ABOUT THE AUTHORS

Assoc. Prof. Michael Nicholas, PhD
Michael has been working in the pain field since 1980 as a clinical psychologist, educator, and researcher. Between 1988 and 1990 Michael was the inaugural director of the inpatient pain management programme (INPUT) at St Thomas’ Hospital in London. This programme was established with the support of the Kings Fund to evaluate the effectiveness of this form of pain management in the UK. The INPUT programme continues to achieve outstanding results and over the years it has received widespread international recognition. Since returning to Australia Michael joined the Pain Management and Research Centre at the Royal North Shore Hospital in Sydney (with the Faculty of Medicine, University of Sydney), where he is now an Associate Professor. In 1994 Michael established the ADAPT programme at the Royal North Shore Hospital. This is based directly on the original INPUT programme in London and is achieving similar results. More recently, he has been involved in assisting the development of similar programmes in Malaysia, Hong Kong, the Philippines and Singapore, as well as Australia. Michael has published over 120 papers in books and scientific journals, on the management of pain, and he has lectured on the field in many countries.

Dr Allan Molloy
Allan is a graduate of The Middlesex Hospital Medical School, University of London, where he was also awarded a BSc (Hons) in Neuropharmacology. After training at Addenbrookes Hospital, Cambridge, the Bristol Royal Infirmary, St. Bartholomew’s Hospital and Great Ormond Street Hospital, London, he qualified as an Anaesthetist
in 1992. He then moved to Australia to further his training in pain management, and is now a Senior Lecturer and Senior Specialist at the Pain Management and Research Centre at the Royal North Shore Hospital in Sydney (with the Faculty of Medicine, University of Sydney). Allan is a Foundation Fellow of the Faculty of Pain Medicine, Australian and New Zealand College of Anaesthetists and he is a member of the Therapeutic Assessment Group (making recommendations on pain-related drugs) for the NSW Department of Health. He has a number of publications in the pain field and is a frequent speaker at medical meetings on pain management.

Lois Tonkin
Lois is a Senior Physiotherapist and an Associate Clinical Lecturer at the Pain Management & Research Centre at the Royal North Shore Hospital, Sydney. She has with more than 20 years specialising in pain management. She has contributed to the development of two intensive pain management programmes. She has also been actively involved in workplace rehabilitation settings where she saw the difficulties caused by poorly managed pain in injured workers. As a result of these experiences Lois has been a leading advocate of improved pain management training for physiotherapists in Australia and internationally.

Lee Beeston
Lee is a senior nurse and had specialised in pain management programmes since their inception in Australia in 1989. Lee has been working on the ADAPT pain management programme since its inception at the Royal North Shore Hospital in 1994. She completed a Masters of Science in Medicine (Pain Management) at the University of Sydney in 2001 and in 2003 she was awarded a Churchill Fellowship which enabled her to visit and study the nurse’s role in pain management programmes in the UK, USA, and Canada. She performs a number of roles in the ADAPT programme, especially in patient preparation for the programme, medication reduction, and communication issues.
Practical and Positive Ways of Adapting to Chronic Pain

