



‘The mastery and compassion of clinicians and leaders in the field leap from the pages of *The Cancer Pain Book*. This complex and daunting subject is dealt with kindness, expertise and empathy.’

Patricia Davidson RN PhD, Vice Chancellor, University of Wollongong,
Dean Emerita Johns Hopkins University School of Nursing

More than half of those with cancer will experience pain. Living through a cancer diagnosis and experiencing changes to physical health, relationships, and emotional and psychological wellbeing can make it difficult to face pain or the prospect of relieving it with any confidence or hope. However, there *is* hope.

The Cancer Pain Book guides you to understand your pain experience – the what, how and why of cancer pain – and the mind-body connection. With a focus on pain management through proven psychosocial interventions including exercise, relaxation, meditation and psychological tools, this guide can assist in building mental resilience, self-compassion and positive thinking.

Using these strategies, you can be hopeful about achieving better control of your cancer pain. Better control means more energy to enjoy the activities you love and time you spend with others. Whatever sort of cancer you have and wherever you are in your journey, this book will help to make one part of it easier.

The Cancer Pain Book is the third title in HammondCare’s Pain Series, following the highly acclaimed *The Pain Book* (2013) and *The Spinal Cord Injury Pain Book* (2014).



the cancer pain book



MELANIE LOVELL REBECCA MCCABE SKYE DONG PHILIP SIDDALL



The Pain Series

the cancer pain book

Move Relax Breathe Reflect **Live**

MELANIE LOVELL REBECCA MCCABE SKYE DONG PHILIP SIDDALL

Praise for *The Cancer Pain Book*

Pain is a daunting and feared experience for individuals and their families, particularly with a cancer diagnosis. The word ‘cancer’ can herald a time of ambiguity, uncertainty and fear. Having made this journey with some of my most loved family members I know that accurate, reliable and compassionate information is one of the anchors in a turbulent storm of emotions.

Having certainty – whether the news is welcome or not – is much better than navigating false hopes, misinformation and indecision. The mastery and compassion of clinicians and leaders in the field leap from the pages of *The Cancer Pain Book*. This complex and daunting subject is dealt with kindness, expertise and empathy.

Not only does it tell the why and how, importantly it tells people with cancer and their families what to do. This important text by Lovell and colleagues does not mince words, it tells the truth with compassion and hope for living our best life. Decades of experience, synthesis of evidence and a genuine commitment to decreasing suffering is the motivation for this text. Pain can be demystified, treated and managed.

For people with the need to reach for this book, I give you my very best wishes for strength at this challenging time. *The Cancer Pain Book* will be an invaluable resource as you navigate the time ahead. Please be reassured that your experience is a well-worn path and you have experts who will partner and support you. The voices of those who have made this journey before are in this text and their experiences honoured. I also commend the care of those professionals who are privileged to travel this path with you.

Peace and blessings,

Patricia Davidson RN PhD

Vice Chancellor, University of Wollongong
Dean Emerita Johns Hopkins University School of Nursing

I am very lucky to have been able to do two courses as part of Greenwich Hospital’s pain management program in Sydney. Being with other people who were in the same situation made me feel less alone with my pain from cancer, and during the courses I learnt many of the things covered in *The Cancer Pain Book*.

In my experience with chronic pain, I have been fearful about the future and how I would cope. Now, I focus on what I can do today to make my life better – things such as stretching, prayer and meditation, and making a gratitude list. I walk almost every day, even when I don’t feel like it – walking is essential. I have felt able to continue these things because of support from my partner, a few friends and health professionals who genuinely care about my wellbeing.

Pain is a common human experience, as are getting old and having cancer. My situation of having cancer and pain is not unique; it’s a shared reality that can be met with dignity, gratitude and a sense of humour.

The Cancer Pain Book would have been very valuable to me at the start of my journey. It discusses many topics that will be helpful to people with pain from cancer. I hope that it will assist many others to have a better quality of life, and to find some peace and happiness in the face of their illness.

Sincerely,

Todd Barlin

Todd is 59 years old and currently lives with blood cancer (Waldenström’s macroglobulinaemia).

