Coping with Pain after Spinal Cord Injury

This leaflet is to help you to understand and manage your pain.

You might find it helpful to share this with your family and friends.

Think about your pain. Does it:

- ✓ keep going even if you are taking medication or other treatments for pain
- ✓ stop you doing daily activities
- ✓ wake you up or stop you falling sleep
- ✓ make you feel down or worried about your pain
- ✓ make it difficult to get on with your rehabilitation

If you answered YES to two or more of these questions, then this information is for you.

Understanding spinal cord injury (SCI) Pain

Pain after spinal cord injury (SCI) can be caused by damage at the time of injury:

- to the bones, muscles and ligaments of the spine
- to spinal cord or the nerves feeding into the spinal cord
- by other injuries sustained at the same time e.g. fractures or muscle injuries of arms, legs or other body parts.

Pain can also happen as a result of the effects of any surgery required to treat these injuries.

This sudden onset (called Acute Pain) may be severe. This pain usually responds to medication and improves over a period of weeks as damage to our body heals.

Unfortunately, sometimes pain persists. This pain is different from acute pain and needs to be treated differently.

Pain lasting more than 12 weeks is called Chronic Pain.

Chronic pain develops because of changes in the central nervous system (the spinal cord and the brain). Continual pain can increase the sensitivity of the pain system and can even radically change the way in which cells in the brain and spinal cord communicate pain. This means pain signals can continue to be generated even after healing has taken place.

Pain after spinal cord injury is common. Some studies suggest 4/5 people experience some level of ongoing pain. Learning how to manage pain early on can help you stay on top of pain and get the best out of your rehabilitation.

Types of pain after SCI

It is important to understand what causes your pain as the different types of pain require different treatments. If you are unsure what type of pain you experience please discuss this with your doctor.

Musculoskeletal pain

At first your muscles will be weak. Lying in bed for a long period of time leads to loss of fitness. This means when you start moving it might be painful at first. Physiotherapists will work with you to build up strength. They will teach you techniques to help prevent pain particularly in shoulders and wrists, as you learn to get mobile.

Musculoskeletal pain often occurs above the level of the injury where there is normal sensation. It's due to inflammation or strain on muscles or joints and can be caused by everyday activities like using a wheelchair or transferring in and out of bed. It can feel like a dull or sharp ache. This type of pain is often made worse on movement or in certain positions.

Back and neck pain can be a common problem after a SCI but it does not necessarily mean anything is wrong. If there has been surgery to strengthen or fuse the bones of the spine, the spine becomes more rigid in these places and this can lead to some stiffness or pain above and below the levels of the bones operated on. This discomfort usually lessens over time.

Neuropathic pain

Neuropathic pain is caused by damage to the nerves in the spinal cord or nerves feeding into the spinal cord which tell your brain how your body is feeling. The brain misinterprets the signals it is getting from the damaged nerve cells and causes you to experience pain coming from below where you have little or no feeling. This is why a person can feel neuropathic pain in an area that is paralysed or has no sensation.

Neuropathic pain is common at, or just below, the level of the SCI. Common sites of neuropathic pain include chest, shoulders, back, arms/hands, abdomen, bottom, legs and feet.

Neuropathic pain may feel different to pain you have experienced before. It is often described as one or more of the following: stabbing, crushing, burning, freezing, electric, tingling, stinging or shooting. It often feels like it comes 'out of the blue'. It can be made worse by spasms, pressure sores if you are ill or have an infection. Stress can also make pain worse.

Pain at the level of SCI can also be accompanied by extreme over sensitivity (called 'hypersensitivity). Even light touch, including sheets or clothes can cause pain. Speak to your Occupational Therapist if you experience hypersensitivity, as there are treatments that can help to reduce this.

Neuropathic Pain is different

You will not hurt yourself if you exercise while you have neuropathic pain, in fact staying active is recommended.

To begin with medication can be helpful but in the long term most people find other ways to manage neuropathic pain.

