improve mood and overall health. It can also be enjoyable and distract you from pain. Your health provider can help you choose physical activities that are safe and appropriate for you.
- Get treatment for depression. Depression can make pain worse. It is best treated through counseling and medication. Getting treatment for depression can help you cope with chronic pain and improve your quality of life.
- Reduce stress. Stress can make pain worse or make the pain harder to manage. You can learn to manage stress through counseling and learning techniques to reduce stress and tension, such as relaxation training, biofeedback and hypnosis. Exercise helps reduce stress.
- Distract yourself. Distraction is one of the best methods for coping with chronic pain. Participat-

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# The LIFE Center's Resource Roundup

The LIFE Center is RIC's education and resource hub providing standardized, best-practice and peer reviewed patient education and consumer health information specific to rehabilitation and disability. To find out more or receive one-on-one assistance call 312-238-5433, e-mail lifecenter@ric.org, or stop by (located in the southeast corner of RIC's lobby). To access free online materials, sign up to become a member at http://lifecenter.ric.org. The following resources below can be found on the LIFE Center web site.

Model Systems are specialized programs of care committed to conducting research to improve the long-term functional, vocational and quality-of-life outcomes for those with spinal cord injury (SCI). The Spinal Cord Injury Model Systems (SCIMS) are national leaders in SCI-related care and research. The SCIMS maintains a National Database that collects data from individuals with SCI at regular intervals. To view published data by the National SCI Database visit https://www.nscisc.uab.edu/ Learn more about all the Model Systems at http://www.msktc.org/about-model-systems and about the Midwest Regional Spinal Cord Injury Care System at http://www.ric.org/research/research-centers--programs/mrscics/

The Model Systems Knowledge Translation Center (MSKTC) summarizes research and provides information resources to help the Model Systems meet the needs of individuals with SCI. The MSKTC offers consumer-oriented factsheets and slideshows on topics related to SCI. They also provide quick reviews on current research as well as publish their own SCI articles. To find out about more resources offered by the MSKTC please visit http://www.msktc.org/

The Reeve Foundation Paralysis Resource Center focuses on providing resources and referral services to those living with a spinal cord injury. They have created a free book to serve as a resource guide and information tool for individuals with SCI and their caregivers and have information specialists available to answer any questions one might have regarding SCI. Find out more at http://www.paralysis.org/

SPINALpedia is a social mentoring network developed to allow those with SCI to connect and motivate each other. The website offers over 5,000 videos of interesting SCI content as well as learning portals to educate and empower the SCI community. Join now at https://spinalpedia.com/

The Spinal Cord Injury Association of Illinois is a non-profit organization dedicated to serving as a comprehensive resource center for individuals with SCI as well as professionals who serve the SCI community. They also conduct welcoming peer support groups throughout the state of Illinois to provide the opportunity to explore thoughts and feelings without judgement. To learn more or to find a support group near you please visit http://www.sci-illinois.org/

Access Living is a change agent committed to working toward full community integration for individuals with disabilities in the Chicagoland area. They provide programs to help individuals with disabilities to advocate for themselves. Access Living also offers resources such as housing services, arts and culture programs, peer and community supports and legal services. Visit https://www.accessliving.org/ to get involved.

Facing Disability is a website designed to help friends and families of individuals with SCI. Personal perspectives from hundreds of people are presented in short video clips to provide an opportunity to see and hear responses to questions asked from the time of injury to living and coping with SCI throughout life. The website also provides interviews with experts to broaden knowledge of things such as preventing pressure sores, spasticity, fertility and adjusting to social life. Learn more at http://www.facingdisability.com/

RIC Vocational Rehabilitation assists people with disabilities in returning to work. A wide range of services are available such as Initial Case Consultation, Work Trial Assessment and Job Placement. A doctor's referral is required. To learn more visit http://www.ric.org/services/vocational-rehabilitation/

RIC Assistive Technology Center offers a variety of services to people with disabilities in order to enhance independence, comfort and general quality of life. Three specialty areas include the Seating and Positioning Center, Technology center for Environment, Computer and Communication and the Rehabilitation Engineering Program. Visit http://www.ric.org/conditions/pcs-specilized/assistive_technology/index.aspx to learn more.

The National Spinal Cord Injury Association educates and empowers survivors of SCI to achieve and maintain the highest levels of independence, health and personal fulfillment. To find a chapter near you visit http://www.spinalcord.org.

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# Pain After Spinal Cord Injury (continued from page 4)

ing in enjoyable and meaningful active- ties can help reduce pain and help you feel more in control of your life, especially when pain is at its worst. When we are bored and inactive, we tend to focus more on pain, and this can make pain feel worse.

- Keep a record. Everyone's pain is a little different. Keep a record of what makes you feel better and what makes pain worse. Understanding things that affect your pain will help you and your doctor find effective ways to reduce pain.
- Get a wheelchair seating evaluation. Poor posture and improper seating can cause serious pain problems. Get your seating evaluated by a physical therapist who specializes in wheelchair seating. If you use a manual wheelchair, try to get a high-strength, fully customizable chair made of the lightest material possible (aluminum or titanium). Learn the proper wheelchair propulsion (pushing) technique from a physical therapist.
- Don't drink to ease pain. Using alcohol as a pain medication can lead to alcohol abuse and other serious problems. Some medications should not be mixed with alcohol. Ask your doctor about drinking alcohol and always read the labels of your prescriptions.

