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OVERCOMING CHRONIC PAIN

*A self-help manual using
Cognitive Behavioral Techniques*

FRANCES COLE,
HELEN MACDONALD,
CATHERINE CARUS and
HAZEL HOWDEN-LEACH

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Frances Cole
Helen Macdonald
Catherine Carus
January 2005

Foreword

People usually try to avoid pain. Sufferers of chronic pain cannot avoid their pain. Fortunately, *Overcoming Chronic Pain* teaches skills that turn pain sufferers into pain managers. By tuning into pain rather than trying to avoid it, sufferers learn to understand personal pain patterns. Understanding pain is the first step towards pain relief. This welcome relief comes about when readers learn a variety of pain management skills taught here in simple, straightforward steps.

This book combines the collective knowledge and wisdom of three pain specialists – Frances Cole (a GP who is also a Cognitive Behavioral Psychotherapist), Helen Macdonald (a Cognitive Behavioral Psychotherapist and mental health nurse) and Catherine Carus (a Physiotherapist) – working as a team with a Learning Technology Adviser, Hazel Howden-Leach. Drawing on feedback from hundreds of pain patients, the authors show readers how to chart a personalized pain model and choose skills to help manage the worst aspects of pain. Over time, readers who practise these skills can become more relaxed, physically fitter, and develop better problem-solving strategies. In addition, chapters teach how to reduce depression, anxiety, anger and the sleep difficulties that often accompany pain.

The biggest challenge to readers of self-help books is to practise the skills taught. No matter how helpful, any book that sits on a shelf offers little benefit. For this reason, chapters in this book are brief. Even a 10-minute read can lead to helpful

knowledge. Most of the exercises taught can be learned quickly and practised in 10- or 15-minute segments. Readers can pace themselves and use this book in whatever timeframe fits each day's planning.

Chronic pain sufferers are often unaware of the progress in pain management achieved over the past few decades. Even some healthcare providers will not be aware of all the information in this book. *Overcoming Chronic Pain* gives an overview of the most up-to-date techniques. It emphasizes ideas and skills that have been validated by research and successfully used by many pain sufferers.

For example, mood management chapters draw on ideas from Cognitive Behavioral Therapy, a form of psychotherapy that research shows is highly effective for depression and anxiety. The chapter on sleep teaches the research-based practice of 'good sleep hygiene'. The chapter on 'Getting Fitter and Being More Active' combines fitness principles with research on pain. So readers of *Overcoming Chronic Pain* can feel secure that the ideas contained within this book are not simply the opinions of these authors. They are summaries of the best information and practice currently available to understand and manage chronic pain.

Chronic pain can affect every aspect of one's life. No single skill is likely to be sufficient to manage this type of pain. The good news is that groups of skills are highly effective in managing chronic pain. This book teaches you how to choose and learn the skills that are best to cope with life with your pain. As you develop your skills, you can measure your progress, and see positive changes in your confidence, and your daily and social activities. At first, the changes achieved may seem small. But those who stick with a programme can move mountains of distress due to pain. I join the authors in wishing you every success in building your own effective pain management programme.

Christine A. Padesky, Ph.D.

Co-author, *Mind Over Mood: Change How You Feel
by Changing the Way You Think*

Introduction

by Peter Cooper

Why cognitive behavioral?

You may have picked up this book uncertain as to why a psychological therapy such as cognitive behavioral and systemic therapy could help you overcome your chronic pain. The first of the two components, cognitive behavior therapy (CBT) was developed initially for the treatment of depression, and the techniques this therapy uses have been found to be extremely effective for a wide range of problems, including compulsive gambling and drug and alcohol addiction. So what is CBT and how does it work?

In the 1950s and 1960s a set of techniques was developed, collectively termed 'behavior therapy'. These techniques shared two basic features. First, they aimed to remove symptoms (such as anxiety) by dealing with those symptoms themselves, rather than their deep-seated underlying historical causes (traditionally the focus of psychoanalysis, the approach developed by Sigmund Freud and his followers). Second, they were techniques loosely related to what laboratory psychologists were finding out about the mechanisms of learning, which could potentially be put to the test, or had already been proven to be of practical value to sufferers. The area where these techniques proved to be of most value was in the treatment of anxiety

disorders, especially specific phobias (such as fear of animals or heights) and agoraphobia, both notoriously difficult to treat using conventional psychotherapies.

After an initial flush of enthusiasm, discontent with behavior therapy grew. There were a number of reasons for this, an important one of which was the fact that behavior therapy did not deal with the internal thoughts which were so obviously central to the distress that patients were experiencing. In particular, behavior therapy proved inadequate when it came to the treatment of depression. In the late 1960s and early 1970s a treatment was developed for depression called 'cognitive therapy'. The pioneer in this enterprise was an American psychiatrist, Professor Aaron T. Beck, who developed a theory of depression which emphasized the importance of people's depressed styles of thinking. He also specified a new form of therapy. It would not be an exaggeration to say that Beck's work has changed the nature of psychotherapy, not just for depression but for a range of psychological problems.

The techniques introduced by Beck have been merged with the techniques developed earlier by the behavior therapists to produce a therapeutic approach which has come to be known as 'cognitive behavioral therapy'. This therapy has been subjected to the strictest scientific testing and it has been found to be a highly successful treatment for a significant proportion of cases of depression. It has now become clear that specific patterns of thinking identified by Beck are associated with a wide range of psychological problems and that the treatments which deal with these styles of thinking are highly effective. So, effective cognitive behavioral treatments have been developed for anxiety disorders, like panic disorder, generalized anxiety disorder, specific phobias and social phobia, obsessive compulsive disorders, and hypochondriasis (health anxiety), as well as for other conditions such as compulsive gambling, alcohol and drug addiction, and eating disorders like bulimia nervosa and binge-eating disorder. Indeed, cognitive behavioral techniques

have a wide application beyond the narrow categories of psychological disorders: they have been applied effectively, for example, to helping people with low self-esteem, those with marital difficulties or weight problems, those who wish to give up smoking, and, as in this book, those living with chronic pain.

