

the
spinal
cord
injury
pain
book

*Foreword by
A/Prof James
Middleton*



PHILIP SIDDALL REBECCA MCCABE ROBIN MURRAY

Praise for The Spinal Cord Injury Pain Book

I get pain. At times it's excruciating. Is it the worst pain in the world? Probably not, but during those times, it sure feels like it is to me. It's all subjective, right? If there is one thing I have learnt about pain, in the 15 years that I have had a spinal cord injury, it's that the more active I am, the less pain I get. It doesn't matter whether it's physical activity, such as playing sport or chasing after the kids, or mental activity, such as being at work or enjoying a hobby. I guess that technically this is because I am too busy to dwell on the pain, but I tend to think that, like a miscreant child, it is because pain doesn't play nicely with others and wants my undivided attention. So it tends to be after a long day at work, when we've finally got the kids to sleep and I have transferred onto the sofa to relax with a spot of TV, that pain pops round for a cup of tea. And like any unwanted guest it overstays its welcome (not that it was ever welcome), it will often stay the night and if you were fortunate enough to get any sleep, will be there to say hello in the morning. So be active. Sounds easy, but what if your pain is so extreme and debilitating that you can't simply get on with daily activities? Well, that's where this fascinating and illuminating book comes in. Not only does it explain why we get pain, with just enough medical background to be enlightening not baffling, but it also provides a host of tools to assist someone with SCI to deal with their pain and get on with leading a fulfilling life. Metaphorically speaking: no longer turning off the TV and hiding under the sheets hoping that your unwanted guest leaves you alone, instead turn the TV up and ignore them altogether!

Chris Nicholls, T6 complete paraplegic
General Manager, Spinal Cord Injuries Australia.

There are many aspects of living with a spinal cord injury that we need to manage effectively and efficiently to maximise our ability. Pain is only one of them, but it is great to be able to have a conversation about another of the invisible challenges of our disability, in the form of detailed information within this book. My pain has come and gone since I crushed L1 in a mountain bike accident at 19. Sometimes constant, sometimes forgotten, my ability to put pain behind me has enabled me to have a fabulous life and work hard to achieve my goals (and there are many more to come). Thanks to the authors for framing pain in such a succinct, manageable and enlightening form. I know that there are lots of us with spinal injuries who appreciate this extra support, understanding and tools, to push through those barriers that threaten our function and sometimes our day-to-day sanity. Enjoy, and take action!

Liesl Tesch, AM, six time Paralympian
gold medallist, sailing, London 2012

This book is a great piece of work and will improve people's awareness of pain and what they can do to help reduce it. Empowering people to manage their own pain is such a big part of the healing from spinal cord injury—or any other cause of pain for that matter.

Susan Thomas, incomplete paraplegia

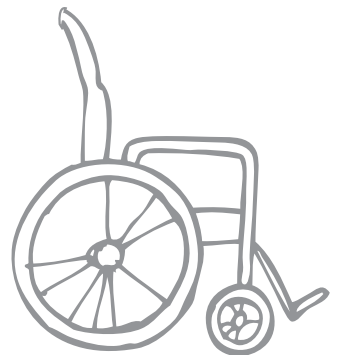
This is an excellent book to assist people with spinal cord injury, at any stage of their recovery, in managing their pain. The descriptions of the particular types of pain are extremely useful—such as musculoskeletal, visceral and neuropathic, as well as how they occur, why they recur and the methods of treating them with a range of therapies such as drugs, relaxation, exercise and mind retraining. It is also beneficial to family members and health professionals who want to learn more about the mysteries of pain post spinal cord injury. The book is practical and well written in concise, reader-friendly prose without being weighed down by impenetrable medical jargon. It is illustrated by clear diagrams and interesting vignettes from the lived experiences of people with a spinal cord injury.

Joan Hume, complete quadriplegia

I have just finished reading *The Spinal Cord Injury Pain Book* and found it to be very easy to understand and an honest appraisal of what might work, while at the same time acknowledging that complete freedom from pain may not yet be possible.

Bruce Nettleton, complete paraplegia

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Contributors

Professor Philip Siddall is Director of the Greenwich Hospital Pain Management Service, HammondCare and Professor in Pain Medicine at the University of Sydney. He has more than 20 years' experience as a researcher and clinician in the field of pain following spinal cord injury. He has published many journal articles and book chapters on this topic and is recognised internationally as a leader in this field.

