

## Coping Successfully with Chronic Illness

The management and treatment of chronic illness plays a major part in Neville Shone's life. An operation to remove a spinal tumour left him almost immobile and in constant pain. His career as a university teacher ended, his professional ambitions were thwarted and his active social life was completely wiped out. These events left him in a state of despair and helplessness, as he struggled to pick up the pieces, heal the resulting emotional scars, restore hope and regain a satisfactory quality of life. Over the past 30 years, Neville has not only helped himself but has worked as a therapist and author to help others to find ways to rebuild their lives. He believes that people have power to help themselves and others to cope with adversity. His books, *Coping Successfully with Pain*, *Cancer – a Family Affair*, *The Chronic Pain Diet Book* and *The Pain Management Handbook* (all published by Sheldon Press), continue to act as a source of inspiration. Neville has broadcast on local and national radio and television on the subject of pain management, and has acted as a consultant to a number of television documentary makers. He is patron to two national pain charities. A graduate of the University of Liverpool, he returned there to teach after a career in social work with children and families. He is qualified as a psychotherapist and hypnotherapist. Neville is married to Eve, and much of the couple's time and energy is spent with their children, grandchildren and thirteen great-grandchildren.

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Overcoming Common Problems

# Coping Successfully with Chronic Illness

Your healing plan

NEVILLE SHONE

**sheldon**<sup>PRESS</sup>

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*This book is dedicated to my grandchildren and  
great-grandchildren, in the hope that they will read it  
to discover more about their family history,  
and that they will enjoy a life full of health and happiness*

A flawed diamond is more valuable than a  
perfect brick.  
(Anon.)

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## Author's note to the reader

If you have any kind of medical problem you must consult your doctor.

The material in this book is to help you to maximize your own health and well-being. It is not intended to replace any advice given by your own medical practitioner. The author can accept no responsibility for actions you undertake as a result of reading this book.

# Introduction

I was sitting alone in an old Victorian hospital ward. It had until recently been used as a sewing room by the housekeeping staff. It seemed to be a curious setting for the first pain management course in the UK and Europe, staffed by a team of doctors, psychologists, occupational and physical therapists as well as teachers of dance and yoga. This highly skilled and strongly motivated team had volunteered to work with chronic pain patients who had been 'written off' when standard medicine had no more to offer in way of treatment.

The room was shabby and sparsely furnished with a few old wooden and plastic chairs scrounged from various parts of the hospital. There were two reasonably comfortable, if battered, armchairs. The floor was covered in brown cracked linoleum from a bygone age. In one corner was a table containing about a dozen coffee mugs, an electric kettle, a tin of instant coffee, a box of teabags, a carton of milk, a bag of sugar and a few spoons. Behind a curtain on the opposite side of the room was an examination table. It was the middle of winter, cloudy and wet outside, and because no lights were on it was extremely dismal inside as well. In this large depressing room with its high ceiling I felt very insignificant, helpless and hopeless.

I was waiting for the arrival of 'Helen the Healer', one of the team of therapists, and I had no idea what to expect. I was beginning the second week of my pain management course and the only feedback I had from the other seven patients who were my companions on the course, and were by now on their third and final week, was that they all felt better as a result of seeing her. They hinted at the release of strong emotions and feelings of extreme heat in various parts of their body.

I had been brought up to think that all healing came from the medical profession, espousing the latest in scientific medicine, drugs and surgical procedures. However, my faith in their abilities had been badly shaken by my own experience of long waiting lists, delays in diagnosis, lost notes, drugs to which I was allergic and an operation which left me with severe chronic pain, walking difficulties and extreme discomfort when standing or sitting. At this point I had little faith in anyone to improve my condition.

All I knew about healing outside the medical profession came from my studies of anthropology, highlighting the work of witch doctors and shamans, and modern depictions of preachers from

the Bible Belt of America dramatically driving out demons from the possessed. Understandably, I was extremely apprehensive about giving myself over to 'witchcraft' but at the same time I was so desperate to achieve some relief from my pain that I was prepared to listen to anyone who might be able to help me.