The starting-point for CBT is that the way we think, feel and behave are all intimately linked, and changing the way we think about ourselves, our experiences and the world around us changes the way we feel and what we are able to do. So, by helping a depressed person identify and challenge their automatic depressive thoughts, a route out of the cycle of depressive thoughts and feelings can be found. Similarly, habitual responses are driven by a nexus of thoughts, feelings and behavior; and CBT, as you will discover from this book, by providing a means for the behavior to be brought under cognitive control, enables these responses to be undermined and a different kind of life to be possible.

Although effective CBT treatments have been developed for a wide range of problems, they are not widely available, and when people try to help themselves they often make matters worse. In recent years the community of cognitive behavioral therapists has responded to this situation. What they have done is to take the principles and techniques of specific cognitive behavioral therapies for particular problems and present them in self-help manuals. These manuals specify a systematic programme of treatment which the individual sufferer is advised to work through to overcome their difficulties. In this way, cognitive behavioral therapeutic techniques of proven value are being made available on the widest possible basis.

Self-help manuals are never going to replace therapists. Many people will need individual treatment from a qualified therapist. It is also the case that, despite the widespread success of cognitive behavioral therapy, some people will not respond to it and will need one of the other treatments available. Nevertheless, although research on the use of these self-help manuals is

at an early stage, the work done to date indicates that for a great many people such a manual will prove sufficient for them to overcome their problems without professional help.

Many people suffer silently and secretly for years. Sometimes appropriate help is not forthcoming despite their efforts to find it. Sometimes they feel too ashamed or guilty to reveal their problems to anyone. For many of these people the cognitive behavioral self-help manual will provide a lifeline to recovery and a better future.

Professor Peter Cooper
The University of Reading, 2005

Introduction

This book is designed to help you manage long-term or chronic pain more confidently. Many people have chronic pain for many different reasons. For example:

- following an injury to bones, joints and other tissues that have healed
- after an operation
- in conditions like diabetes
- in nerve disorders like trigeminal neuralgia or peripheral neuropathy
- after a viral infection like shingles
- in different arthritis conditions like osteoarthritis or rheumatoid arthritis

It may have started gradually, like back pain or fibromyalgia, or suddenly with no clear cause. There are usually several reasons for chronic pain, rather than one specific reason.

Chronic pain has an impact on all areas of a person's life and on the people around them. This book aims to help you understand pain and its effects on your body and also looks at medical investigations and drug treatments. It covers ways of managing your activity levels, solving everyday problems, overcoming mood changes and unhelpful thinking patterns, coping with poor sleep and using relaxation techniques.

Who might benefit from using this book?

People who:

- are learning to cope with a chronic pain problem and want to be more confident about managing their lives better.
- would like to be as fit and active as possible even though they have pain.
- would like help while investigations and treatments for pain are waiting to be done or have been done.
- have found out that no more new medical treatments are likely to help.
- have a stable dose of medicines they use (if any).
- would be willing to use self-help written materials either by themselves or with support.

What does chronic pain mean?

Chronic pain problems are very common. About 10 per cent of adults in the UK are affected by pain in different parts of the body at any one time. If you have chronic pain, you will have found out that it is more than a very distressing sensation in the body. The pain can affect all aspects of you as a person and your life situation, including your feelings, your thinking, your activities, your working life, your home life, your relationships and your hobbies.

Pain is usually defined as 'an unpleasant sensory and emotional experience which is due to actual or potential tissue damage or which is expressed in terms of such damage'. Chronic pain usually means pain that has lasted for at least three months. Sometimes different words are used by

healthcare professionals, such as ‘long-term’, ‘persistent’ or ‘long-lasting’ pain. Sometimes pain lasting six months or more is defined as chronic pain. It can be confusing, as these terms are all used to mean the same thing. The definition used in this book is pain that has lasted three months or more. Sometimes in chronic pain the nerves carrying the pain messages may have developed a ‘memory’ for pain that is difficult to change. This is a bit like an annoying tune that you find yourself humming all day. Sometimes the reasons for the pain are not discovered even when many tests or scans are done.

For some people, chronic pain means slight restrictions on lifestyle. For others, there may be a severe loss of independence and confidence. Pain can become long-term in spite of efforts to relieve the pain itself, or its causes if known.

People with pain problems often worry about what it means for them, their lifestyle and their future. Being limited by the effects of pain can be difficult and frustrating, especially if no ‘cure’ is possible. This can in turn lead to anxiety or worry and depression for some people.

What is Cognitive Behavioral Therapy?

Cognitive Behavioral Therapy (often called CBT) is a talking therapy. Talking with a trained CBT therapist helps to identify and understand what the problems are at present. This approach enables you to understand the links between body symptoms, thoughts, feelings and behavior, and how this affects your everyday life.

‘Cognitive’ means ‘to do with thinking and beliefs’; ‘behavioral’ is about what we do or do not do, our behaviors or actions.

CBT was developed by Professor Aaron Beck in the 1970s, based on previous research which showed that changing the

environment and using rewards could help people to function more successfully. This was the basis for behavioral therapies. Professor Beck demonstrated that CBT could be a successful treatment for a number of problems, including anxiety and depression. CBT is also useful for managing widespread chronic pain, chronic fatigue syndrome, sleeping problems, worry and panic attacks, anger and frustration, severe angina and other health problems and relationship difficulties.