Rebecca McCabe is a physiotherapist who specialises in chronic pain and has had many years' experience in private practice and hospital pain management centres. As part of her training, she has spent time in a major spinal unit in Sydney and is very familiar with the specific issues facing those with spinal cord injuries.

Dr Robin Murray has a PhD in clinical psychology and has practised and taught in the field of pain management for many years in both hospitals and private practice. She has also been involved in research looking at psychological aspects of pain following spinal cord injury and has published on this topic.

‘This book offers a wonderful approach to pain management by suggesting we control what we can through knowledge and practical solutions.’

Associate Professor Kathryn Nicholson Perry is a clinical psychologist who specialises in working with people with medical conditions. She has a PhD which explored using psychological methods to improve the quality of life of people with spinal cord injury related pain, and has been involved in a number of projects which aim to assist people coping with this problem.

Lyndall Katte is a physiotherapist with 15 years’ experience working with people with spinal cord injuries in various services including Prince of Wales Hospital Spinal Injury Unit, Royal Rehab Spinal Injury Unit and the NSW Spinal Outreach Service. She has assisted with research studies into physiotherapy treatments after spinal cord injury and has a particular interest in shoulder and upper limb preservation strategies.

Foreword

It is truly a privilege to be asked to write a foreword to a book that is so valuable and necessary in helping people with a spinal cord injury to learn ways to more effectively manage chronic pain.

Pain after spinal cord injury is a very common and pervasive problem that can interfere significantly with function and independence in everyday living, as well as participation in life roles, often also contributing to lowered mood, poorer sleep and reduced overall quality of life.

Professor Siddall and his co-authors bring together their extensive research knowledge and wealth of clinical expertise and understanding about pain and its management in a simple, clear and comprehensive way for the reader to follow. The addition of the real experience of people living with pain through the examples provided, adds greatly to the relevance of this book.

The structure helps the reader to firstly understand how pain works, and then how to build a 'pain toolkit' to manage the experience of pain. There are also tips for carers and health professionals. It provides easy to read information that covers a range of topics, including how pain affects us, the role of medications, physical activity and the impact of learned psychological strategies on the pain experience. It integrates the new scientific knowledge to elegantly explain how the reader can 'retrain the brain' to achieve better control of their pain and life activities.

‘a unique and important contribution in guiding a better understanding of pain and skills to enhance self-management capability.’

It logically builds on knowledge and skills in self-management of chronic pain through clear practical examples and ‘fact files’. It has tips, as well as testimonies from people living with spinal cord injury and pain, who have learned to reduce the impact of pain on their daily lives through employing these techniques.

The book guides the reader through to a logical understanding of pain, where there is hope for a more positive future. Trial and practice of the new strategies, perseverance, courage and building a good team of people are explored as part of the process.

This book helps us to understand that ‘the body has a powerful system in our brain and spinal cord to block out and control pain, and this system is influenced by what we do, think and feel. This means if we can learn to modify our actions, thoughts and feelings, we can not only feel better and do more, but actually reduce our pain’.

I heartily commend this book to those living with pain and spinal cord injury, and those who care for or support them. It offers a unique and important contribution in guiding a better understanding of pain and skills to enhance self-management capability.

Associate Professor James W Middleton
MBBS, PhD, FACRM, FAFRM (RACP)
Director, State Spinal Cord Injury Service,
NSW Agency for Clinical Innovation, Australia

Introduction

Pain has been described as the hidden epidemic. One in five people suffer from chronic pain and so clearly it has a wide impact on our community. Behind the numbers is something that is often harder to see, and that is the impact of pain on the individual. Chronic pain takes its toll on the body and it almost always affects the way a person thinks and feels. For some, the effect is so overwhelming that they even question whether life is worth living.

Among the one in five people in our community who experience chronic pain are people with spinal cord injuries. If you have had a spinal cord injury, unfortunately your chances of having chronic pain are even higher than in the general community. Studies from Australia and around the world have shown that around two out of every three people with a spinal cord injury are experiencing ongoing pain of some sort. In one third of these people, the pain is severe. Many people with a spinal cord injury rate dealing with pain as one of the most difficult consequences of their injury.