## Finding help

It is important to get treatment for pain. The ideal source of help would be a physician and psychologist familiar with SCI and pain management, working together.

If you do not have access to such experts, the next best alternative is to seek help from a multi- disciplinary pain clinic where physicians and psychologists are available. Work closely with a health care provider with who you trust and who understands your condition.

Chronic pain is not hopeless. Try not to become discouraged if one treatment doesn't work, and be open to trying different techniques. While complete relief from pain may not be possible, living better despite pain is a realistic goal.

## Resources

- Pain Connection http://www.painconnection.org
- American Pain Society http://www.ampainsoc.org
- American Pain Foundation http://www.painfoundation.org
- CareCure Community Moderated Forums, including a pain forum http://sci.rutgers.edu/forum/
- See more at: http://www.msktc.org/sci/factsheets/Pain#sthash.Yolhbzif.dpuf

## Authorship:

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# Activity Modification for Musculoskeletal Pain (continued from page 1)

- For cardiovascular exercise, use upper limb ergometry equipment, such as a stationary bicycle powered by the arms, or a hand-cranked sports wheelchair. You can also box with a speed-bag instead of pushing a manual wheelchair for exercise. These exercises can reduce stress on the shoulders and wrists.

- Make sure your back and shoulder muscles are strong enough to support wheeling and transferring. It is especially important that there is a balance between your left and right sides. Ask your physical therapist to evaluate you and to prescribe strengthening exercises if you need them.

### Using a Wheelchair

- Repetitive pushing of wheel rims is a major cause of musculoskeletal pain. Consider obtaining a power or power-assist wheelchair if you:
  - Have significant shoulder, elbow or hand pain.
  - Have tetraplegia (quadriplegia).
  - Have a prior injury to an upper limb.
  - Are overweight.
  - Are elderly.
  - Live in a challenging environment such as on a steep hill or near rough terrain.
- If you use a manual wheelchair, make sure it is the lightest model (made from aluminum or titanium) you can afford or your insurer will pay for. Lighter models require less effort to push around and can often be customized to make it easier for you to propel the chair.
- If you do use a manual wheelchair, reduce the number of strokes you use per distance traveled. Rather than quick short pushes, use long smooth strokes.
- If you use a manual wheelchair, make sure it is in good repair and set up in a way that allows you to get around with minimal effort. Ask your therapist to check whether your seat is in the right position relative to your rear axle. Have your therapist check that your chair and cushion give you good stability.
- Get your wheelchair seating, posture and pushing technique evaluated by a rehabilitation professional periodically since your needs, habits or activities may change over time.
- Keep your tires well-inflated to minimize rolling resistance.
- Wheel your chair over concrete and linoleum rather than through sand, grass or heavy carpeting. The reduced resistance to your wheels lessens the load on your arms.

### Shoulder Health

- Minimize the frequency of arm/hand tasks, especially tasks that involve lifting heavy loads higher than your shoulder. Let someone get that book off a high shelf for you.
- If possible, do not do tasks repetitively that require you to bring your hand higher than your shoulder. Doing so may require reorganizing your house. Talk with your occupational therapist about home modifications.

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- Minimize lifting heavy loads. If you cannot get someone to do the heavy lifting, hold whatever you need close to your chest rather than at the end of an outstretched arm.
- Avoid doing push-up pressure reliefs (weight shifts), which can harm your shoulder joint. Instead, perform side-to-side or forward-lean pressure reliefs. Work with a therapist to learn proper technique for these methods or see the MSKTC fact sheet "How to do Pressure Reliefs (Weight Shifts)" before discontinuing push-ups.

### Transfers

- The heaviest thing you lift generally will be yourself. Reduce the number of transfers you do each day, and do them in a way that minimizes risk of injury.
- Transferring from a high point to a lower one is not as hard on your wrists, elbows and shoulders as transferring from a low to a higher point. It is better to make two level transfers rather than one downhill transfer followed by one uphill transfer.
- Use sliding boards and lifts in making transfers.
- When transferring, use a handgrip if available, rather than putting your hand on a fl at surface.
- When transferring, don't spread your hand flat and rest on it. Make a fist, and rest on your knuckles.
- When transferring, position your hands as close to your body as possible so that your arms are straight up and down and your weight hangs between them.
- Alternate which one of your arms is the lead arm in transferring. Different muscles are used by the lead and trailing arms during transfers, and alternating the arms keeps muscles balanced.
- Maintain your ideal weight. Being overweight is hard on your shoulders, arms, and wrists when you do transfers or push your wheelchair.

Authorship:
Please see the Spinal Cord Injury Model Systems Consumer Information publication Pain after Spinal Cord Injury for information about authorship.

Reference:
Consortium for Spinal Cord Medicine. Preservation of upper limb function following spinal cord injury: a clinical practice guideline for health-care professionals. J Spinal Cord Med 2005; 28:433-70.

## We want to hear from you!

Interested in other SCI topics? Want more info? Need to update your contact information? Want to receive this newsletter by email?
Let us know, contact **Kelsey Stipp** at **312-238-1405** or **kstipp@ric.org.**

## Want to get involved in more research at RIC?

Contact **Katharine Davis** at **312-238-1624** or **kdavis02@ric.org** to learn about the Center for Rehabilitation Outcomes Research's (CROR) registry. After you enroll in this registry, we will contact you about CROR's upcoming studies.
Visit **www.ric.org/research/clinical-trials/** for a list of RIC's research studies and clinical trials.

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