Pain after surgery

Operations can be an important part of treatment: for example, to strengthen your spine, repair skin wounds or if a certain type of catheter is required. After surgery it is common to experience a temporary increase in pain as healing takes place.

Research has shown that for acute pain distraction activities can all be helpful and might cut down the time you need to rely on stronger pain relief. These activities can be simple strategies like counting down a minute on a clock, or more complex activities like mental games/puzzles, playing computer games or using relaxation techniques. Please ask a member of your team if you are unsure about what to expect.

Other common causes of pain

Visceral Pain is often felt as dull ache or cramping in the abdomen (stomach and digestive area). It can be caused by urinary tract infections, bladder or kidney stones, or constipation. A person with SCI may not have the usual symptoms associated with these conditions so it's important to discuss this with your spinal consultant and nursing team.

Sometimes, even though you may not feel pain below the level of your injury, say from a cut or bruise, or even a blocked catheter, there can be a sudden reflex reaction called 'Autonomic Dysreflexia' (often referred to as AD). This only applies to people with SCI above the level T6. If this is relevant to you your rehabilitation team will ensure you are given information so you know how to manage it. If you are unsure please ask a member of your team.

The role of medication

After SCI it is common for people to be taking several different medications.

During your rehabilitation one of the goals will be to ensure you only take the medication needed as you prepare to leave hospital.

You should always discuss your medication with your Consultant.

Your medical team will help you to carefully balance the pain relief you receive from medication against any side-effects. Medication can help keep background levels of pain manageable when used regularly. Evidence suggests that using pain relief tends to be less effective over time; higher doses can have less effect and some medications may be addictive. Where strong pain relief like opiates are used, this is usually recommended for short term use only or to manage a flare-up acute of pain.

Looking at the timing of your pain medication can be important. For example, do you need to take short acting pain relief before exercise? Is your sleep disturbed by pain? We know that getting sleep is very important to recovery and to managing day-time pain. Hospital routines can already make getting a good night's sleep harder. Good positioning in bed can also help, especially if you cannot roll over independently.

Most people find medication is not the main strategy they rely on in the longer term to help with pain. This leaflet introduces other strategies you can try.

Physical treatments

SCI pain can respond well to 'hands on' treatment.

- hot or cold treatments
- strengthening work
- Pilates
- stretching
- using different mobility equipment
- trying alternative methods of pressure relief
- electrotherapy (TENS machines)
- vibration treatments
- treatment like applying graded pressure to your skin to reduce oversensitivity to touch
- Acupuncture and therapeutic massage can also be used very effectively for pain relief.

These treatments can be explained by your Physiotherapist and Occupational Therapist.

Activity and pain

The longer you have pain the harder it can be to stay active.

How often and how long you exercise for is important. Building up stamina and fitness should be done in a way that doesn't make your pain so bad afterwards that you are not able to do anything.

Pacing is a technique for balancing out activity and rest in a way that is right for you and doesn't cause your pain to flare up. By pacing yourself you can gradually build up on the activity that you can do.

There are links to more information about exercise and fitness and pacing at the end of this leaflet. If in doubt, speak to your Physiotherapist and/or Occupational Therapist about how to pace your activities.

Psychological aspects of pain

Pain after SCI is real. It is generated in the brain after damage to nerves in the spinal cord disrupts communication between the body and the brain. Our brains are hard-wired to pay attention to pain to keep us safe which makes it hard to ignore.

Research has shown that our previous experience of pain, our thoughts and beliefs about pain, our mood and stress levels can all affect the way the brain generates pain. Even the way others respond to us when we are in pain can have an impact on our brain's responses.

No one wants to be in pain. Being in pain all the time can be exhausting and frustrating. Pain is upsetting and affects our ability to get on with life. It can affect our mood, sleep and relationships. Coping with a SCI is stressful, and pain can cause or make worse problems of depression or anxiety. With chronic pain there are going to be good and bad days. Pain is likely to be a part of daily life too, which can be hard to deal with in addition to everything else that you are adjusting to after SCI.