In the past, people with pain following spinal cord injury may have found they were sometimes treated with scepticism. Even many health professionals found it difficult to understand how someone who had a spinal cord injury and had lost sensation below the level of their injury could still experience pain in that area. Fortunately, we have moved on. In the past 30 years, we have seen a wealth of scientific research that helps us understand why people with spinal cord injuries experience pain. It is no longer the mystery it was 100 or even 50 years ago.

Although our understanding of pain following spinal cord injury has advanced enormously in the past few decades, it has been difficult to translate this new knowledge into effective treatments. There are some new treatments that can be helpful for many people, however a large proportion of people with a spinal cord injury have ongoing pain that is very difficult to relieve.

That does not mean there is no hope. There may not be a simple, single solution to treating pain following a spinal cord injury but there are a range of medications, techniques, skills and strategies that

are helpful. These range from the best new medications available, through to new technology and the use of skills such as exercise, distraction, relaxation and meditation. Used in isolation, they are rarely the complete answer. Together, though, they can provide an approach that can substantially reduce pain as well as deal with the many ways that pain impacts someone's life.

If you have a spinal cord injury and pain, *The Spinal Cord Injury Pain Book* is written for you. It provides the latest information about our understanding of what causes the pain. It also provides information about how pain works generally and what that means for how we can control it. The book also describes the different types of pain that occur following spinal cord injury and the most up to date information on the best treatments available. These treatments include a range of medications, procedures, skills and tools that are now known to be an important part of treating pain.

Read this book on your own and it will provide interesting and helpful information. However, you will almost certainly get the most benefit by going through it with your team of health professionals. They can help further explain the information, put in place treatments to relieve your pain as much as possible, and teach the skills and tools that are contained in the book. Links to helpful resources are provided after some chapters and in *Further reading* at the end of the book. As you go through the book, we suggest you write down the ideas you find helpful, any questions you may have and a plan of how you are going to put these things into place. They can then be discussed with your health professional when you see them next. To help you in these discussions, we have provided some information in 'information in the *Appendix* for health professionals' for health professionals about working with you.

We know from research and from experience that although there is often no easy answer to treating pain following spinal cord injury, the information and the skills contained in this book can be hugely beneficial for those living with pain. It is our hope that what you find in these pages will enable you to gain greater control over your pain.

The Spinal Cord Injury Pain Book follows on from *The Pain Book: Finding hope when it hurts* and utilises relevant general pain information from the first book combined with new material written especially for people living with spinal cord injury pain and the people that support them.

SAMPLE

Part one

The manual

SAMPLE



Chapter 1

Understanding pain

SAMPLE

‘The greater understanding we have of pain and how it works, the better equipped we are to manage it...’

The first step in treatment: knowledge

You may have heard it said that knowledge is power. In the case of dealing with pain, this is certainly true. The greater understanding we have of pain and how it works, the better equipped we are to manage it and the more sense of control we have over it. Time and time again, we see people who have had pain for many years but have little understanding of what it is or how it works. This adds to their sense of helplessness and frustration.

You may already have an understanding that pain can come directly from the damage to your spinal cord. But there are many things about the way that pain is experienced that are complex, not well explained, and often misunderstood. By getting to know your pain, you are giving yourself the best possible chance of reducing the pain as well as the distress and suffering it can cause in your life.

Remember, everyone’s pain is different. We will go into the various ways that pain can present following a spinal cord injury and enable you to identify and understand your particular pain. We will explore the latest information from scientific research that helps you understand what is happening in your body when you feel pain. We will look at the impact that pain can have on a person. We will also look at important and exciting new research that has increased our understanding of how we can use various tools to tap into our nervous system and control pain.

Some of this may be familiar—much of it will almost certainly be new. It is based on the latest information available on understanding and treating pain. What is exciting is that recent research has uncovered important clues that hold great promise for being able to treat pain. These chapters are much more than information—they are the first steps in treating your pain.

Acute pain

Pain is usually divided into two main types according to how long it is present: acute and chronic. Acute pain is pain that lasts for a short time and is usually associated with damage or disease that can be treated. For example, pain from a fractured arm, burns, surgery, kidney stones or giving birth are all examples of acute pain. Once the fracture or wound is healed or the kidney stone is passed or the baby is born, the pain usually goes away.

Most people who have a spinal cord injury experience pain in the first few weeks following their injury because of damage to bones, joints, muscles and the spinal cord itself. This is acute pain. Those who have undergone surgery will almost always experience acute postoperative pain in the early stages after the operation while their body is healing. This generally goes away in the weeks or months following surgery. Damage to the spinal cord and nerves can also cause pain very early after the injury. People can get sharp, shooting or burning pain in a band around their body or down the arms or legs.