Research and clinical experience with CBT has shown that it can help people with chronic pain manage their lives better. CBT is a practical approach to learning how to make changes in the problems caused by the impact of chronic pain.

How can a book help?

You may have tried many different approaches to managing your pain and you may have lots of ideas about how to deal with the impact it has on your life. Alternatively, you may feel completely overwhelmed and 'stuck'. Or you may just think that a few suggestions would help. Whatever your situation at present, this book aims to give you the tools you need to manage your chronic pain better. Many people are told that there is no 'relief or cure' for the pain and they will have to 'learn to live with it'. But this can be hard if you don't have the information and skills you need.

The chapters in this book suggest ways of overcoming low mood, and a sense of loss and frustration. They help increase skills to lessen worry and anxiety, deal with unhelpful thoughts and beliefs about chronic pain. They offer ways to talk and share issues with those close to you.

Practical problem-solving can help to increase your quality of life. For example, you can find ways of getting necessary things done, and doing enjoyable activities. You can set goals

and plan ways of achieving them step by step. You can also learn pacing skills to balance activity and rest. These skills will help you to gradually boost what you do, enabling you to increase your fitness without overdoing it and causing a setback.

New skills can be learned to reduce the impact of the pain. This is how a book like this can be helpful. Your pleasure and self-confidence can increase and your frustration and worry can be reduced.

A Cognitive Behavioral Therapist, a General Practitioner and a Physiotherapist have written this book jointly, with support and ideas from many confident people with chronic pain. In chronic pain services, different health professionals often work together as a team to enable people to become skilled at managing pain.

How can I get the most out of using this book?

Your pain is very personal to you. Only you know how it feels and how it affects your life. So you can use this book in the way that seems most helpful to you and your personal situation. For instance:

- The book contains a lot of questions to help you think through and apply the ideas to your own situation. If you keep a notebook close at hand, to jot down your answers, you will have a written record of your progress.
- You can read through the whole book quickly and pick up some useful tips, or you can work through more slowly – at whatever pace is best for you. When you have setbacks or flare-ups it may be helpful to work through some chapters again, learning more new tips or techniques to put into practice.

- You will probably get the most out of the book by working through a maximum of one chapter per week. Set time aside every day to work on your pain management – 20 to 30 minutes would be about right. Finding time and energy to do this can be a challenge. But it is time well spent on managing your pain better in the long term.
- You might want to work on some chapters with a friend, partner or healthcare professional. Having someone to encourage you and support you can really help but is not essential.
- Use the books, tapes, websites and organizations listed under Useful Information at the end of the book to find further specific information for your needs.

What do the chapters cover?

Part One of this book is called ‘What is Chronic Pain?’ and includes Chapters 1 to 5. These chapters will help you understand the impact of pain, and explain how chronic pain differs from acute pain. They also look at the roles of healthcare professionals, investigations, medicines and treatments in managing pain.

Part Two, called ‘Overcoming Chronic Pain’, includes Chapters 6 to 17. These practical, self-help chapters give you new approaches to think about, as well as opportunities to practise new ways of living with pain. They will help you ‘learn to live with it’ with more confidence.

CHAPTER 1: UNDERSTANDING THE IMPACT OF PAIN AND MAKING CHANGES

This chapter is an important introduction to the rest of the book. Understanding in more detail how chronic pain

impacts on all areas of your life will help you to make the best use of the other chapters and apply them to your own situation.

CHAPTER 2: UNDERSTANDING CHRONIC PAIN AND PAIN SYSTEMS

This chapter explains what we currently understand about pain and how pain systems in the body work. Many people with chronic pain find that they can use this information to become their own 'experts' in handling their pain and its impact better.

CHAPTER 3: UNDERSTANDING INVESTIGATIONS FOR PAIN

It is likely that you will have had investigations for your pain. These might have included blood tests or x-rays or more complicated tests. This chapter explains the most common investigations and how they help healthcare professionals and the person with long-term pain.

CHAPTER 4: UNDERSTANDING THE ROLES OF HEALTHCARE PROFESSIONALS

This chapter explains the roles of healthcare professionals for people with chronic pain. This will help you access the services you need from the services available to you locally.

CHAPTER 5: UNDERSTANDING MEDICINES AND USING THEM BETTER

This chapter helps you to understand which medicines are useful for pain. It looks at how to make the best use of medicines. It also offers suggestions if you choose to stop or reduce them safely.

8 OVERCOMING CHRONIC PAIN

CHAPTER 6: SETTING GOALS

This chapter helps you set and achieve goals in different areas of your life.

CHAPTER 7: GIVING YOURSELF REWARDS

This chapter helps you understand how to use rewards for progress and efforts.

CHAPTER 8: UNDERSTANDING PACING SKILLS

This chapter explains how to plan and pace your activities every day. These are key skills to learn.

CHAPTER 9: GETTING FITTER AND BEING MORE ACTIVE

This chapter explains the importance of getting more active and how to become gradually fitter. This helps improve stamina and strength along with flexibility, so that pain limits your activities less.

CHAPTER 10: UNDERSTANDING PROBLEM-SOLVING

This chapter offers practical ways to look at and solve day-to-day difficulties.

CHAPTER 11: UNDERSTANDING SLEEP AND SLEEP PROBLEMS

This chapter looks at the kinds of sleeping difficulties people can face. It offers practical advice and ideas to help improve sleep patterns in spite of pain.

CHAPTER 12: RELAXATION

Relaxation is an important skill for people who have pain. This chapter covers how relaxation can help, and how to learn to relax.

CHAPTER 13: PAIN, COMMUNICATION AND RELATIONSHIPS

This chapter looks at the ways in which pain can affect relationships. It gives suggestions for dealing with these difficulties, including sexual problems due to pain.