Contents

6	Foreword	
8	Acknowledgements	
16	Introduction	
18	Note for practitioners	
20	Chapter 1: Cancer pain and our bodies	
22	Where pain can come from	
24	How pain starts	
25	How long pain lasts	
26	When chronic pain flares up	
26	When pain stays 'switched on'	
28	Chapter 2: Pathways, gates and the pain experience	
30	Pain is different for everyone	
30	The gate theory: a breakthrough!	
31	The gate and our experience of pain	
33	The power of neuroplasticity	
35	If you feel pain, it's real	
36	Chapter 3: Pain – the long and the short of it	
38	The changing experience of pain	
38	Cancer pain can heighten negative emotions and cause depression	
39	State of mind can worsen pain	
40	When cancer pain becomes a cycle	
42	Chapter 4: Talking about and treating pain	
44	Speaking clearly about cancer pain	
46	Many professionals are here to help	
47	How can health professionals help?	
52	Managing pain	
54	Chapter 5: Motivation, movement and being active	
56	Getting motivated	
56	Being active helps with cancer pain	
57	Being active can help protect against some cancers	
58	Stretching helps with strain and stiffness	
61	Strength = support	
69	Aerobic activity: a natural high	
70	Tai chi: meditation in motion	
78	Planning to be active	
80	Chapter 6: Learning to relax	
82	Cancer pain and the 'fight–flee–freeze' response	
83	Nurturing the nervous system	
83	Does relaxation really work for cancer pain?	
85	Which types of relaxation work best for cancer pain?	
86	Relaxation is different to relaxing	
87	Using the breath to relax	
92	Deeper relaxation	
96	Desensitisation to pain	
97	Relaxation as a part of life	
98	Chapter 7: Mindfulness and inner life	
100	Mindfulness: being in the moment	
100	Informal mindfulness	
102	Mindfulness or meditation?	
102	Mindfulness meditation deepens awareness	
103	Mindfulness meditation reduces fear about cancer pain	
105	Mindfulness meditations for pain and cancer	
110	Reflection after meditation	
110	Further mindfulness meditations	
110	Mindfulness tools during intense pain and emotions	
115	Learning to let go	

116 Chapter 8: Upstairs, downstairs: thinking about thinking

- 118 Living with uncertainties of cancer pain
- 118 The body's response to trauma and emotions
- 121 Responding to negative thoughts
- 124 Processing grief and loss
- 124 Life reflection: dealing with thoughts and feelings
- 126 Accepting what is
- 127 Cancer pain and gratitude: is that possible?
- 131 Accessing further support

132 Chapter 9: The good things in life

- 138 Afterword**
- 139 Endnotes**
- 144 Glossary**
- 149 Further resources**
- 152 About the authors**
- 156 Index**
- 163 The Cancer Pain App**
- 164 More from The Pain Series**

SAMPLE

Chapter 2

Pathways, gates and the pain experience

'I found that, watching a movie, laughing took my mind off the pain and all of a sudden I'd realise it was gone.'

MARK, 56



There are many things that aren't understood about pain. How is it that someone can have a serious injury or illness and not feel pain? These experiences can teach us many things about overcoming it.

Scientists have done a remarkable job of unravelling the mysteries of pain. Their findings have sparked new ways of thinking about and treating it.

KEY IDEAS

- Pain is different for everyone.
- Your nervous system is constantly changing.
- Pain is influenced by how you think and feel.
- Thought challenging is like an anti-inflammatory for your mind.

Pain is different for everyone

For most of history, people have regarded pain as a message that simply warns us about damage. Using this logic, we should all feel pain pretty much the same way. We should expect more pain from a broken leg than from a sprained ankle, and two people with a broken leg should both experience the same amount of pain.

This is far from true – pain is very different for everyone. It is true that what switches on the nerves is nearly the same for all of us. However, when messages reach the spinal cord, everything changes. By the time the brain gets hold of them, they will be even more different.

Most of us have observed or felt this ourselves. People playing sport can have severe injuries and not feel any pain. Soldiers in battle can have terrible wounds and yet not feel much pain. Some people with a minor injury experience severe pain. The gate theory helps us to understand why.

The gate theory: a breakthrough!

In 1965, Canadian psychologist Ronald Melzack and British neuroscientist Patrick Wall proposed something that had a huge impact on the way we understand pain.³

Their gate theory stated that pain messages coming into the spinal cord did not just go straight up to the brain. Instead, there is a kind of gate in the spinal cord that controls the messages. This gate acts like a volume control. It can be opened and the volume turned up so that we feel more pain. Or it can be closed and the volume turned down so that we feel less pain.

The gate in the spinal cord means that the amount of pain we feel isn't directly related to how much damage is present. If the gate is open and the volume turned up, the pain may be severe even when the damage is minor. If the gate is more closed, the pain may be minor even when the damage is major.

The brain helps to control the gate and the amount of information coming through. This is important because it means that, through our brains, we can control the amount of pain we experience.