‘Although completely conscious throughout the initial trauma, I was in shock and remember only a searing neck pain, difficulty in breathing and an unfamiliar motionlessness of my lower body. And desperately craving a cigarette... I had no idea I was paralysed until several weeks later. Before moving to the spinal unit I was in Intensive Care for 10 days in a fog of delirium and pain.’

Joan, complete quadriplegia

Chronic pain

For some people, these pains may settle down over the three to six months following their injury. In particular, the musculoskeletal pain associated with the initial injury and any surgery will tend to gradually settle. However, others may have ongoing pain which doesn't settle, or pain which starts months or even years following their injury.

Pain that continues beyond three to six months is regarded as chronic or persistent pain. In other words, pain that lasts for a long time. Chronic pain can be due to many conditions, such as arthritis, migraine and tendonitis. Chronic pain is also common after neurological injury, often referred to as nerve pain, where the spinal cord, peripheral nerves or brain are affected. Nerve pain can occur following spinal cord injury, traumatic brain injury or stroke, as well as with conditions such as multiple sclerosis, diabetes, shingles or trigeminal neuralgia.

The reason it is important to distinguish between acute and chronic pain is that the best ways of managing them are different.

The challenge of chronic pain

Of the two types of pain, chronic pain is usually more difficult to treat. Acute pain can be severe but it usually lessens as the tissue damage or injury heals. We also have fairly good ways of keeping it under control. On the other hand, it is often difficult to work out what is causing chronic pain, despite many investigations and visits to health professionals. Even if a cause can be found, often there are no treatments that provide good relief and treatments that do help may cause side effects that make life even more miserable. One of the most perplexing things about chronic pain is that it is rarely stable, and instead goes through periods when it is better or worse (known as a 'pain flare-up'). These challenges in treating chronic pain often leave people feeling frustrated, disappointed and hopeless—without the right support and advice.

Nociceptive pain

Health professionals also classify pain on the basis of where it comes from in the body. Nociceptive pain includes somatic pain that comes from the skin, muscles, bones, joints and ligaments. Muscle, bone and joint pain is the most common type of chronic pain in the community as a whole and is referred to as musculoskeletal pain. This type of pain can be dull and aching or localised and sharp. Musculoskeletal pain is usually made worse by movement and eased by rest. It often responds to treatments such as heat, physical therapies, anti-inflammatory medications, paracetamol and opioid medications such as morphine. Examples of musculoskeletal pain include arthritis pain, most types of low back and neck pain and tendonitis.

The second type of nociceptive pain is visceral pain which comes from the stomach and other organs in the abdomen. It includes pain such as appendicitis, kidney stones or a heart attack. Your level of spinal cord injury will often influence the way you experience visceral pain and it is usually dull and aching or cramping and difficult to localise. Visceral pain can also cause referred pain so that pain caused by a body organ is felt somewhere else. For example, people experiencing a heart attack may feel the pain going down their arm or into their jaw.

Neuropathic pain

As well as nociceptive pain, the other major type is called neuropathic pain. This type of pain occurs following damage to the nervous system in conditions such as diabetes, stroke or spinal cord injury. Sometimes it is referred to as nerve damage pain or nerve pain.

Another example of neuropathic pain is the pain that many people experience after an episode of shingles. Shingles is a condition that affects the nerves, where people get a rash, usually in a strip around the chest wall or another part of the body. Once the rash goes away, people can be left with numbness, tingling and severe shooting and burning pain. Again, this is due to the damaged nerves sending messages that cause pain.

Phantom pain is another type of neuropathic pain. This is the pain that people experience following amputation of an arm or leg.

It may feel as though the limb is still present and there may be sharp, shooting pains or a sensation of burning. Even though the limb is not there, this pain is very real and is due to the damaged nerves sending signals back to the brain and causing the sensation of pain.

Neuropathic pain is often described as shooting, electric or burning and people often have abnormal sensation in the area surrounding their pain. The skin can be extremely sensitive to touch so that even the wind or sheets touching the skin can cause severe pain. Other people feel as though the skin has a numb feeling 'like cardboard' or they have a feeling of ants crawling under the skin. Neuropathic pain is not usually helped much by anti-inflammatory medications or even strong painkillers like morphine. However, it may be helped by more specialised treatments that we will look at later.