CHAPTER 14: MANAGING DEPRESSION, ANXIETY AND ANGER

This chapter offers ways to try to lessen depression, anxiety and anger, as well as ways of understanding and dealing with unhelpful thinking patterns.

CHAPTER 15: ACCEPTANCE

Many people with long-term pain find that there are challenges in coming to terms with what has happened. This chapter offers some ideas that can be used in adjusting to changes in health and life circumstances.

CHAPTER 16: MAINTAINING PROGRESS AND MANAGING SETBACKS

This chapter helps build further confidence in the skills you have already learnt, to cope with pain better and deal with setbacks.

CHAPTER 17: LOOKING TO THE FUTURE AND MANAGING WORK

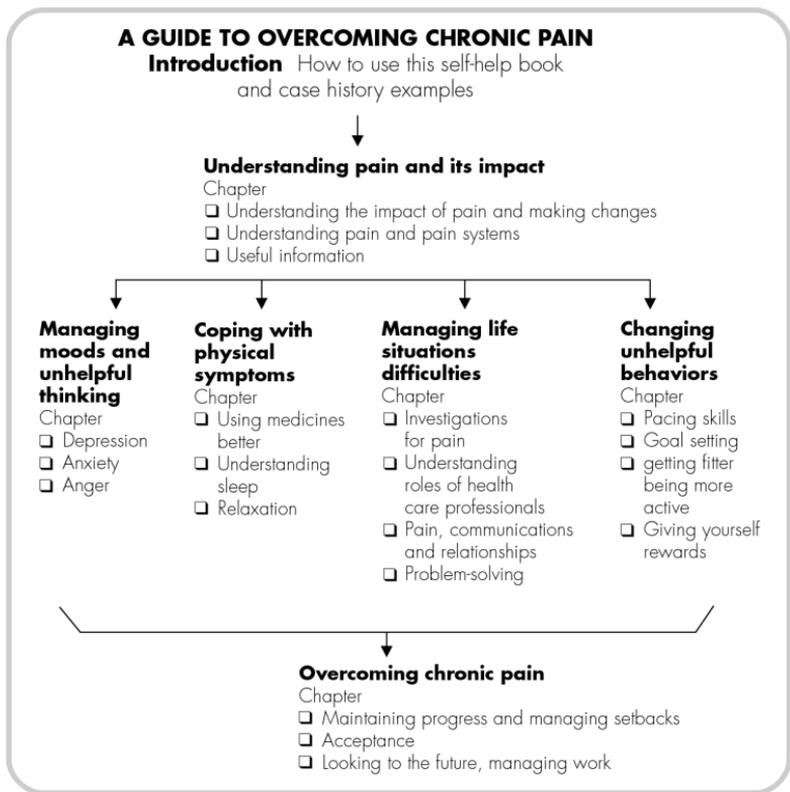
This chapter looks at beginning new roles or new ways of life, for example returning to work, starting a new job or retraining. It also shows you how to gather evidence of your success at managing life, despite the pain, to build up your confidence.

USEFUL INFORMATION

This section offers a range of sources of further help: books, tapes, websites, self-help groups and professional organizations.

How do I start using this book?

Following this Introduction, there is a Guide to Overcoming Chronic Pain, which explains the role of all the chapters in the book. After the Guide, there are four Case Histories, showing how pain has affected four people's lives in different ways. The people in these case histories are mentioned in many of the chapters – for example, Razia learning pacing skills in Chapter 8 and Jim trying to deal with his worries in Chapter 14 on anxiety.



- You may find it helpful to start by reading the first two chapters, which are aimed at everyone with chronic pain. Chapter 1 will give an opportunity to set your own targets for change. Then Chapter 2 will give you the background knowledge you need, explaining more about acute and chronic pain.
- After that, you can choose the most relevant chapters for your own needs or targets for change, using the Guide to Overcoming Chronic Pain (see p. 10) to guide you. You can use this guide to help you work through the book, ticking off the chapters as you read them.
- Alternatively, you could start by reading the case histories and trying to find an example that seems to relate to your difficulties and needs. Later you can track how these individuals make changes in the different chapters and experiment with the new skills they learn.

Four case histories

Here are some case history examples to show how chronic pain affects people and their lives in different ways. You can follow these people and their progress in learning to cope and become confident with their pain in the different chapters within the book. You will also see how they try out new skills to help reduce the impact of pain on their lives.

Maria

I am useless, I cannot do anything anymore

Maria, aged 47, was a school meals service cook. She has had a pain problem for three years since a fall at work. She lives

alone now. She used to be married but was physically abused by her ex-husband and divorced him 20 years ago while her children were young. All her four children live nearby. She has seen several hospital specialists and her GP. She has been told that she has a bulging disc, osteoporosis and spondylosis. She does not really know what is wrong or what these labels or diseases mean. She is frightened that her spine may wear out. She is concerned that she will have more pain and end up bed-ridden like her mother.

Pain sites: Maria has had pain in her neck, left shoulder and arm since her fall.

Pacing of activities: On bad pain days, Maria often spends most of the day in a chair or in bed. On better days, she tries to get everything done that she has had to put off for so long. She finds the next day she is very tired and the pain can be severe.

Mood changes: Maria realizes she has changed. She used to be a bright, cheerful, amiable person, who loved her job and would help others out. Now she often cannot be bothered to tidy the house, cook meals for herself, or look after the garden. She can be very tearful, moans out loud a lot and gets very angry, even violent at times with herself or with other people.

She blames herself for rushing at work, so causing the fall in the first place.

Relationships: The family are at a loss, as Maria is often grumpy. She often shouts at them when things are left lying around the house after their visits. Maria realizes how it affects them and is frightened that they will stop visiting her. She says, 'It is the pain, it has so changed my life, I hate it.' She misses her work colleagues. She would love to get back to work but does not know how, or what she can do to help herself.