MANAGE YOUR PAIN

Revised, updated and expanded edition

DR MICHAEL NICHOLAS • DR ALLAN MOLLOY
LOIS TONKIN • LEE BEESTON

Foreword by Charles Pither FRCA
Medical Director, RealHealth Institute, London

SOUVENIR PRESS
Contents

Acknowledgments ix
Foreword xi
Introduction 1
1 What is Chronic Pain? 9
2 Questions You May Have 20
3 What’s Going On In Your Body When You Have Pain? 27
4 What X-rays, CT and MRI Scans Tell Us 43
5 Working with Your Doctor 47
6 Treatments for Chronic Pain 52
7 Using Pacing to Overcome the Effects of Chronic Pain on Activities 79
8 Setting Goals 93
9 Recognising and Overcoming Obstacles to Change 101
10 Stretching and Exercising 111
11 Challenging Ways of Thinking About Pain 148
12 Using Relaxation 173
13 Attentional Techniques 179
14 Improving Sleep 187
15 Stress and Problem Solving 197
16 Interacting with Those Around You 210
17 Dealing with Flare-ups and Setbacks 237
18 Pain and Work 244
19 Pain Self-Management for Seniors 253
20 Keeping It Up 258
Glossary 265
Appendix 1 267
Appendix 2 271
The journey of those who suffer from chronic pain is long and often arduous. It starts innocently enough with a problem which seems just like any other, passes through a time of bewilderment, disbelief and disillusionment; visits desolate places of loneliness, anger and self-doubt, and even then seems to have no end. Sufferers’ struggling to come to terms with the reality of chronic pain know all too well the emptiest reaches of the human condition. Many such individuals talk of hitting ‘rock bottom’ at a time when they dare not admit to themselves that the doctors and medical systems in whom they had put such trust are apparently unable to help them. The rounds of consultations, the litany of explanations and the numerous worrisome treatments all take their toll, physically and emotionally. Sleeplessness and the side-effects of medications conspire to destroy concentration and add to the burden of fatigue. The inability to do things leads to stiffness and a decline in fitness. Inactivity leads to weight-gain which further dents fragile self-esteem. The chronic pain sufferer rightly wonders where it will all end.

How can it be, then, that I can recount hundreds of tales of people who have been down this awful road, but who have ultimately found a path out of the wasteland? Such people speak of a journey of self-discovery, which ultimately proved to be fulfilling because it provided them with an unbidden, but nevertheless ennobling, opportunity to learn more about themselves and the world in which they live. This journey has been described as the journey from patient to person, from avoidance to confrontation, from helplessness to control, from passive sufferer to active coper.
How have these voyagers managed this seemingly impossible turnaround? Have they found the miracle cure delivered by the all-knowing wise physician? Have they finally located the ‘last resort’ and had the winning operation? Alas! Not usually. They have, however, found their way through the desolation, by realising that the most important person on the road to recovery is the traveller him or herself. They have come to the painful recognition that if they are to get better they have to do this themselves. This realisation has not usually occurred in an instant; rather it has been a gradual awareness, like waking from a deep sleep. They have read and listened to other travellers who have made the successful journey, and perhaps been advised by those specialists in the field of chronic pain who appreciate where treatment is most fruitfully directed: giving people proper and detailed information and training in techniques to aid themselves best.

The acceptance that rescue from the all-knowing doctor is not going to occur and the dawning that they have to act themselves is perhaps the first step on the road to recovery. This is followed by the search for information about what this entails and how it is done. They ask friends and acquaintances, talk to their doctor, seek advice and surf the web. They start hearing about ‘pain management’ and at first find it a rather confusing notion. How can an illness that has stressed and taxed them to the ends of their sanity be managed? Besides the idea of improved management comes with the implication that up until this point in time they have been managing their problem badly. The truth is that many people do manage their pain less than optimally, but this should not imply fault or blame. If a person has never had a lesson they would not be expected to speak perfect French. They might have a few ideas but these could be improved considerably by a language course and practical instruction. It is clear that the ideas underpinning modern pain management techniques are now well proven and can dramatically alter the sufferer’s life for the better. What is more they can be taught by therapists and experts who are not themselves pain sufferers. Learning pain management skills can be
achieved by attending a pain management programme or seeing an individual therapist, and such treatment may be required and recommended. For many people, however, an excellent starting point is a self-help manual such as this.

There are many such books on the market and for the expectant sufferer it can be difficult to make a choice. As a pain specialist who has been preaching the merits of interdisciplinary pain management for fifteen years, I can vouch that the search for a high quality comprehensive self-help manual stops here. I say this for a number of reasons.

Dr Michael Nicholas and colleagues are respected across the world for their knowledge and understanding of chronic pain and how it can be managed effectively. They run a comprehensive and excellent programme at the University of Sydney which achieves exceptional results and incorporates many effective and usable techniques. Their research has taught us much about the reasons why chronic pain develops and how it can best be treated. They have adapted the practical knowledge gleaned from their work with many hundreds of patients and distilled it into this book. The result is not a theoretical treatise but a usable handbook moulded by the real-life problems of pain sufferers. There is nothing quirky or alternative about the ideas in this volume: they are all based on the reality of everyday life. The pain sufferer who works through it logically and follows the recommendations will be able to reduce much of the fear and uncertainty that contributes so much to the distress and despair of chronic pain. They will find tips on returning to fitness and learn about pacing techniques. They will already know how easy it is to fall into traps of negative thinking, but here they will learn more about how such situations can be perpetuated unwittingly and how they can be challenged effectively by using cognitive techniques. They will find information about using relaxation techniques and tips on how to make a gradual return to meaningful and pleasurable pastimes.