Even after such a short time on the pain management course I knew that something was happening to me that indicated some improvement. What it was I was not sure at this stage, because my pain and mobility were still much the same. I had had a week learning how to breathe properly and how to relax deeply, and had followed a daily programme of progressive exercise. I tried to analyse the cause of this change. It was something I had not experienced before. Our group of eight was led through a series of guided discussions and activities and everyone was given space and time to express their views, their feelings and their hopes for the immediate and long-term future. Was it the group itself that was bringing about a change in my feelings? Was it the flow of endorphins coming from the unaccustomed exercise and relaxation sessions? My professional background in working with children and families, teaching social work and probation officer students about groups and leading therapeutic groups told me that the group is a very powerful instrument in bringing about change for the better. However, I was not there just to feel better. I *needed* to have less pain and I *needed* to be more mobile. When was this going to happen?

I learned from those running the course, and the other attendees, that if we were going to progress we were going to have to work very hard at physical conditioning. It involved not only training muscles that had been unused for more than five years and straightening a body that had become twisted but also re-learning the fundamentals of walking and sitting, while at the same time finding ways to change many aspects of our behaviour, our habits and our ways of relating to people. This was only the beginning, where we learned the necessary skills to use as a foundation we could build on when the course finished in four weeks. Do-it-yourself was the order of the day!

Support lasted as long as the group was together, but once you graduated you were on your own. I saw this as the crisis point – learn the skills and survive, or go under! I got the message that the medical profession generally still had very little to offer in treating chronic pain. Would I fare any better with this new approach to treatment? At this stage it was hard to believe that the small gains

I had made in the first two weeks of the course would continue – and for how long?

My thoughts were interrupted by the door opening. In walked a very ordinary-looking woman, perhaps mid-50s, greying, but with a bright smile which lit up the dim room. Introductions over, we sat down and Helen told me she had missed the chance to meet me the first week I was on the course. This was because she had been away ‘recharging her batteries’. She explained that working intensively with people could be very exhausting, and I knew this well from my own work experience with students and families suffering breakdown. We had an immediate point of contact. She went on to say her work with me had nothing to do with my religious experience or faith or the intervention of some outside force, but she was there to focus my own energy so that I could use it to strengthen my own ability to heal myself. She asserted that the only sure healing came from within, but that life experience and illness can so easily overwhelm the ability we all have to mend damage to the mind and body. I could relate to this. It made sense to me, as for the last few years my illness had taken such a grip on me that I had no time or energy left for other things.

Helen then invited me to choose whether to lie on the examination couch, to stand up or to sit down, whichever was more comfortable for me. Standing was out of the question and I felt too vulnerable to lie on a couch (too much like the Hollywood version of visiting a psychiatrist). I chose to sit on one of the plastic chairs, not normally a comfortable experience for me.

Helen stood behind me and explained that she would take a little time to scan my body with her hands, but no contact would be made. I could not see how this would help my pain. I had expected some form of ‘the laying on of hands’ but this did not happen. Instead, she raised her hands, one to the front and one to the back of my head just about three inches away. As she did so she said, ‘*You know what to do,*’ and began to scan slowly down my torso. I didn’t understand her remark – or so I thought. The only thing I could think she meant was that I should close my eyes and breathe slowly into my diaphragm as I had been taught in the relaxation classes. As she scanned, I was very aware of the position of her hands through a sensation of warmth. (You can experience this for yourself by holding the palms of your hands about three inches apart and closing your eyes. This is an excellent way to relax, especially if you slow down your breathing at the same time.) The feeling of warmth and relaxation was all I could

feel, until she reached my midriff area. Nothing had prepared me for what happened next.

I experienced an enormous knot of tension in my chest that completely interrupted my ability to breathe smoothly. I felt myself gasping for breath, sweating, and I was overtaken by an upsurge of emotion expressed in tears. I gasped out, 'I don't know where that came from.' I was possessed by these strong feelings for some time and I began to talk about all the things that I had bottled up over a number of years: my feelings of letting down the family; my anger at the loss of my job, my income, my status, my hobbies; my confusion and fear for my future and my sanity.