Razia

I can't get to do things; the pain spoils every day

Razia is 28 years old, with two young sons aged five and seven. She is married to Hassian, who is a postal worker. He leaves for work early in the morning, sometimes six days a week. This means leaving Razia to get the children up and take them to the nearby school. Razia's elderly parents live next-door. They both have difficulty walking because of arthritis in their knees and back.

Pain sites: Razia has chronic widespread pain mainly in the neck, both shoulders and lower back. The pain moves around her body and some days she has severe headaches. Razia finds that each day is different, as she does not know where the pain will be the next day. 'I can't plan anything,' she says.

Physical function: In the morning, Razia's stiffness can be very severe. Razia finds that some of her daily routines make this stiffness much worse, e.g. bathing her youngest child. Razia has difficulty managing her pain, especially when her pain levels are high. This means that her physical functioning is limited. She says, 'I rest until the pain settles which could be a couple of days. This means I get so little done in the house.'

Pacing of activities: Razia finds her pain and stiffness very unpredictable and says that it is hard for her to plan and pace her days. Razia tends to rest as much as possible to save her energy and lessen her pain levels. She does this so that when her husband and children come home she can 'see to them'.

Sleep problems: Razia complains that she has difficulty dropping off to sleep because she can't get comfortable. She sleeps about six hours a night but wakes up feeling tired most mornings: 'I'm as tired as when I went to bed last night.' Razia says she feels 'tired all of the time'. She often

has a couple of short sleep breaks during the day but still finds she has little energy and is very irritable with the children, which upsets her a lot.

Medication: Razia has been given Amitriptyline, 10 mg daily. This helps her sleep better but she doesn't like the drowsy feeling the next day. She only takes the medication if her husband is having a day off work, so that he can look after the children.

Relationships: Razia relies heavily on her husband and children to help her out. When her husband is at work, she says, 'My children have to put my shoes on for me.' Hassian, her husband, can't understand what is wrong and is beginning to ask why things aren't done when he gets home. There is a family wedding in two months' time and Razia's mother sometimes expects her to do things to help her out. This is an added stress, especially when Razia has a bad pain day. Razia finds it difficult to refuse her mother's requests.

Mood changes: Razia was very low after the birth of her second child. She is beginning to have the same depressed feelings again. She worries about the pain and what it might mean for her and her family in the future. She is frustrated that 'I can't do the same things that I used to, like cooking and swimming.'

Previous treatment: Razia was seeing a physiotherapist who gave her some stretches to loosen her muscles. She stopped going after two sessions, as the physiotherapist 'wasn't helping my pain at all'.

Jim

Why won't the pain leave me?

Jim has severe pain around the left side of his chest and abdomen after an attack of shingles (herpes zoster) five years ago. He is married to Ann, and they have had a close

relationship over their thirty years of marriage. Jim is 59 and his pain problem has made him tired and worried. It made sense to both Ann and Jim for him to retire from his job as a secondary school teacher over two years ago. It had been a difficult time, with many stresses in his life over the last three years. These included his long-term pain after his shingles, his early retirement, Ann's heart condition and the death of his elderly parents. Since his retirement, Jim has taken on many household tasks to fill his day. This has also helped Ann because some days she is short of breath because of her heart problems.

Pain sites: Jim finds the stinging pain around the left side of his abdomen and his left shoulder blade area unbearable at times. His skin is extremely sensitive and irritable, and his clothes feel very uncomfortable on his skin. He is frightened of anyone coming close to him on the left side in case they touch him. He sometimes moves out of the way when people come towards him on his left-hand side.

Pacing: Jim tries to do everything himself. He shops every day for food and he cooks most of the meals. He does all the vacuuming, washing and ironing and most of the other housework. Ann and Jim have a large garden. Jim usually spends the rest of his time weeding, planting out and mowing the lawn. He thinks that this is only fair as he is not working any more and Ann is sometimes quite unwell. He likes to feel useful and that he has achieved something every day. He says, 'It helps to keep busy, as it takes my mind off the pain.'

Sleep problems: Jim is tired when he goes to bed. He has difficulty getting off to sleep as he thinks over recent events and worries about what the future holds. He would like to sleep in. However Ann often gets up very early, around 6 a.m. and Jim thinks he should start his day at that time too. He is quite groggy in the morning but he tries to be bright

and cheerful for Ann. He is not sure how she would cope if he seemed depressed. Jim notices that when he is tired, his pain seems worse.

Medication: Jim no longer wants to take his medication because ‘it doesn’t work and he wants to feel in control’. He is worried that if he does take tablets he will ‘become addicted’. He saw his mother become dependent on tranquilizers and he’s ‘not going to become like her’.

Relationships: Jim feels irritable and stressed because of the high standards that he sets himself. He is worried about the future, especially at times when the pain is severe. He doesn’t know if he can continue at this pace for much longer. He doesn’t want to let Ann know his worries: ‘She has enough problems without worrying about me.’ His skin is so sensitive that he is often frightened of being hugged by his grandchildren or by Ann. This upsets Ann as it makes her feel less close to Jim, just when she feels worried because of her illness.

Mood changes: Jim is aware that he is having difficulty relaxing and it has been getting worse recently. He used to enjoy walking and reading. But he can’t seem to find the time now, especially as Ann’s health recently had a setback. He is worried that if the pain gets worse he won’t be able to manage: ‘What will happen to us then?’

Previous treatment: Jim has been to the pain clinic and had medication and acupuncture. He is not sure why the treatments haven’t worked and why the nerve pain does not settle down.

Steve

Why can’t they fix the pain?

