'Informative, practical and clear, it will have a transforming effect on those who live with chronic pain.'

Prof Bruce Robinson, Dean of Medicine, USYD



## Finding hope when it hurts

PHILIP SIDDALL REBECCA MCCABE ROBIN MURRAY

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# Praise for The pain book

This is a superb book. It is what you would expect from three highly regarded and expert professionals who have a huge amount of experience in this field. It is not surprising that they have come up with a book of this calibre. Informative, practical and clear, it will have a transforming effect on those who live with chronic pain.

**Professor Bruce Robinson**, AM MD MSc FRACP Dean of the Faculty of Medicine, University of Sydney

The Pain Book is an excellent guide to understanding the processes underlying the experience of pain and how it can be managed more effectively. Grounded in scientific research, it presents recent findings in a very accessible way. From conventional medical treatments to innovative psychological methods based on cognitive behaviour therapy and positive psychology, the strategies are explained in a very clear and practical way. I recommend this book to any person who is suffering from pain—you will never think about it in the same way again.

Dr Sarah Edelman, Clinical Psychologist and author, Change Your Thinking.

An outstanding book about living with the misery of chronic pain written by three remarkable people who are specialists in this particular field. The Pain Book is informative, interesting and offers hope and relief to its readers.

Anne Deveson AO, Writer and Broadcaster

The Pain Book can be your lifeline to recovery. It is so simply and beautifully written that it was easy to become immersed and not be conscious you are grappling with the complexity of the mechanisms of pain. Take heart and have hope that pain can become like your shadow—there, but following, not leading your life. The Pain Book will help you find the courage, stamina and skills to retrain the nervous system and get your life back on track.

Elizabeth Carrigan, CEO, Australian Pain Management Association Inc. (APMA)

At last a book that embodies a new relationship between health service providers and people in pain. While many books purport to provide answers for people living with chronic pain, rarely do you find one that has true healing power. The Pain Book not only provides practical pathways for taking control of pain, but also bravely and respectfully speaks of the deeper and transformative journey that many people in pain travel.

Coralie Wales, PhD, Founder and President Chronic Pain Australia

# the **JBC**

## Finding hope when it hurts



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## Dedication

Throughout this book, we hear from many people who tell their stories of pain. These are the voices of people we have seen in our own practice over many years. Thank you for graciously telling your story.

We dedicate this book to you.

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## Foreword

I don't think you need to have pain of any kind to get something from this book.

The reality is, though, most of us are in pain. It may not be physical, or at least may not manifest that way. Whatever your experience, this book outlines ideas and strategies that are extremely useful when it comes to just living your life.

I should probably mention that I tend to be a little slow on the uptake when it comes to working stuff out. For a long time my way of dealing with pain or discomfort of any kind was to block it by annihilating myself. I was often filled with self-pity if not anger or hopelessness (no wonder I was single). It took me a long time to realise that life was about balance and it took decades before I worked out how important physical activity was to my wellbeing.

For me this activity happened to be yoga and this slowly led me to understand just how important is the connection between mind, body and spirit. Ultimately, that led me to making a series for the ABC called *Judith Lucy's Spiritual Journey* (where I was lucky enough to meet one of the authors of this book, Rebecca McCabe). As part of the show, I went on a 10-day silent meditation retreat and that's where I discovered how much my mind was like Mickey Rourke's face; a disturbing, inexplicable mess that I really needed to befriend.

The difficult part of the retreat, certainly for me, was not the silence or even the lack of shiraz, it was the pain I experienced from sitting in essentially the same position for more than 10 hours a day. After a few days, three hour-long sittings of 'strong determination' 'This book offers a wonderful approach to pain management by suggesting we control what we can through knowledge and practical solutions.'

were introduced during which we were very much encouraged not to move a muscle. My lower back was my issue and initially I focused so much on my discomfort that I honestly thought that I was going to have to approach one of the staff and request some sort of medical attention lest I wind up in a wheel chair. I am not exaggerating here. I really thought that I was doing irreparable damage to myself and of course the more I dwelt on it, the worse it became.