How can a Psychologist help with pain?

Chronic pain can only be managed by taking a whole person approach. Clinical Psychologists are part of the team at the NSIC. We are here to help people manage the stress associated with spinal cord injury. Psychologists are trained to support people in managing chronic pain. We can help you map out your personal experience of pain. By working with you we can look at how to help you gain more control over your pain.

Managing pain is complex. No single strategy will work for everyone. Most people find out what helps by trying out different strategies. A Psychologist can be involved in your goal planning to support you and the Pain Management. Often, you'll need help from many different professionals but an overall psychological awareness of the factors relevant specifically to you can be helpful. You can ask any team member,

including the ward nurses who you see every day, to refer you to a Clinical Psychologist for pain management advice.

Seeking support

Getting support from your rehabilitation team, family and friends is a really important part of coping with pain. It can be hard for families and friends to see someone in pain and chronic pain requires different ways of helping. By sharing this information with them will help them understand why you are doing what you are doing. For example, providing your Consultant says you are medically able to, staying active and being able to do things despite chronic pain is recommended, and is not harmful. Having times when you don't focus on your pain helps you be yourself with your family and can be really beneficial.

Always discuss your pain at goal planning as well as discussing it with your medical team on ward rounds.

Useful resources

Pain Management Network

This website has been designed by researchers, therapists and people with pain after SCI themselves.

It has some short videos to help you understand pain and introduces you to lots of different strategies – with examples of people who are living with pain.

It has good information about neuropathic pain.

https://www.aci.health.nsw.gov.au/chronic-pain/spinal-cord-injury-pain

Pacing, exercise & fitness

https://www.aci.health.nsw.gov.au/chronic-pain/spinal-cord-injury-pain/spinal-cord-injury-pain-physical-activity-and-exercise

Some studies suggest that 4/5 people have ongoing pain and that over half of this pain is musculoskeletal and neuropathic.

This website is for people with musculoskeletal pain but the pacing strategies are really relevant to people with SCI.

https://painhealth.csse.uwa.edu.au/pain-module/pacing-and-goal-setting/

Backup Trust and Spinal Injuries Association (SIA) are both UK Charities that support people with SCI and their families. Both organisations have lots of people with SCI working for them and it's a good way to have contact with people with experience of living with SCI.

Backup Trust

Is one of the UK charities that offers a range or services to support people with SCI and their families. This website has good, user friendly information, including videos by people with SCI living with pain who share their experiences about what helped them.

https://www.backuptrust.org.uk/support-for-you/information-section/pain-management

Spinal Injuries Association (SIA)

This is another national charity that is here to support people with SCI and their families. You need to register for a free membership to access all the information. They have information about pain among other topics.

https://www.spinal.co.uk/how-we-help/join_sia/

Mindfulness

There is evidence that mindfulness can help people with long term health conditions with pain. It is a type of meditation that can help people to manage stress and can reduce the unpleasantness of pain. Speak to a Psychologist at the NSIC if you would like to find out more.

Good information about why mindfulness is good for people with chronic pain can be found here:

https://painhealth.csse.uwa.edu.au/pain-module/mindfulness-and-pain/

How can I help reduce healthcare associated infections?

Infection prevention & control is important to the well-being of our patients and for that reason we have infection prevention & control procedures in place. Keeping your hands clean is an effective way of preventing the spread of infections. We ask that you, and anyone visiting you, use the hand sanitiser available at the entrance to every ward before coming in to and after leaving the ward. In some situations hands may need to be washed at the sink using soap and water rather than using the hand sanitiser as hand sanitisers are not suitable for use when dealing with patients who have symptoms of diarrhoea.

If you need advice or further assistance, please contact our patient advice and liaison service (PALS): call 01296 316042 or email bht.pals@nhs.net

Please remember that this leaflet is intended as general information only. We aim to make the information as up to date and accurate as possible, but please note that it is subject to change. Please therefore always check specific advice on any concerns you may have with your doctor.