Steve is 26 and used to be a very active cyclist and runner and loved canoeing. He was an electronic technician and was

due for promotion. He used to cycle to work most days. One day a car hit him from behind while he was waiting at a pedestrian crossing. He was thrown from his bike and landed awkwardly on his back. He felt something in his back split. He was stunned but was able to get up and walk about. His bike was smashed beyond repair. He went for a hospital check-up and there was no evidence of any fractures or serious damage. He was advised to rest and was given some pain relief drugs. For several days he had pain in his back, then it seemed to improve. After two weeks he decided he would go back to work but the pain started to get much worse. His back and leg movements were much stiffer and at the end of the working day he had to go to bed. After two months he could not manage work anymore. He has not been able to cycle since the accident. He can only hobble around the house. He has started to get up much later each morning, and finds that lying down helps ease his pain.

Pain sites: About 18 months after the accident, Steve's pain was in his lower back and had spread into his left leg and his right shoulder. He sometimes had pins and needles in his right arm and his left knee would give way.

Mood changes: Steve is getting very frustrated. He has lost his job and is not able to do his hobbies. He often thinks about all the things he used to do, like mountain biking on Saturdays. He isn't able to join in the local bike race events anymore. He wanted to go back to karate classes and has not been able to get there. He often thinks, 'It's not fair that I have this pain. It was that driver's fault. He blamed me for stopping for the pedestrian crossing.' Steve has been fed-up about the long wait to see the specialist. He eventually had an MRI scan of his back, but the scan showed no evidence of spinal problems in his discs or bones. This made him even angrier. He would shout at Nicole, his girlfriend. He sometimes drinks too much beer as it helps his pain and calms him

down. He then seems to get snappier the next day. 'I just want to do the things I used to do, I am not going to go on living like this.'

Relationships: Steve's mood changes have been affecting Nicole, who has been getting really worried about him. Steve seems to be less physically close to Nicole. He often sleeps in the spare bedroom. This means he can get up in the night and use the computer. This has helped him, as he has found some useful websites for pain sufferers. He can use their chat rooms to find out more about pain. This upsets Nicole, as she seems to be living in the day and Steve seems to be living in the night. If Nicole tries to talk about it with Steve he just says it is the pain and he can't cope any other way.

Previous treatment: Steve has tried at least six or seven different drugs for his pain but he finds that they only work for the first two or three weeks. Then their pain relief effect lessens. His GP can only suggest more tablets and Steve is not keen to try anymore. He is fed up with the side-effects, especially constipation and a dry mouth. He hates eating fruit to help his constipation. He enjoys his takeaways, especially fish and chips, as this seems to be his only pleasure. But he does not like the fact that he has put on about 30 lb.

Sleep problems: Nicole has noticed that Steve is a very restless sleeper and often has bad dreams or nightmares, sometimes breaking out into sweats. This means that he will sleep in until midday and sometimes stay in his bedroom, near the toilet, until late afternoon.

Physical function: Some days, Steve finds it almost impossible to climb the stairs. He tells Nicole, 'I am not coming downstairs. I'm staying in the bedroom – it is close to the toilet.' He finds a walking stick helpful but refuses to go to the shops on bad days if he has to use it: 'Other people think I have a glass back.'

Legal and financial issues: Steve has decided to sue the driver because of all the problems he has had since the accident. He has now seen six different specialists for his legal case. He is very confused about why he still has the pain. His solicitor wants him to see a psychologist about his nightmares and angry moods. Nicole and Steve are also beginning to struggle financially. Their credit card and electric bills are overdue. Nicole only works part-time. Steve is worried about how they are going to pay their bills. They have already had a loan from Steve's mother and just don't know what to do next.

PART ONE

What is Chronic Pain?

manage your pain. Once you know what the problems are, then you can see what to change.

This book will help you to be more confident in knowing how to manage the problems and make simple changes happen yourself. In other words, you can begin to take back control of your life. The changes may not be easy to make at first, but they will be worth it in the end.

People who have been on pain management courses have found that understanding **what** are the problems and learning **how** to manage them has meant better days, better nights and generally better times in their lives. They have become more confident in managing their lives despite the pain.

I can now cope with family life much better. I know more about dealing with the pain, I am more in control of it. My confidence has really grown in my new skills, like pacing my day and night, using relaxation and dealing with worries. I see myself being better at coping, better to live with, my husband has a new wife again. I can live life to the full again but very differently.

Previous pain sufferer

Using the person-centred model

Using the model or guide shown on the next page can be helpful. It describes the five parts of a whole person and is known as a person-centred model. The model will help you and others to understand you as a person and the impact the pain has on you **now**.

PERSON-CENTRED MODEL

Body symptoms

(Type of pain or sensation)

Moods

(Emotions)

Thoughts

(Thinking in words or pictures, memories and beliefs or rules)

Behaviors

(What you do or do not do)