We have to be realistic and accept that books such as this are not the only treatment that pain sufferers need. Were that the case,
specialists like myself who run pain clinics could shut our doors and retire. However, the basic principles and ideas set out in this book are so important that they should be part of a treatment programme offered to all chronic pain sufferers. The road may still be a tough one and there may be pitfalls and diversions along the way, but the chapters in this volume serve as both map and guidebook for the persons lost in the wastelands of chronic pain.

The message is clear – there is life after chronic pain. The path out of the wilderness starts here.

Good luck!

Charles Pither FRCA
Medical Director
RealHealth Institute
London, UK
‘... but don’t wait for the light to appear at the end of the tunnel.
Stride down there . . . and light the bloody thing yourself!’

SARA HENDERSON
Pain is something that almost everyone experiences, but what may be surprising to learn is that around 20 per cent of the population have what is called chronic or persisting pain at any one time. Chronic pain is usually described as having pain on most days for at least three months. The causes of chronic pain are many, from nonspecific back complaints to arthritis to injuries to cancer. At present, most of these conditions do not have effective or lasting cures.

Some people are affected by chronic pain more than others, but it is estimated that about 10 per cent of the population of countries such as the UK, Australia, the United States, Canada, and those of northern Europe, report that persisting pain is interfering in their daily life. In some cases the pain can be quite severe and debilitating, where people may spend most days (and nights) lying down or are very restricted in their activities. In the other 10 per cent of the population, people with persisting pain report that while they don’t like being in pain, they have found ways to get around it and to get on with their lives to a reasonable extent.

This book is intended primarily for all those with chronic or persisting pain who would like to manage better than they are at present. Those who feel they are managing quite well already, may also benefit from some ‘finetuning’ or perhaps support for what they are already doing.

To give you an idea of whether this book could help you, try answering the questions in the checklist on page 2. On items 1 and 2, if you score 2 or less you should have something to gain from this book. On any of the items 3 to 18, if you score 2, 3 or 4, you should
### Pain Self-management Checklist

M.K. Nicholas; University of Sydney Pain Management & Research Centre
Royal North Shore Hospital, 1999 ©

How often have you used these pain self-management strategies (over the last month). Indicate your answer by circling one of the numbers (0–4) beside each item.

**Thinking back over the last month, how often have you done these?**

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>Sometimes</th>
<th>Very often</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. If pain stops you doing something, do you ever work out other ways to do it. (Like, if you normally sit to do a task, but find sitting is difficult due to pain, have you worked out other ways to do it? Think of an example.)</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>2. Taking <strong>regular</strong> short breaks when engaging in activities, including sitting or standing, which stir-up your pain (such as, stand up for 5 minutes every 20 minutes).</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>3. Thinking that your doctors will find a cure for your pain?</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>4. Using pain killers to allow you to do something you know will stir up your pain (like driving or standing too long, or carrying too much).</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>5. Taking more than the recommended dose of any drug related to your pain; or using alcohol for pain relief.</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>6. Taking a drug which only ‘takes the edge off’ your pain.</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>7. Having one or more long rest periods (more than 45 minutes) (lying or sitting) through the day (8.00 am to 8.00 pm).</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>8. Lying in bed at night worrying or getting stressed.</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>9. Due to pain, having others perform your normal household duties (like washing-up, cooking, vacuuming).</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>10. Doing an activity or task until it is completed <strong>regardless</strong> of pain and then resting.</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>11. Due to pain, using aids (like sticks, braces, or collars).</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>
also have something to gain from reading and learning from this book. If you don’t score any 2s, 3s or 4s you probably don’t need to read this book, but you might find it interesting to compare your own methods with the ones described in these pages.

