



PAIN

Most people living with spinal cord injury experience some type of pain after injury, including in areas of the body that have lost sensation. Identifying and understanding the root causes of different types of pain can help manage and reduce symptoms.



Q: What is pain?

Pain is a sensation that alerts the body to a harmful change or warns it of imminent danger. It is experienced differently by everyone and can be fleeting or long-lasting. Acute pain is typically short-lived and treatable, caused by the sudden onset of disease,

injury or inflammation of the tissue. Episodic pain can be irregular, brought on by known triggers or unknown causes. Chronic pain can last for months or years, evolving from acute pain or persisting for unknown reasons.

People living with SCI typically experience some combination of chronic musculoskeletal, neuropathic and visceral pain.

Q: What is musculoskeletal pain?

Musculoskeletal pain affects muscles, bones, joints, ligaments and tendons; this kind of pain may feel achy, throbbing, stiff, sore or sharp.

People with SCI often experience musculoskeletal pain caused by the overuse of muscles. For example, individuals living with paraplegia develop shoulder, elbow and arm pain stemming from repetitive motions including wheelchair use, transfers, and weight shifting to prevent pressure sores. Similarly, the continuous use of mouth-operated joysticks can cause neck pain, while hand and arm pain can be caused by using a hand controller to operate a power wheelchair.

Other types of musculoskeletal pain may occur due to spasticity or surgical interventions such as spinal fusion. People living with SCI who can walk but still have weakness may also develop back pain.

Musculoskeletal pain can affect mobility and range of motion, progressively diminishing the ability to perform activities of daily living and harming overall independence.

Q: What is neuropathic pain?

Neuropathic pain can be caused by damage to nerves in the spinal cord or to the nerve roots extending from the spinal cord. This type of pain, which can affect a small area of the body or the entire area below injury, has been described as a burning, stabbing, electric, numb, or tingling sensation.

Q: What is visceral pain?

Visceral pain occurs in the abdominal area and can be caused by ulcers, constipation, kidney stones or appendicitis. Symptoms, including aching and cramping, that signal these medical problems may not be felt by a person with SCI. Alternately, the pain may be felt in an area unrelated to the problem, such as shoulder pain that stems from gall bladder disease. Visceral pain may be missed by a doctor with limited experience caring for patients with SCI; for this reason, if possible, seek primary care with a physiatrist – a doctor who treats medical conditions affecting the brain and spinal cord – or a doctor who has previously treated patients with SCI.

Q: How is pain diagnosed?

Doctors will work with patients to carefully evaluate the location, type, severity and potential cause of pain. It is helpful if patients keep notes tracking and describing their experiences, including a description of the pain, when it began, where it is located, what makes it feel better or worse, and how it affects other aspects of life (work, socializing, sleep, etc.) X-rays or MRIs may be used to investigate pain sources; neuropathic pain that develops more than a year after the injury may indicate a new medical issue.

Q: What effects can pain have beyond physical symptoms?

Chronic pain can negatively affect many aspects of a life. It can impact work, causing distraction or making the commute to the office difficult or impossible. It can affect a person's ability and desire to leave the house or socialize, disrupt sleep, and diminish appetite. It can lead to isolation and depression.

People living with chronic pain should not ignore the physical or mental challenges. Seek support and strategies not only from doctors, but mental health professionals who can play an important role in coping with pain.

Q: What options do I have for treating pain?

A multidisciplinary team of healthcare providers can offer a range of treatments to help manage pain. Working with a physical therapist to strengthen muscles and add targeted exercise can help people reduce and prevent musculoskeletal pain. Occupational therapists might recommend new transfer techniques to help relieve pressure and vary the muscles being used to avoid overuse. Stretching, massage and acupuncture might also relax stiff muscles.

Neuropathic pain, which varies widely from individual to individual, is often difficult to treat. Nerve stimulation may be used to try to help train the brain to ignore the pain. Medication, relaxation exercises and psychotherapy can also help train the brain to better manage physical pain.

Potential Treatments for Pain

- **Activity Modification**
- **Physical Therapy**
- **Electrical Stimulation**
- **Acupuncture**
- **Therapeutic Massage**
- **Relaxation and Biofeedback Techniques**
- **Meditation**
- **Psychotherapy**
- **Medication**
- **Biofeedback**
- **Behavior modification may also be employed.**

Q: What kinds of medication might be prescribed for pain symptoms?

Medications will vary depending on the type and source of pain. Muscle relaxers and neurotoxin injections may be prescribed for spasticity, while topical anesthetics such as lidocaine may be used to treat pain caused by sensitive skin. Anti-inflammatory drugs such as Advil or injectable steroids may be used to target musculoskeletal pain. Anti-seizure and anti-depressant medications may be used to treat nerve pain. For cases of chronic and severe musculoskeletal pain, opioids may be prescribed.

Q: What should I know about opioids and managing pain after SCI?

Doctors might prescribe opioids for severe pain that has lasted for more than three months and has not responded to any other non-opioid treatments, including physical therapy.

A low dose of opioids may be prescribed for no more than three months if the outcome lowers pain levels and improves the ability to perform daily tasks.