Present/past life situation

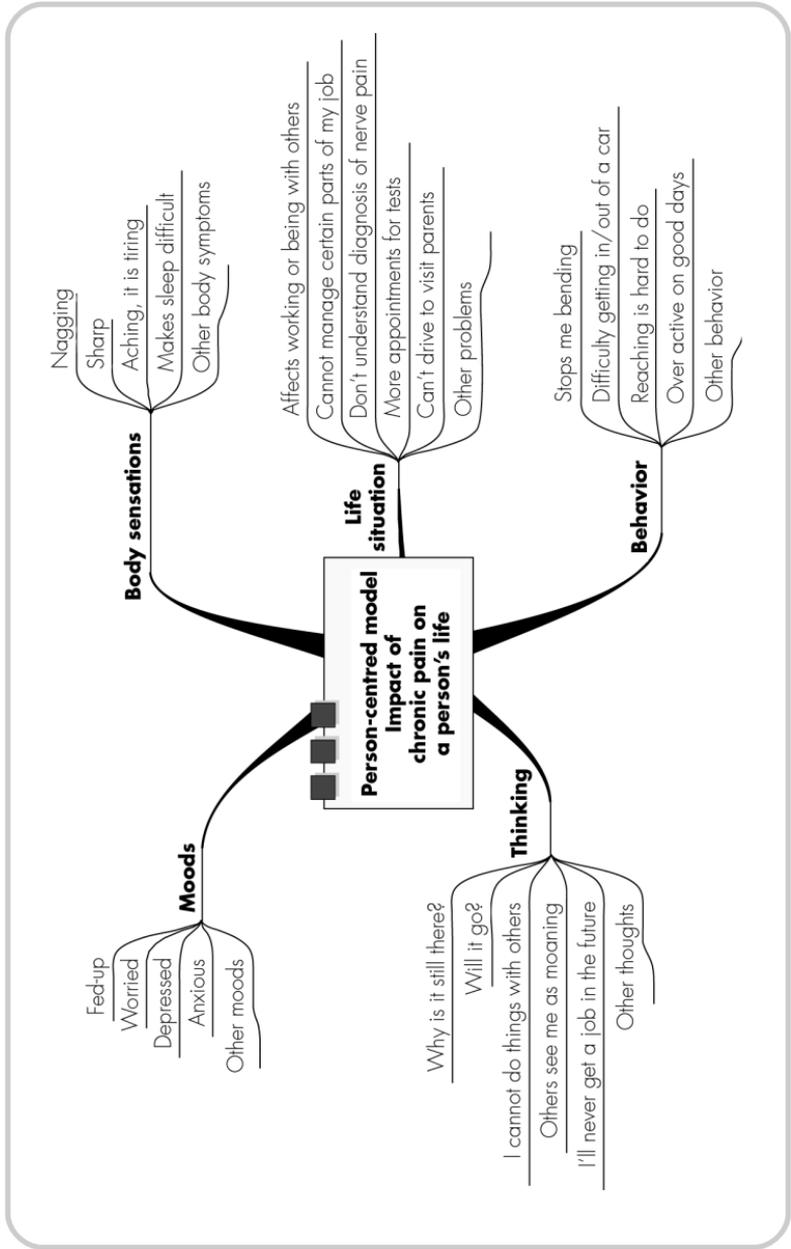
(Environment, work, relationships, etc)

An example of the impact of chronic pain on a person using the model:

Maria and the person-centred model

You may find it helpful to consider Maria's case history in relation to the person-centred model, in order to understand the impact of chronic pain on Maria and her life.

Maria, aged 47, used to be a school meals service cook. She has had a pain problem for three years since a fall at work. She lives alone now. She used to be married but was physically abused by her ex-husband and divorced him 20 years ago while her children were young. All her four children live nearby. She has seen several hospital specialists and her GP. She has been told that she has a bulging disc, osteoporosis and spondylosis. She does not really know what is wrong or what these labels or diseases mean.



Maria realizes she has changed. She used to be a bright, cheerful, amiable person, who loved her job and would help others out. Now she often cannot be bothered to tidy the house, cook meals for herself, or look after the garden. She can be very tearful, moans out loud a lot and gets very angry, even violent at times with herself or with other people.

She completed the person-centred model like this:

BODY SYMPTOMS

The pain 'crucifies me'.

The tablets 'make me a zombie' and constipated.

I have severe spasms 'like a horse kicked me in the back'.

I have sleep problems, waking up to five times each night.

My back is so stiff I sometimes can't get out of bed in the morning.

MOODS

I feel angry and frustrated.

I feel depressed and hopeless at times.

I feel so frightened, especially about the future.

I am embarrassed.

THOUGHTS

I don't want to be a wimp; I used to be a strong person.

I would top myself if I went into a home, it would end the pain.

I try not to take tablets, as it means I can't stand the pain.

I hate people doing things for me. I do things for others.

Others see me as moaning and getting violent.

BEHAVIORS (WHAT YOU DO OR DON'T DO)

I spend 70 per cent of the day in a chair or in bed.

I rarely cook for myself these days.

I am in tears a lot.

I am always grumpy and shouting, especially with the family.

PRESENT/PAST LIFE SITUATION

I have lost my job and my work friends. I have far less money. I have always worked seven days a week, and I don't now.

I am stuck at home; I can't get out alone, so it's the same four walls every day.

I used to love going dancing, sometimes five times a week. My neighbours now check on me in case I have fallen or I am stuck on the toilet.

My family don't understand what is happening to me.

I survived as a single parent, but this pain beats me.

The specialist never saw me after the scan test.

The model shows how the pain has taken over Maria's life. This person-centred model also helps to show what can be changed. A helpful change in any of the five parts or categories can lead to changes in the other parts.

The person-centred model can also help to highlight other difficulties that are not obviously linked to the pain.

How did the model help Maria make changes for the better?

Problem: Maria had stiffness in her back (**body symptom**), especially in the mornings, so she had great difficulty getting out of bed.

Change: She made a change in her **behavior**. She started trying to do a few specific stretch and strength exercises to ease her back stiffness while in bed in the morning.

Result: This helped reduce the stiffness and getting out of bed was 50 per cent easier for Maria. She felt less frightened (**mood**) and more confident (**mood**). She started to think that she could manage and not rely as much on help from others (**thought**).

Problem: Maria felt depressed (**mood**) because she thought she could not manage at home (**thought**).

Change: She changed her **behavior**. She started to keep a record of the times she did manage her days fairly well.

Result: The evidence from this record helped her to feel less depressed (**mood**) despite her pain. It was evidence that she did manage many days fairly well.