If you score 3 or 4 on several of these items you should read this book closely and discuss it with your doctor. It might also help if you discussed it with a physiotherapist and a clinical psychologist with experience and training in cognitive-behavioural treatments.

If you have had this pain for more than six months to a year and no treatment seems to be helping, you should speak to your doctor about being referred to a multidisciplinary pain clinic for specialist assessment and help. Most large hospitals have a multidisciplinary pain clinic and many of these will have people who use the types of methods described in this book.

This book is based on the authors’ clinical experiences in hospitals in Australia and England over the past 30 years of treating

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>Sometimes</th>
<th>Very often</th>
</tr>
</thead>
<tbody>
<tr>
<td>12. Seeing a physiotherapist or doctor or chiropractor or other health care provider about your pain (in the last month).</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>13. Thinking that increased pain means you might have injured yourself (or made your injury worse).</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>14. Thinking that doctors have missed something, or that you need more investigations to explain your pain.</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>15. Thinking that pain relief is necessary before you can become more active generally.</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>16. When your pain gets worse, do you ever have upsetting thoughts (eg, ‘I can’t go on; not again; why me?’)</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>17. When your pain gets worse, do you ever take a tablet or have an injection?</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>18. Do you ever make comparisons between what you are like now and how you were before the onset of your pain?</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>
people with chronic pain. It is also based on the work and studies of clinicians and researchers from different disciplines in many countries, starting with Professor Wilbert Fordyce and colleagues from Seattle in the US in the early 1970's.

More specifically, the program described in this book has been developed by the authors at the University of Sydney Pain Management and Research Centre at the Royal North Shore Hospital in Sydney since 1994. We call our program ADAPT, as that really sums up what it’s about. The ADAPT program that we run at the hospital is very intensive. Patients attend all day, Monday to Friday, for three weeks. This book is the basic manual we use. It has been revised so it can be used as a self-help book, but we recommend that it be used in conjunction with your doctor, or other health provider.

ADAPT was itself based on work done by Dr Nicholas and colleagues at St Thomas's Hospital in London, beginning in 1988. The program at St Thomas's, which we called INPUT, started out as a research project to evaluate the effectiveness of the treatment over a one-year period. Two versions of the program were compared with standard medical management of mainly just medication. The results showed that patients doing the two programs improved more than those receiving standard medical management only. Of the two versions of the program, those who attended the more intensive approach did better and this effect was still evident one year later. The more intensive version involved staying in hostel accommodation at the hospital and attending the program all day, Monday to Friday, for four weeks. The less intensive version involved patients staying at home and coming to the hospital one afternoon a week for eight weeks. Patients who attended the programs did better in terms of reduced use of medication, improved mood, improved confidence and improved activity levels. They became a lot happier and could do a lot more of their normal daily activities. They still had their pain, but it was no worse and it didn't trouble them as much as it had before.
If you are interested, an account of this study was published in the journal *Pain* in 1996 (Volume 66, pages 13–22). This journal is published by the International Association for the Study of Pain (IASP) and it is the leading international scientific journal in the field of pain.

The two main lessons we took from this study were first, the methods taught in the program are more effective than just taking medication alone, and second, the methods taught in the program are more effective if the person doing it works on them as intensively as possible.

In other words, simply doing the program in a half-hearted way is not likely to be as effective as really putting some concentrated effort into it. So, if you don’t feel confident about doing this program on your own, you should ask your doctor if he or she can suggest a local clinical psychologist and physiotherapist who might be able to help. Alternatively, your closest pain management clinic might have a similar program on offer.

Although claims have been made for many different treatments for chronic pain, especially back pain, the reality is that there is no magic bullet or simple solution for chronic pain and the many problems it causes. As attractive as a quick fix would be, it is essential that all consumers of health care services remain critical of reports of breakthroughs and cures in this complex and difficult area. Almost without exception, reports in the popular media about breakthroughs in treating chronic pain have proved false. Even treatments with seemingly good scientific support do not help everyone. Equally, some people seem to benefit from almost any treatment that is devised, but that doesn’t mean the treatment works for most people with the problem. Some treatments are even harmful.