Pain flare-ups

Chronic pain may be ongoing but it is rarely felt at the same intensity all the time. For most people, the pain will vary according to what they do, how they feel and other factors such as the time of day or the weather. Most people also experience 'pain flare-ups' which are periods when the pain is more severe. Pain flare-ups can occur for a variety of reasons, such as changes in activity, travel, lack of sleep, stress or changes in hormones. Sometimes it isn't possible to identify anything particular causing the increase in pain.

Pain flare-ups can last from a few hours to a few weeks. They can be a result of changes within the body, such as muscle spasm or inflammation, which increase pain temporarily but settle over time. For example, pain flare-ups may be from a predictable or known cause such as an increase or change in wheelchair use, posture or activities that cause an increase in pain. With rest from the activity or change in posture this pain settles down. Usually management of a flare-up doesn't require investigations or special treatments, and it is a question of working out a plan to get through it as quickly and easily as possible.

‘Just last Friday I was in a lot of pain—I tried to ignore it—it wouldn’t go away and was really getting me down royally! By the time my wife came home, I worked out that that it was not my normal pain and I was feeling sick and I realised that I was in trouble, so we called an ambulance and we found out I had a urinary tract infection (UTI) and a blocked catheter—I’m still on antibiotics tablets a week later.’

Tony, complete paraplegia

In people with spinal cord injury, however, an increase in neuropathic pain can also be due to other things going on in the body. It can be a signal that below the level of the spinal cord injury, there is a problem that your body detects even if you have impaired sensation in the area. For example, many people with a spinal cord injury notice that a urinary tract infection or constipation increases their neuropathic pain. It is important to be aware and recognise if an increase in neuropathic pain is signalling a problem somewhere else in the body and then treating it accordingly.

‘Pain increases with bladder problems for me—but it is a bit different to normal—I feel hot somehow. If I get a UTI or a blocked catheter, I get bladder spasm, increased pain, I feel hot and my blood pressure goes up.’

Caroline, incomplete quadriplegia

Sometimes, pain may appear in a new area or have a different quality. For example, someone with a spinal cord injury may start to experience a new pain in the area close to the level of their injury, and may even have some further loss of sensation or loss of strength. In this situation, where a pain is new or different, it should not be

treated like a flare-up. A new and different pain, especially if it occurs at the same time as a new loss of sensation or muscle strength, may signal a new problem such as a change in the spinal cord (a cyst or syrinx). It is important to investigate this properly and discuss your symptoms with your doctor.

If the pain is in the same area and has the same sort of qualities as your pain that has been there for a while, it can be regarded as a flare-up and does not necessarily signal a worsening problem. It usually just signals a change in your circumstances or what you have been doing. It can also be due to short term, reversible changes in the nervous system that temporarily amplify the messages coming from the area of pain. In these situations, it may not be possible to identify any particular factor that has caused the increase in pain.

Some other pain conditions

Many chronic pain conditions can't be labelled neatly as nociceptive or neuropathic. For example, many people with spinal cord injury have a mixture of nociceptive pain caused by problems in the muscles and joints as well as neuropathic pain caused by damage to nerve or the spinal cord.

People can also have more than one type of pain at the same time, both requiring different approaches to treatment. There are also several other types of pain that are more difficult to group into these categories and may affect some people with spinal cord injury. These include conditions such as irritable bowel syndrome, fibromyalgia and complex regional pain syndrome. With irritable bowel syndrome, people get a mix of symptoms such as pain, diarrhoea, constipation and bloating but investigations usually find little if anything wrong with the stomach or bowel. With fibromyalgia, people report widespread muscle pain, tenderness and stiffness. Again there is little to find in the muscles that would seem to explain the severe pain.

Complex regional pain syndrome typically affects a whole arm or leg. It can occur after even the most minor trauma but can also be associated with damage to the nerves or spinal cord and is present in some people with a spinal cord injury. People can have severe pain and the hand, foot or whole limb can change colour or temperature. Although the pain may be experienced in the limb, the pain is arising from damage to the nervous system rather than the limb itself.

Understanding Pain: Fact file

- Everyone's pain is different.
- Acute pain is different from chronic pain
- There are several major types of pain
- A damaged nervous system may cause pain
- The more we know about pain, the better we can manage it.