What is the gate really like?

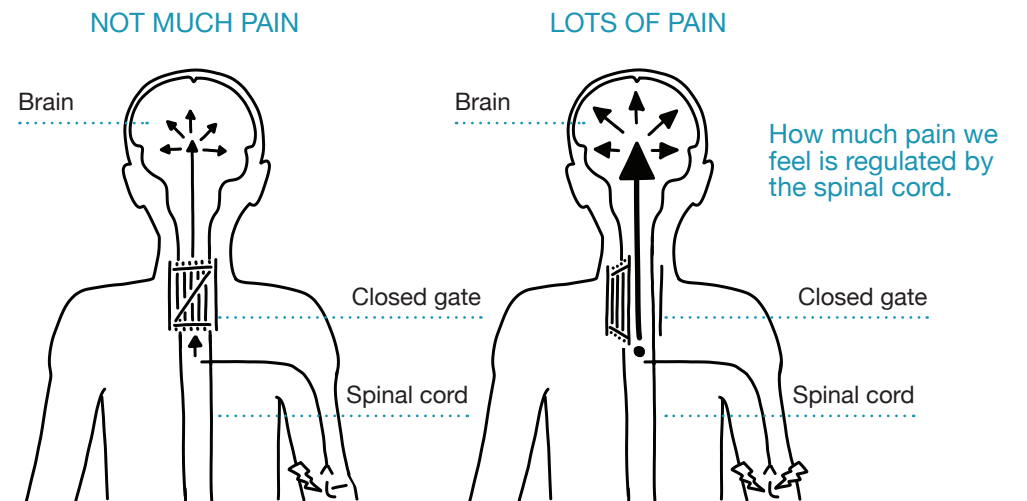
In reality, the gate is made up of very small nerve cells whose job it is to block or filter information coming from different parts of the body. These cells are throughout the spinal cord and in the thalamus, the relay station in the centre of the brain that receives messages from the spinal cord and sends them to different parts of the brain.

You can imagine how many messages are coming from every part of your body at any one time. To name just a few, there is information about your last meal, your skin temperature, your breathing, the tightness of your clothes and the fullness of your bladder. If you had to consciously process all of that information, your brain would go into overload!

The nerve cells in the spinal cord and brain avoid overload by helping to regulate the amount of information that goes to the brain. They constantly block and filter information, allowing the brain to focus on what it needs or wants to know about. If they are switched on, they reduce the amount of information and close the gate. If they are switched off, the gate is allowed to open.

The gate and our experience of pain

The setting of the gate in the spinal cord can vary from person to person, and from moment to moment. Some people have a gate that is wide open, so they experience more pain. This may be genetic, or previous experiences may have changed the settings of the gate, leaving it further open. The way that we think and feel also changes the settings. This can change very quickly with emotions, which increases or decreases pain.



Chapter 6

Learning to relax

‘Learning to breathe and release tension properly has changed the way I face cancer. You become better at monitoring your body. You just watch and things have sort of been – I like to call it sort of “stably, unstable”... I use my breath to manage my pain and monitor how I’m going day to day within myself. I guess it gives me a sense of control over it.’

TOM, 65

It is very difficult to relax when facing both pain and cancer.

When your body is in pain, the natural response of the muscles is to tense up. Coping with a real threat like cancer can add to muscle tension. Understandably, your body switches easily into a continuous stress mode as a natural form of protection.

KEY IDEAS

- The stress of cancer pain causes physical tension, which worsens pain.
- Relaxation reduces stress and helps relieve pain.
- Breathing techniques, muscle relaxation and guided imagery can help relieve pain.



Cancer pain and the ‘fight–flee–freeze’ response

The body’s stress mode – being ready to fight, flee or freeze – is controlled by the sympathetic nervous system. Stress hormones flood the body, heart rate and blood pressure rise, we breathe faster, our stomach and chest tighten, and digestion slows. Too much stress can overload the nervous system, making us want to withdraw and shut down. It can stop us from relaxing, or from falling or staying asleep – our minds are in overdrive, and we can’t ‘switch off’. When this pathway persists, it is very hard on the body and sets up a vicious cycle of muscle tension, anxiety and withdrawal from life.