However, towards the end of the retreat, I was amazed at how quickly those hours flew by and by how little pain I now seemed to be experiencing. Nothing had changed apart from my approach. I no longer dwelt on the pain, I accepted it and not only that, during those days I had moments where I felt incredibly grateful, sometimes for nothing more than the sound of the rain, and this also led to a feeling of connection to something greater than myself.

This book offers a wonderful approach to pain management by suggesting we control what we can through knowledge and practical solutions. What I particularly love is the way it then encourages us to find hope and courage in our lives through the things we cannot control; by fostering gratitude, acceptance and by trying to find some sort of meaning—whatever that might be.

Good advice for dealing with pain and just a great way to live your life.

#### Judith Lucy

# Introduction

#### Hope in the face of a hidden epidemic

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 many people, the impact of chronic pain is so deep and so strong that they lose hope that life will ever be the same again. For some, the effect is so overwhelming that they even question whether life is worth living.

In the face of such a problem, it is difficult to find hope. In the past few decades, some brilliant researchers have uncovered many of the mechanisms that underlie the experience of pain. As a result, new treatments are starting to flow through to the clinic and help many people with different types of pain. However, we still don't have the answer. For people with chronic pain, there is still no ready cure. What can we offer to the person who is living with chronic pain?

The answer lies in the pages of this book. The authors are all experts in the field. Philip Siddall is Professor in Pain Medicine at the University of Sydney with more than 30 years of clinical experience and international recognition for his research in this area. Rebecca McCabe is a physiotherapist with a special interest in chronic pain and many years experience in private practice and hospital pain management centres. Robin Murray is a clinical psychologist who also has practised and taught in the field of pain management for many years in both hospitals and private practice. Together, they bring a breadth of knowledge and experience that is hard to equal.

This book provides an up to date overview of the latest understanding of how pain works as well as a summary of what is currently available for the treatment of pain. Above all, it provides a simple but effective step-by-step approach to treating pain using the most recent findings in the field of pain management.

This approach is based on the latest research. More than theory, the skills and techniques described in this book form the basis of a successful pain program run by the authors at Greenwich Hospital which is a teaching hospital of the University of Sydney managed by independent Christian charity, HammondCare. Careful evaluation of outcomes from this program tells us that people who put this approach into practice show significant improvements in how they think, how they feel and what they can do. In addition, their pain is reduced.

So, if you have pain, there is hope. There is hope that life can be better than it is right now. A life that contains less fear and more joy. A life that includes relationships and activities that bring satisfaction and pleasure. And a life that is free from the demands and control of pain. It is possible to face pain and to find hope when it hurts.

# Part one Facing pain



# Understanding pain

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

#### Getting to know your pain

You may have heard it said that knowledge is power. In the case of dealing with pain, it 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.

Everyone's pain is different. We will explore the various ways that pain can present and enable you to identify and understand your pain. We will delve into the latest information from scientific research that helps you understand what is happening in your body. And we will look at the impact of pain on the person as well as the treatments that are currently available.

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

#### Two main types of pain

#### Acute and chronic

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.

**Chronic (persistent) pain** is pain that lasts for a long time. The definitions vary and the division can be a little artificial. However, in clinical practice, pain that lasts longer than three months is generally regarded as chronic. Chronic non-cancer pain can be due to many conditions, such as arthritis, migraine and tendonitis. It can also be due to nerve damage associated with conditions such as shingles, diabetes, trigeminal neuralgia and spinal cord injury.

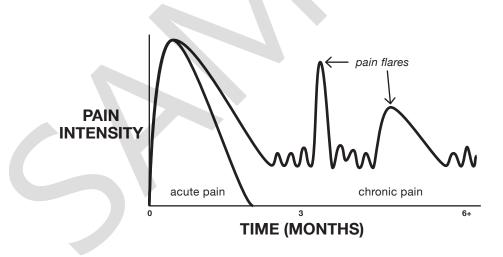
Chronic pain may be ongoing but it is rarely felt at the same intensity all the time. For most people, the pain will vary according to what they do, how they feel and other factors such as the time of day or the weather. Most people also experience 'pain flares'. These are periods when the pain is more severe. 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 won't be possible to identify anything particular that caused the increase in pain. Pain flare-ups can last from a few hours to a few weeks but do not necessarily signal a worsening problem. They can be a result of changes within the body, such as muscle spasm or inflammation, which increase pain temporarily but settle over time. But they can also be due to short term, reversible changes in the nervous system that temporarily amplify the messages coming from the area where you feel pain.