Maria's list of problems due to pain became her **targets for change**:

- Pain in my back
- My stiff back and neck in the mornings
- Difficulty getting out of bed/climbing the stairs/hanging out the washing
- Sleep problems – waking with pain/not being able to turn over
- Mood changes – feeling depressed/feeling angry/feeling frightened and thinking I will fall and get stuck on the toilet
- No social life – no dancing/spending all day on my own
- Can't understand why the pains won't go away
- Scan result – what did it say? What does the result mean?

How can the person-centred model help you get ready to make some changes?

You can use the blank person-centred model below as a guide to work out what difficulties pain causes you and how your pain affects your life. Filling in each section will give you a list of problems to think about, so that you can decide what you really want to change. It may help to look back at how Maria filled in the person-centred model earlier.

PERSON-CENTRED MODEL
Body symptoms (Type of pain or body sensation)
Moods (Emotions)
Thoughts (Words, pictures, memories, beliefs or rules)
Behaviors (What you do or don't do)
Your present/past life situation (Environment, work, relationships, etc)

Now you can look at your problem list and decide what changes you want to make.

A problem list can help you (and your family and friends) see which of your problems are mainly due to pain.

Ask yourself: What are the main difficulties at present which I would value changing or improving?

Tick the difficulties you want to change or improve:

- Problems with walking and moving about
- Problems with balance
- Lack of fitness and energy
- Side-effects or problems with current medicines for pain
- Unhelpful pacing (a pattern of doing too much, getting more pain, then doing too little and resting)
- Insufficient pain relief
- Not understanding why long-term pain occurs
- Disturbed sleep
- Moods, e.g. depression, guilt, anger or anxiety/worry
- Relationship difficulties because of pain
- Sexual problems
- Not being able to work or continue working
- Financial difficulties
- Resolving legal claims
- Other difficulties that are important to change (write them down in your notebook)

Do you know what you would want to change from this list? If not, it may help to share your list with someone else. Maria saw her GP, who helped her work through her problem list. Other people you could work with include physiotherapists, practice or specialist nurses, occupational therapists, community mental health nurses, pharmacists, family members, friends, work colleagues, local pain support group members and local health fitness centres.

If you ticked more than three areas of your life above think about which three areas you would value changing most. Choose, even if only little changes are possible now.

Write these changes in your notebook:

These are your **targets for change** and will help you draw up an action plan.

Avoid the wish list trap. People often say to themselves: 'All of it!!!' Well, that is not possible or realistic. But it is possible to make little changes even in the biggest problems – just as it is possible to build a big house, one brick at a time.

Getting started

When you have been in pain for a long time, it is sometimes difficult to know where to start and what to do to change the situation. People can often be held back by fears about becoming more disabled or being a burden, doing themselves harm or the pain getting worse. These concerns can lead them to overdo activities, battle on and then have a setback. They can also lead them to avoid doing things and limit activities more than is needed.

Managing pain includes taking into account what is happening *now*. Sometimes it is very difficult to face up to the idea that you cannot do everything the way you used to (see Chapter 8 on Pacing).

Reducing the impact of pain on your daily life

Using your three **targets to change**, write down in your notebook what you would most like to change about your 'typical day'.

What three things would be different if you managed your pain and life better?

Write down in your notebook what you would most like to change to achieve your targets:

- What physical activities would you change?
- What about enjoyable things (like hobbies)?

In reaching these targets, who would you spend more or less time with?

More time with	Less time with
e.g. my daughter	e.g. the doctor

After you have written down your ideas, write down what would be **better** if things were different:

- What would be better about social activities?
- What would be better about household tasks?
- What else?

How do you or others see these changes occurring?

When you have put down your ideas, it is helpful to see that there are some points in favour of doing things in a different way.

Next, see if you can think of any advantages of things staying the way they are now. This may seem like a strange idea, but you may have concerns or worries about changing. These also need to be thought about.

What could be positive about not changing things?

For instance:

- It can simply seem too hard to make changes.
- It is nice to have people who look after us when we are ill.
- It can be an advantage not to have to go out with family.

Next, write in your notebook four reasons for things staying the same. Small or silly reasons are fine, as well as important ones.

Have a look at what you have written down so far, and think about the advantages and disadvantages of putting effort into changing. When everyday things are already difficult, it is important to have good reasons to try something new.

Now think about your **most important** reasons for changing, and your **main concerns** about what this would involve.

Write them in your notebook:

Do you have other concerns? If so, make a note of them in your notebook:

Now, spend a little time thinking about what you can and **do** manage. Try not to compare yourself with how you used to be before your pain. This can be quite a challenge! What are your strengths? Try to write down at least three. (The more you can find, the better you are likely to feel.)

What helps you to keep going? Write down at least three things.

Now you have had time to think about the advantages and possible disadvantages of making changes, think about how important it is to you that things change.

Put a mark X on the line below to indicate how **important** it is to you that your three identified targets from page 31 change.

1	2	3	4	5	6	7	8	9	10
Not at all important								Extremely important	

Put a mark X on the line below to indicate how confident you are about changing your targets.

1	2	3	4	5	6	7	8	9	10
Not at all confident								Extremely confident	

Put a mark X on the line below to indicate how **ready** you are to change **now**.

1	2	3	4	5	6	7	8	9	10
Not at all ready								Extremely ready to change	

CHAPTER SUMMARY

- Pain can affect all five parts of a person: their body symptoms, their moods, their thoughts, their behaviors and their life situation.
- Understanding the impact of chronic pain will help you to be clear about your targets to change.
- It is important to focus on what can be changed, as the pain itself is often not very easy to change.
- In order to get started, you need to be clear about the advantages and disadvantages of making changes for yourself.

- Working through different chapters in this book will help you find out how to make these changes. You can choose to do this either alone or with support from a partner, family, friends or a healthcare professional.