This book does not claim to have all the answers, but the methods and strategies described have been supported by research in a number of countries and a list of many of these studies is provided in Appendix 1 on page 267.

Unlike a new drug or device that might be expected to ‘fix’ your
Overview Of ADAPT Program
The main stages of the program are outlined here. See the individual chapters for further information on each topic.

Understand the nature of the pain
- ensure no treatable cause of pain
- clarify differences between chronic and acute pain (Chapters 1–4)

Possibly, try another treatment (Chapters 5 & 6)

Discuss treatment options with your GP or a specialist
- clarify that no cures are available
- agree you have to learn to live with it (Chapters 5 & 6)

Set your goals (be realistic)
- identify obstacles to achieving goals
- Work out ways of dealing with obstacles (Chapters 7–9)

Change course; accept pain, learn and apply skills
(Chapters: 9–19)
- pacing (Ch. 7)
- problem solving
- change unhelpful ways of thinking
- relaxation and desensitization
- develop exercise program
- cease unhelpful medication (with the help of your doctor)
- improve sleep
- improve ways of interacting with those around you

Maintenance
(Chapters 11, 15–17 & 20)
- dealing with setbacks and stress
- returning to work, sport, home life, social activities

Collaborate with your doctor (and employer, family, as appropriate)
(Chapters 5, 16 & 18)
pains for you, this book offers no instant relief. Nor does it promise total relief at some time in the future. Instead, it describes an approach to managing pain in which you, the person in pain, are expected to play an active and ongoing role. Whether it helps you achieve your goals will depend on many things. These include:

- how realistic your goals are (going parachuting may be too much to expect)
- how well you put the methods into practice (just as if you clean your teeth only once a week you wouldn’t expect to have good teeth)
- how much you actually want to achieve your goals (if it would only be ‘nice’ but not really important, you probably won’t try)
- how much support you have in your environment, at home and at work.

At different points in the book you will be asked to think about each of these issues, along with many others. The essential point is that the book is a manual. The information in the book will not change your life by itself. Only you can do that. To some extent, you have to become your own doctor/physiotherapist/psychologist. But don’t despair, the book will provide guidance on all these matters.

It is our intention that the book should provide a person experiencing persisting pain with a useful guide to managing their pain themselves. We would recommend that those intending to use the book should first discuss it with their doctor, physiotherapist, chiropractor or other health care providers. If possible, it would be useful to work through the book with a health care provider acting as a sounding board. We do not want to suggest that the methods described in the book are always easy to apply, especially if you are feeling overwhelmed by your pain. If you or your doctor feel that you might need more help then it may be appropriate for you to attend a local pain management clinic where specialists in pain medicine could assess you and provide expert help.

We would also strongly recommend that you see a qualified
medical practitioner to assess your pain before you try to use the book. Your doctor may not be able to offer you any curative treatment, but he or she can certainly make sure there is nothing seriously wrong with you.

If necessary, your doctor may need to refer you to a specialist. At least you should be able to get a reasonable idea of why you have persisting pain in the first place. Clearly, if the cause is treatable, it should be treated. If there is no cure available, you will need to come to terms with having persisting pain for the foreseeable future. Fruitlessly searching for a non-existent cure can end in frustration, helplessness and even despair. Not to mention the costs, to you and your family. Hopefully, you will find that this book can help you to avoid the pitfalls we all face when pain persists.

If your doctor or other health care provider disagrees with some or all of the approaches used in this book, we suggest that you discuss it with him or her. It may also be helpful to get another opinion. You could also ask your doctor if they have any better solutions and what evidence there is to support them. We strongly advise against simply accepting advice from any health care provider based only on their opinion or experience with another patient. Such opinions do not amount to good evidence in medicine these days. All health care providers have a responsibility to give you evidence to support their opinions, and that evidence should stand up to scrutiny by their peers.

The book is divided into topics. We advise you to move back and forth through different chapters as recommended in the text. Thoughtful reading and discussion, especially with other family members or good friends, can help someone suffering from persisting pain to gain new perspectives on their pain. Practising the methods outlined in this book will help you to improve your pain management skills. In turn, these improvements can result in less suffering and restoration of a more normal lifestyle despite persisting pain.