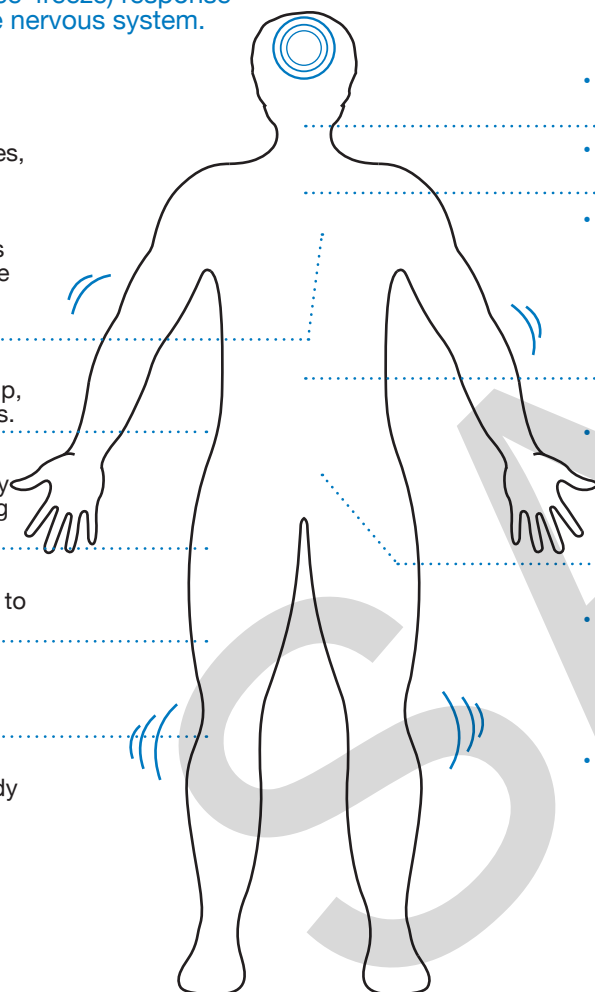


Being physically active helps improve sleep. Improved sleep further reduces anxiety and tension, improves mood and relieves pain. See chapter 5 to learn more.

The stress (fight–flee–freeze) response is controlled by the nervous system.

The brain becomes aware of danger as a result of messages received from the eyes, ears, etc. Hormones are released and the involuntary nervous system sends signals to various parts of the body, resulting in the following changes.

- Heartbeat speeds up, blood pressure rises.
- Blood clotting ability increases, preparing for possible injury.
- Sweating increases to help cool the body.
- Blood is diverted to the muscles.
- Muscles tense, ready for action.



- Mind becomes alert.
- Less saliva – dry mouth.
- Breathing rate speeds up, nostrils and air passages in lungs open wider to get in air more quickly.
- Liver releases sugar to provide quick energy.
- Sphincter muscles contract to close openings of bowel and bladder.
- Immune responses decrease, which is useful in the short term to allow massive response to immediate threat. This is harmful over a long period.

Nurturing the nervous system

It is important to have ways to deal with cancer, pain and stress that reduce muscle tension and counter the ‘fight–flee–freeze’ response. The body has a system that does just that: the parasympathetic nervous system or relaxation response. This response was named by Harvard Medical School physician Herbert Benson. In the 1960s, he pioneered what has become known as mind–body medicine – recognition that the state of the mind and emotions influences the health of the body.

Benson’s work showed that, during meditation and some other relaxation activities, physiological changes occur. The body uses less oxygen, breathing and heart rate become slower, and high lactate levels and blood pressure (often associated with stress and anxiety) are reduced.

Benson proposed that, in the same way the stress response is essential to survival, the relaxation response is an adaptation to survival – that one counteracts the effects of the other.

The good news is that we can nurture the nervous system by learning to relax. We can successfully release tension and quieten the body by harnessing this adaptive response. Learned relaxation, in whatever form it takes, is a vital initial step in managing cancer pain and the stress response.

Does relaxation really work for cancer pain?

Relaxation is a powerful way to counteract the effects of the fight–flee–freeze response, particularly in people with cancer. Medicines often don’t completely relieve cancer pain, despite over half of people diagnosed with cancer suffering from pain. Relaxation, mind–body techniques, meditation and mindfulness-based strategies (in combination with medication) all improve pain severity, pain-related distress, anxiety, stress, depression and quality of life in people living with a variety of cancers and pain.

Meditation in modern-day complementary health care has been used in ancient systems such as yoga for thousands of years. Yoga meditation practices have been found to be associated with pain relief – they have a painkiller effect by acting on the stress response regions of the brain.²²



For more about meditation, see chapter 7.

