

“There are different kinds of pain that I experience. It is paradoxical to describe the presence and absence of pain. There is always a hum through my whole body – the pins and needles. But pain is more like the dull aching pain I get in my neck, or the throbbing aching I get in my shoulders – particularly the right shoulder, or the sharp knife like pain in my wrist and thumb, or the deep vague ache I get in my hip. I have had severe acute pain too – severe nerve pain in my arm when I injured it in a fall a few years ago – it was electric and sharp and burning “

Joan, C8 quadriplegia





After a spinal cord injury, people can experience many different types of pain. Pain can be caused by physical trauma, or it can come from changes that happen in your body after an injury. Pain can sometimes come and go without any clear cause. Pain can be felt above or below the level of SCI and can also be felt in areas of the body where there is either little or even no sensation at all!

Pain affects people in many ways. Pain can get in the way of going out with friends or exercising. It can make self-care more difficult and interfere with sleep. Pain can make it seem hard to return to work or study and pain can make you feel sad, tired, frustrated or angry.

**It is important to learn about the different types of pain that can happen after spinal cord injury as this will help you to develop the best pain management strategies for your particular pain**




## Pain Types

Pain after SCI can come from many different sources. Pain can be from:




-  damage to the nerves in the spinal cord itself or the nerves nearby
-  changes to the nervous system in the period after injury
-  strain of muscles or joints from everyday activities or with ageing
-  irritation of your body's internal organs

There is a way of naming the different pains after spinal cord injury and this is called the **International Spinal Cord Injury Pain Classification**.

Pain can be from stimulation of specific pain nerves called **nociceptors** causing pains such as:


-  **Musculoskeletal pain** (eg: shoulder pain)
-  **Visceral pain** (eg: abdominal pain)
-  **Other nociceptive pain** (eg: Autonomic Dysreflexia headache)

Pain can also be from irritation of or damage to the **nerves** themselves and this can lead to:

-  **At-level neuropathic pain** (eg: band like pain at the level of your injury)
-  **Below-level neuropathic pain** (eg: pins and needles or electric shocks in your legs)
-  **Other neuropathic pain** (eg: carpal tunnel syndrome)

The International Spinal Cord Injury Pain Classification – Part 1 (Bryce et al 2012)


By providing the following information to your doctor– you can name & Classify your pain



### THE SPINAL CORD INJURY PAIN QUESTIONNAIRE


For you pain, provide the following details:

Where is the pain located?	
Is the pain above or below your level of SCI? **	<input type="checkbox"/> Above <input type="checkbox"/> Below
Is the pain in a region of reduced sensation? **	<input type="checkbox"/> Yes <input type="checkbox"/> No
When did the pain start? (Date of onset*)	____/____/____
Was there an event that triggered the pain?	<input type="checkbox"/> Yes <input type="checkbox"/> No Details: _____
What words best describe your pain? ** (tick all that apply)	<input type="checkbox"/> Aching <input type="checkbox"/> Burning <input type="checkbox"/> Dull <input type="checkbox"/> Icy cold <input type="checkbox"/> Cramping <input type="checkbox"/> Electric Shocks <input type="checkbox"/> Tender <input type="checkbox"/> Pins & Needles <input type="checkbox"/> Squeezing <input type="checkbox"/> Tingling <input type="checkbox"/> Sharp <input type="checkbox"/> Other: _____
How does pain change over the course of the day?	
What makes the pain feel worse? **	<input type="checkbox"/> Personal care <input type="checkbox"/> Fatigue <input type="checkbox"/> Mobility - transfers <input type="checkbox"/> Stress <input type="checkbox"/> Mobility – wheelchair <input type="checkbox"/> Anxiety <input type="checkbox"/> Mobility – walking <input type="checkbox"/> Constipation <input type="checkbox"/> Exercise/recreation <input type="checkbox"/> Bloating <input type="checkbox"/> Spasm <input type="checkbox"/> Bladder infection <input type="checkbox"/> Other: _____ <input type="checkbox"/> Other: _____
What makes the pain feel better? **	<input type="checkbox"/> Rest <input type="checkbox"/> Medications <input type="checkbox"/> Position change <input type="checkbox"/> Distraction <input type="checkbox"/> Activity Pacing <input type="checkbox"/> Exercise <input type="checkbox"/> _____ <input type="checkbox"/> _____
What medications or treatments are used?	