#### Chronic: the most challenging pain

Of the two types, 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.

## 'Pain flare-ups can last from a few hours to a few weeks but do not necessarily signal a worsening problem.'

Even if a cause can be found, often there are no treatments that provide good relief. Treatments that do help may cause side effects that make life even more miserable. Therefore, chronic pain can prove the most challenging type to treat and people are often left frustrated, disappointed and hopeless.



#### Cancer pain

Some people regard **cancer pain** as a specific type of pain but it can take many forms. Pain may occur from the spread of cancer into bones, pressure from a tumour on nerves or local pressure as a tumour expands. Although cancer pain is often feared, there are now many treatments that can keep it under reasonably good control.

#### The expert's perspective: Nociceptive and neuropathic pain

Health professionals also classify pain on the basis of where it is coming from and this generally falls into two major types. **Nociceptive pain** comes from two broad areas of the body. The first is **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 and referred to as **musculoskeletal pain**. It includes arthritis pain, most types of low back and neck pain and tendonitis. 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, anti-inflammatory medications, paracetamol and opioid medications such as morphine.

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. 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.

#### Phantoms, shingles and crawling ants

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 shingles, diabetes, spinal cord injury or stroke. Sometimes this type of pain is referred to as nerve damage pain.

A typical example is the phantom pain that people experience following loss of an arm or leg. After the arm or leg has been amputated, it may feel as though the limb is still there and, even worse, it is extremely painful. 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.

Another example 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

## 'The skin can be extremely sensitive to touch so that even the wind or sheets touching the skin can cause severe pain.'

be left with numbness, tingling and terrible shooting and burning pain. Again, this is due to the damaged nerves sending messages that cause 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 discuss later (see page 43).

#### Some other pain conditions

Many chronic pain conditions cannot be neatly labelled as nociceptive or neuropathic. For example, many people with low back pain have a mixture of nociceptive pain caused by problems in the muscles and joints as well as neuropathic pain caused by a bulging disc irritating or pressing on nerves going down the leg (sciatica).

1 These and the following numbers throughout the book refer to articles that describe findings from research. If you are interested, these articles are listed at the back of the book.

There are also several other types of pain that are more difficult to group into these categories. 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 people can have severe pain, weakness and the whole limb can change colour or temperature. Once again, although there is often a history of injury, the expected healing time is well past and there is little if any damage to find at the site of trauma.

#### If it's hurting, it's pain

Because it's difficult to find damage in these conditions, people are sometimes treated with scepticism and even labelled as neurotic. However, researchers have shown that the pain experienced may be due to an overactive or sensitised nervous system that amplifies messages coming from the site of pain.<sup>1</sup> Even though the messages coming from the bowel (in the case of irritable bowel syndrome) or the muscles (in the case of fibromyalgia) are not strong, the nervous system may be so sensitised that the messages are hugely amplified, resulting in ongoing pain. This means that the message is distorted or out of proportion to what is causing it, but is still very real.

Why the nervous system becomes so sensitised in some people is a matter that is being closely studied and we already have a few clues as to why this may be. What we have uncovered is that the way that we experience pain is due not only to what is happening in our bones, joints, muscles or organs but also the way that our nervous system registers and processes this information. This leads us into the next chapter where we will explore the fascinating insights that science has given us on how pain works and answer some of the questions about why we experience pain the way we do.

#### **Fact File**

- Everyone's pain is different.
- O Chronic pain is very different from acute pain
- A sensitised nervous system may amplify pain.
- The more we know about pain, the better we can manage it.