Chapter 7

Mindfulness and inner life

‘Cancer is humbling because it makes you realise how little you really control. I ran around like a self-important guard dog for years, yapping and jumping and fretting, thinking I really made things happen. Cancer plucks you out of that illusion and drops you in a deep and unknown space ... The only way out is to dive into your inner self and start some realignment. It teaches you that the only reality is the inner life, from which all outer manifestations arise.’²⁸

ANNA, 42



The ongoing uncertainty and lack of control over cancer pain aren't easy, even when we are healthy. A cancer diagnosis confronts us with our own mortality and the limitations of human control. It can highlight our vulnerability and fragility.

The process of adjusting to cancer pain hardly ever progresses in a straight line – we can cycle through many different ways of thinking, feeling and coping.

KEY IDEAS

- Mindfulness moves you from 'doing' mode to 'being' mode.
- Regular meditation helps with stress, anxiety, mood and quality of life.
- Mindfulness meditation can help you face cancer pain and soothe the mind's perception of pain.
- Self-compassion, self-kindness and gratitude are important partners of mindfulness.

Mindfulness: being in the moment

Although mindfulness draws on many concepts within Buddhism, the notion is embedded in traditions, cultures, religions and spiritual practices around the world.

What is mindfulness?

There are many ways of describing mindfulness.

Some leading mindfulness researchers have described it as ‘the awareness that emerges through paying attention in a particular way: on purpose, in the present moment, and non-judgementally to things as they are. It allows us to see clearly whatever is happening in our lives’.²⁹

This definition shows how it can be seen as a quality of mind, or a way of being. It could be described as simply being in the immediate experience of the present moment and relating to whatever arises with interest and openness. It has become a scientifically researched approach to learning how to pay attention as non-reactively as possible.

When experiencing cancer pain, you can be mindful of any aspects of your current experience: the quality of your breath as it changes across the day; body sensations that you may label as pain; states of mind such as difficult feelings or pleasant thoughts; what you see, smell, taste, touch or hear; and your behaviour or the effects you have on others.

Mindfulness to immediate experience is characterised by curiosity, openness, kindness, acceptance, non-judgement, non-striving, letting be, patience, gratitude, compassion and a ‘beginner’s mind’ – a way of looking at the world as if it is new or seen for the first time. We will look at some of these qualities in more detail later in the chapter.

Informal mindfulness

‘Doing’ versus ‘being’ modes of mind

When most of us go about our daily lives, our minds wander from the actual activity we are participating in to other thoughts, sensations or worries. This is especially common when faced with the chronic stressor of cancer pain, when there are so many demands on attention. You may go from one appointment to the next, without noticing your body or savouring the present moment. When you experience cancer pain, your thoughts can travel further into the stressful contents of the past or future, and how to solve problems. This is the ‘doing’ mode, or ‘monkey mind’.

When experiencing the worry, deep anxiety, or emotional distress that comes with cancer, it is helpful to embrace the present moment, choosing to do things in ‘being’ mode that help you feel more grounded and in control. Mindfulness can help you move from the common, overdoing monkey mind, and being on automatic pilot, to ‘being’ mode, where your attention is on the present moment as fully as possible.

‘Doing’ mode versus ‘being’ mode.

‘DOING’ MODE (automatic pilot)

- Not noticing what you are doing
- Focuses on past or future
- Absorbed in stressful thoughts and ideas (thinking about where you wish you were, not where you are right now; nothing feels satisfactory)
- Believe thoughts are true (cannot observe the mind’s workings; mood is controlled by thoughts)
- Reactive, harsh (tries to avoid unpleasant experiences)



‘BEING’ MODE

- Paying attention to the moment
- Living in the now
- Absorbed in current experience (able to fully taste, smell, touch, feel; able to fully connect with others; radical acceptance)
- Freedom from believing the thoughts (understands the transient nature of thoughts; observes mental events as they come and go; tolerates unpleasantness)
- Self-aware, curious, kind (approaches all experience with interest)



Taking a break from the frenetic pace of life means you can embrace the slow, ‘be’ with time and surrender into the present moment that is in front of you. This might include the natural beauty of clouds or the ocean, the perfume and colour of a rose or the warmth of a loving embrace. Perhaps you will choose to focus on deeper and more meaningful relationships. This is an opportunity to discover an inner landscape; be curious to your experience and see what emerges.

Benefits of informal mindfulness

How can being mindful of daily experience be helpful, especially when faced with cancer pain? Having a mindful stance to living can’t take away all of life’s stressors, but it can help you respond to them in a way that is kinder and more compassionate to yourself and others.

Informal ways of being mindful throughout the day can have a powerful effect on self-soothing pain responses. These are pauses that can help you notice when pain is flaring up. Engaging in activities that require