Pain after Spinal Cord Injury

6

For more information, contact your nearest SCI Model System. For a list of SCI Model Systems go to: http://www.msktc.org/sci/model-system-centers

This publication was produced by the SCI Model Systems in collaboration with the University of Washington Model Systems Knowledge Translation Center with funding from the National Institute on Disability and Rehabilitation Research in the U.S. Department of Education, grant no. H133A060070.

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 very real and can have a negative impact 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 instead 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 completely eliminate but often can be managed or reduced enough so that it doesn't overwhelm your life.

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 difficult chronic pain problems after SCI have found relief using techniques described here.

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 MRI (magnetic resonance imaging).

Neuropathic pain

Neuropathic pain ("neurogenic pain") is caused by abnormal communication between the nerves that were damaged by your spinal cord injury and the brain, where nerve signals that inform your brain how your body feels are interpreted. In neuropathic pain, it is thought that the brain "misunderstands" or amplifies the intensity of the signals it is getting from around the area of your injury. This can cause you to experience pain coming from areas of your body below where you have little or no feeling. 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 a great deal from person to person. It is often very difficult to treat, and frequently a combination of treatments must be used.

Note: 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 very 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.

Musculoskeletal pain

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

Musculoskeletal pain can be caused by injury, overuse or strain, arthritic changes, or wear and tear of the joints, often from wheelchair use (including inadequate support for sitting) and/or 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
 from doing transfers and pressure relief maneuvers and from pushing a wheelchair. It can occur
 months or many years after injury. People with
 higher level injuries who use computers or joysticks 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 for you 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 als 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 medical conditions, it is important to see a doctor who has had experience caring for SCI patients in order to get a correct diagnosis and treatment.

Pain that comes from a visceral problem is sometimes 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 psychological treatments, and this may take some 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 pain in your muscles and joints. Exercises that strengthen and balance your joints can also help reduce musculoskeletal pain. For information, please see the supplement "Activity Modification for 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. This method 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 your skin and send low levels of electrical current into your body. The current blocks signals from the areas of nerve damage that are triggering a pain response.

Psychological treatments for pain

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 techniques proven to be effective in reducing the intensity and impact of pain.

- Relaxation techniques and/or biofeedback designed 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 actually 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 different 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 problems.

- Antiseizure medications such as gabapentin (Neurontin) and Pregabalin (Lyrica) are used to treat neuropathic pain. Side effects include dizzyness, 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 used to treat neuropathic and musculoskeletal pain. These drugs have many side effects, including constipation and sleepiness, and can be habit forming. You may also develop dependency on these drugs and may have withdrawal symptoms if you suddenly stop taking them. However, they can be used effectively for many people, and while not the first consideration for chronic pain management, should not be dismissed because of fears about dependency or side effects
- Muscle relaxants and anti-spasticity 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 lightly touched (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 spasmrelated 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.

Prevention and self-care

- Get treatment for medical problems. Overall health can have a big impact 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 physiccal activities that are safe and appropriate for you. Also see the supplement "Activity Modification for Musculoskeletal Pain."
- 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 cope with. You can learn to manage stress through counseling and learning techniques to help you 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. Participating in enjoyable and meaningful activeties can help reduce pain and help you feel more in control of your life, especially when pain is at its worst. When you are bored and inactive, you tend to focus more on your pain, and this can make your 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 to find effective ways to reduce your 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. (See the supplement "Activity Modification for Musculoskeletal Pain.")
- Do not use alcohol 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

If you have pain, it is important to get treatment for it. The ideal source of help would be a physiccian and psychologist familiar with SCI and pain management, working together.

If you do not have easy 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 whom you are comfortable 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 a variety of different techniques. While complete relief from pain may not be possible, living better despite pain is a realistic goal.

Resources

- Pain Connection, www.painconnection.org
- CareCure Community Moderated Forums, including a pain forum. http://sci.rutgers.edu/forum/

Source

Our health information content is based on research evidence and/or professional consensus and has been reviewed and approved by an editorial team of experts from the SCI Model Systems.

Authorship

Pain after Spinal Cord Injury was developed by J. Scott Richards, PhD, Trevor Dyson-Hudson, MD, Thomas N. Bryce, MD, and Anthony Chiodo, MD, in collaboration with the University of Washington Model Systems Knowledge Translation Center.

Portions of this document were adapted from materials developed by the UAB SCI Model System, University of Michigan Model SCI Care System, Northwest Regional SCI System, and Craig Hospital.

Pain after Spinal Cord Injury

SUPPLEMENT: Activity Modification for Musculoskeletal Pain

Spinal Cord Injury Model System Consumer Information



For more information, contact your nearest SCI Model System. For a list of SCI Model Systems go to: http://www.msktc.org/ sci/model-systemcenters

This publication was produced by the SCI Model Systems in collaboration with the University of Washington Model Systems Knowledge Translation Center with funding from the National Institute on Disability and Rehabilitation Research in the U.S. Department of Education, grant no. H133A060070.

Exercise

- Almost everyone can benefit from a fitness program that includes resistance training of the muscles that stabilize the shoulder. This will help prevent shoulder pain from occurring as well as treat overuse pain. Strong muscles are much less likely to be injured. Talk with your doctor or therapist about starting a program of resistance exercises that emphasizes those muscles that are often neglected during everyday activities, such as during transfers and wheelchair propulsion.
- 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. Such equipment will 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 problem activity causing musculoskeletal pain. Consider obtaining a power or power-assist wheelchair
 - Have significant upper limb (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 very 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 give you less weight 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
- 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. Also have him/her check that the chair and cushion together give you good stability.
- Get your wheelchair seating, posture and pushing technique evaluated by a rehab 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 else 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. This may require reorganizing your house. Talk with your occupational therapist about ways to do so.
- Minimize lifting heavy loads. If you cannot get someone else 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 other assistive devices (such as lifts) in making transfers.
- When transferring, use a handgrip if available, rather than putting your hand on a flat 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 closely 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.

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.

Authorship

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