Opioids should always be prescribed at the lowest possible effective dose. Higher doses, which increase the risk of misuse or overdose, have not been proven to reduce pain over the long-term.

For more information about opioids, please refer to the National Paralysis Resource Center Opioids Factsheet, available on our website at <https://www.christopherreeve.org/wp-content/uploads/2024/05/Opioids-QA-1-24-A.pdf>.

Q: Are there clinical trials for chronic pain?

Yes. Researchers at universities and rehabilitative hospitals across the country regularly conduct studies related to pain caused by spinal cord injury. To find current trials, visit ClinicalTrials.gov(<https://www.clinicaltrials.gov/ct2/home>), a searchable website for publicly and privately supported clinical studies maintained by the National Library of Medicine(<https://www.nlm.nih.gov/>) at the National Institutes of Health(<https://www.nih.gov/>).

Q: Where can I find other resources about managing pain after spinal cord injury?

Contact large regional hospitals and rehabilitative centers to ask about specialized pain clinics, treatment options and support groups. (See some listings in Resources below.) A video series about pain management and SCI is also available from Model Systems Knowledge Translation Centers. To learn more, visit its website at <https://msktc.org/sci/videos/asking-about-pain>.

Sources: Model Systems Knowledge Translation Center, National Institute of Neurological Disorders and Stroke, Craig Hospital, Northwest Regional Spinal Cord Injury System.

Need to talk to someone?

Our Information Specialists are available to answer your questions.

Call toll-free 1-800-539-7309 Mon-Fri, 7 am -8 pm EST.

Or schedule a call or ask a question online at

<https://www.ChristopherReeve.org/Ask>.

Resources for Pain:

American Chronic Pain Association (ACPA)

<https://www.acpanow.com/>

11937 W. 119th Street

Suite 216

Overland Park, KS 66213

Phone 913-991-4740

Email: ACPA@theACPA.com

ACPA offers peer support and education in pain management skills to people with pain, their family and friends, and health care professionals.

Brigham and Women's Hospital: Translational Pain Research

<http://www.paintrials.org>

Department of Anesthesiology, Perioperative and Pain Medicine

Brigham and Women's Hospital

75 Francis Street MRB 604

Boston, MA 02115

Phone: 617-535-7246

Email: paintrials@partners.org

The Translational Pain Research Group conducts research to systematically evaluate new drugs for pain and to determine the cause of different types of pain to improve therapy.

Christopher & Dana Reeve Foundation: Pain Management booklet

<http://s3.amazonaws.com/reeve-assets-production/Pain-MgmtBooklet-FINAL-4-17-19.pdf>

Please call the Reeve Foundation at 800-539-7309 for a free print copy of this booklet.

Craig Hospital

<https://craighospital.org/>

3425 S. Clarkson St.

Englewood, CO 80113

[303-789-8000](tel:303-789-8000)

Email: rehab@craighospital.org

Craig Hospital is a rehabilitation center that specializes in neurorehabilitation and research for people living with spinal cord injury and brain injury.

Craig Hospital: Aching Shoulders

<https://craighospital.org/resources/le-duelen-los-hombros>

Craig Hospital: Activity Modification for Musculoskeletal Pain

<https://craighospital.org/wp-content/uploads/sites/Educational-PDFs/Model-Systems/364.Model-System-Pain-after-SCI-Activity-Modifications.pdf>

Craig Hospital: Pain Resources

<https://craighospital.org/resources/topics/pain>

Defense & Veterans Center for Integrative Pain Management (DVCIPM)

<https://dvcipm.usuhs.edu/>

4301 Jones Bridge Rd.

Bethesda, MD 20814

Phone: 800-515-5257

DVCIPM is the DoD's designated Center of Excellence for Pain Management and serves as the central pain management advisory organization for pain management policy, research, and education & training.

International Association for the Study of Pain (IASP)

<http://www.iasp-pain.org>

IASP Secretariat
712 H St. NE, #55
Washington, DC 20002
Phone: 202-856-7400

Email: IASPdesk@iasp-pain.org

IASP is a non-profit professional organization dedicated to furthering research on pain and improving the care of patients with pain. Membership is open to scientists, physicians, dentists, psychologists, nurses, physical therapists, and other health professionals actively engaged in pain research and to those who have a special interest in the diagnosis and treatment of pain.

Medtronic

<http://www.medtronic.com>

710 Medtronic Parkway
Minneapolis, MN 55432-5640
Phone: 763-514-4000

Medtronic is a medical technology company, which provides therapeutic, diagnostic, and monitoring products for people with chronic pain.

Model Systems Knowledge Translation Center (MSKTC)

<https://msktc.org/>

American Institutes for Research
1400 Crystal Drive
10th Floor
Arlington, VA 22202
Phone: 202-403-5600
Email: msktc@air.org

MSKTC is a national center that works to put research into practice to serve the needs of people with traumatic brain injuries, spinal cord injuries, and burn injuries.