Lifetime Care & Support Authority

[www.aci.health.nsw.gov.au/chronic-pain](http://www.aci.health.nsw.gov.au/chronic-pain)



ACI NSW Agency for Clinical Innovation

\*Questions from the International Spinal Cord Injury Pain Basic Data Set: Version 2 (Widerstrom-Noga et al 2014)

\*\* Questions to help identify SCI Pain Type - International Spinal Cord Injury Pain Classification (Bryce et al 2012)

### Musculoskeletal Pain



**Pain location:**

In an area of preserved sensation

**Above or below SCI level:**

Above or below level of SCI, but usually an area with sensation

**Pain description:**

Dull, sharp, tender, aching

**Things that make pain worse:**

Certain postures or movement, lifting bodyweight, transfers, driving, mobility, exercise or sport

**Things that reduce the pain:**

Rest, position change, some medications, equipment changes

**Examples of musculoskeletal pain include:** shoulder pain from tendonitis, wrist arthritis, back ache

### Visceral Pain



**Pain location:**

Abdomen, chest or pelvis

**Above or below SCI level:**

Above, at or below level of SCI  
May or may not be in an area with sensation

**Pain description:**

Dull, cramping, aching, colicky, intermittent

**Things that make pain worse:**

Constipation, bladder infection, kidney stones, blocked catheter

**Things that reduce the pain:**

Achieve a bowel result, unblock catheter, antibiotics for infection

**Examples of visceral pain include:** bloating, constipation, cramping, bladder infection

### Neuropathic Pain



**Pain location:**

May be in feet, legs, arms, hands, abdomen, buttocks or trunk depending of SCI level

**Above or below SCI level:**

May be At-level of SCI  
May be Below-level of SCI

**Pain description:**

May be Other neuropathic pain (eg: above-level carpal tunnel syndrome)  
Hot, burning/hot, sharp, electric shocks, icy/cold, squeezing or constriction, tingling or pins and needles

**Things that make pain worse:**

Stress, bladder infection, constipation, fatigue

**Things that reduce the pain:**

Medications, being distracted, gentle exercise

**Examples of neuropathic pain include:** Burning pain in the feet or electric shocks in the legs

**NOTE:** if you experience nerve pain **above** your SCI level – see your Doctor for assessment and advice

Do you know what type of pain do you have?

☐ Musculoskeletal

☐ At-level neuropathic

☐ Other nociceptive

☐ Visceral

☐ Below-level neuropathic

☐ Other neuropathic



### Changes in Pain

It is normal for pain to fluctuate in intensity during the day or from day to day. You may have **good pain days** and **bad pain days**. Bad pain days are often called **pain flare ups**. These flare ups are normal day-to-day changes for chronic pain.

It is a good idea to have a **flare up plan** to help deal with the pain on the bad days – choose 3 things to put on your flare up plan that help your pain.

However, sometimes after a spinal cord injury, an **increase in your pain** or **change in your symptoms** can mean that something else is going on in your body.

If you experience pain that is related to **any of the following**, it is recommended that you see your doctor as soon as possible to discuss your symptoms.



**Q: Do any of these apply to you?** ☐ YES ☐ NO

*If the answer is yes – see your doctor as soon as possible*

“When I get abdominal pain, excruciating abdominal pain, like a burning sensation, it is usually a bladder infection – a UTI. This causes a lot of stinging, a lot of ache, and I spasm with that as well, because I can’t actually feel it fully, and so my body tells me there is something wrong, and all of a sudden that flares up and my blood pressure goes up – my body automatically goes into Autonomic Dysreflexia – AD”

Vito, C5/6 quadriplegia

**TOP TIP!** For more information please visit:

- <http://www.aci.health.nsw.gov.au/chronic-pain/spinal-cord-injury-pain/introduction-to-spinal-cord-injury-and-chronic-pain>
- Read Chapter 2 of *The Spinal Cord Injury Pain Book* by Siddall, McCabe & Murray (2014 HammondCare Media)