MSKTC: Pain after Spinal Cord Injury

<http://www.msktc.org/sci/factsheets/pain>

<http://www.msktc.org/sci/slideshows/Pain-After-Spinal-Cord-Injury>

<https://msktc.org/sci/sci-topics/managing-pain-after-sci>

National Institute of Neurological Disorders and Stroke (NINDS)

<https://www.ninds.nih.gov/>

National Institutes of Health
9000 Rockville Pike
Bethesda, MD, 20892
Phone: 800-352-9424

The NINDS supports, performs and promotes basic, translational, and clinical neuroscience research to improve neurological health for the public.

NINDS: Central Pain Syndrome Information

<https://www.ninds.nih.gov/health-information/disorders/central-pain-syndrome>

NINDS: Pain: Hope Through Research booklet

<https://catalog.ninds.nih.gov/sites/default/files/publications/pain-hope-through-research.pdf>

National Center on Health, Physical Activity and Disability (NCHPAD)

<https://www.nchpad.org/>

University of Alabama at Birmingham School of Health Professions

3810 Ridgeway Drive

Birmingham, Alabama 35209

Phone: 866-866-8896

This NCHPAD resource has information on treatment and exercises options for pain related to spinal cord injury, limb loss, cerebral palsy, fibromyalgia, Parkinson's, rheumatoid arthritis, osteoarthritis, and post-polio syndrome.

NCHPAD: Primer on Pain

<https://www.nchpad.org/resources/primer-on-pain/>

Northwest Regional Spinal Cord Injury System (NWRSCIS)

<https://sci.washington.edu/index.asp>

University of Washington

Rehabilitation Medicine, Box 356490

Seattle, WA 98195

Phone: 206-616-2183

Email: nwrscis@u.washington.edu

The NWRSCIS is a regional center of spinal cord injury care, research and education in the Department of Rehabilitation Medicine at the University of Washington.

NWRSCIS: Pain and Spinal Cord Injury

http://sci.washington.edu/info/pamphlets/pain_sci.asp

NWRSCIS: Multidisciplinary Management of Pain in Spinal Cord Injury – An Approach to Improve Pain, Function and Psychological Coping

http://sci.washington.edu/info/forums/reports/pain_2010.asp

Pain Connection

<https://painconnection.org/>

15 North Main St., Unit 100

West Hartford, CT 06107

Phone: 800-910-0664

Email: contact@uspainfoundation.org

A program of the U.S. Pain Foundation, Pain Connection is dedicated to empowering people with chronic pain to improve their quality of life, decrease their sense of isolation, and take a more active role in their treatment.

U.S. Pain Foundation

www.USPainFoundation.org

15 North Main Street, Unit 100
West Hartford, CT 06107
Phone: 800-910-2462

Email: contact@uspainfoundation.org

The U.S. Pain Foundation is a non-profit organization whose mission is to connect, inform, educate and empower those living with pain while advocating on behalf of the entire pain community.

Alternative Medicine Resources:

AxioBionics Wearable Therapy

<http://www.wearabletherapy.com/>

6111 Jackson Road, Suite 200
Ann Arbor, MI 48103
Phone: 734-327-2946

Email: eval@axiobionics.com

AxioBionics develops and markets medical devices for pain control and neuro rehabilitation, specializing in the design of custom-made electrical stimulation technology and orthotic and prosthetic devices.

Craig Hospital: Complementary & Alternative Medicine Resources

<https://craighospital.org/resources/complementary-and-alternative-medicine-general-overview>

This brochure provides an overview and description of some of the alternative practices gaining popularity in the U.S.

National Center for Complementary and Alternative Medicine (NCCAM)

<https://www.nccih.nih.gov/>

NCCAM Clearinghouse
National Institutes of Health
9000 Rockville Pike
Bethesda, Maryland 20892
Phone: 888-644-6226

Email: info@nccam.nih.gov

NCCAM is the federal government's lead agency for scientific research on the diverse medical and health care systems, practices, and products that are not generally considered part of conventional medicine. The site has information on medical conditions and on alternative therapies.

Articles and Other Publications:

New Mobility: The Pain That Never Stops (Neuropathic Pain). March 2017

www.newmobility.com/2017/03/neuropathic-pain

Online Forums:

CareCure Community

[Carecure.net](https://www.carecure.net)

CareCure online forums provide a platform for people to share information about spinal cord injury care, caregiving, cure, funding, life, pain, sex, links, research, and trials.

The information contained in this message is presented for the purpose of educating and informing you about paralysis and its effects. Nothing contained in this message should be construed nor is intended to be used for medical diagnosis or treatment. It should not be used in place of the advice of your physician or other qualified health care provider. Should you have any health care related questions, please call or see your physician or other qualified health care provider promptly. Always consult with your physician or other qualified health care provider before embarking on a new treatment, diet or fitness program. You should never disregard medical advice or delay in seeking it because of something you have read in this message.

This publication is supported by the Administration for Community Living (ACL), U.S. Department of Health and Human Services (HHS) as part of a financial assistance award totaling \$10,000,000 with 100 percent funding by ACL/HHS. The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by ACL/HHS, or the U.S. Government.