We talked about these things for what seemed like an age. It was the first time I had talked about my feelings and anxieties, and I realized I had been spending so much time and energy putting on a brave face to convince those around me that I was coping. This was the first time I had admitted to anyone that I was not coping – that I was terrified and helpless and saw the future as being completely black. Helen picked up on this. She said that she liked to work with colours and asked me to see if I could bring about any change mentally by altering the black into something brighter. As I focused my mind I noticed my breathing slowing down and becoming much deeper. I began to sweat profusely, and it seemed an age before I experienced flashes of colour at the edges of the blackness. Flashes of purple . . . changing to blue . . . which eventually and after much concentration and mental effort . . . began to push away much of the blackness. With encouragement from Helen I continued and finally was able to fill the black space with whiteness. At this point I felt an overwhelming sense of euphoria – a wonderful feeling of achievement – and I felt a flow of energy begin to flood through my body, bringing with it exhilaration and joy, feelings I had forgotten and never expected to regain. I was soaking with sweat and felt completely exhausted.

These strong, positive feelings stayed with me throughout the following week when I was able to feel more involved with my family and put more energy into the pain management course. I looked forward to my next session with Helen.

I cannot recall in absolute detail everything that happened in the following session but I do remember that it was just as intense and just as exhilarating. It ended with me walking triumphantly from one end of the room to the other without the aid of sticks and without stooping or limping. And what followed was even more unexpected. Helen showed me into the corridor and urged

me to climb the grand Victorian staircase to the next floor. I started hesitantly, thinking Helen was being too ambitious and that there would be tears before bedtime. However, she had thrown down the gauntlet, I was desperate to succeed and I was not one to shirk a challenge. Deep down I trusted Helen enough to know she would not put me in danger. With each step my confidence grew, even though I could feel the strength draining from my legs. I was shaking from head to foot by the time I reached the landing but, for the first time in five years, I was fully mobile!

Looking back, I can only describe this as a truly healing experience, but not in the sense of being 'cured'. More than 30 years on I still have my spinal condition, I still have chronic pain, allergies and mobility problems, but what I experienced in those meetings with Helen was so intense and positive that it was really life-changing. For the first time I saw the possibility that I could move on, and this enabled me to break free from being dominated by my illness and to plan ahead without fear or anxiety.

Anyone who is chronically sick who reaches the stage where it is possible to think positively about the future with confidence is well on the way to being healed.

What was gloom is now bright; where there was once helplessness there is a feeling of control; where there was once despair there is hope. These new positive feelings did not come all at once, but over the following days and months I began to become less focused on my physical body and its defects. I began to pick up on family relationships, take more interest in things going on around me, set myself goals and feel confident enough to grasp opportunities. In spite of the fact that I still had reservations about my physical capacities I was delighted when I was asked to make a contribution to the pain management programme, using my skills in group therapy that I had practised as a family social worker and taught for many years as a university teacher. This was the start of a new career for me, as very soon I was able to retrain, over a period of three years, as a psychotherapist and hypnotherapist and run my own practice treating individual patients. I found my new skills invaluable in working with the endless procession of people with pain when they were referred to the increasingly popular and effective pain management programme.

I soon learned that many of the people seeking help, whether coming to me for individual attention or attending the pain management course, were suffering from a variety of chronic illnesses and were desperate to find some relief from their pain, anxiety,

sleeplessness, stress and depression. As time went on I felt that the focus of my work was not so much towards treatment as towards education, enabling my 'students' to use and enhance their own inner resources, learning new coping skills and ways of thinking and behaving in order to bring about their own healing. The more students were able to embrace this new learning and incorporate it into their daily lives, the more it was possible to see real changes taking place as they were able to find ways of conquering some if not all of the troublesome symptoms of their illness. As I developed this educational approach more, I thought that it would be helpful to conduct such a course in the community away from all the usual connotations of hospital, white coats, disease, trauma, high tech equipment and emphasis on drugs. In my first book *Coping Successfully with Pain* (Sheldon, 2002) I have described how it was possible to work in this way.

Human beings are extremely complex, and in the case of chronic illness it is arrogant to think that it is sufficient to treat only the physical body. There is a complex interaction between the mind, thoughts, feelings, spirit and physiology of a person. Life experience can disrupt this process, giving rise to chronic illness. In this book I hope to throw some light on how this can happen and demonstrate how it is possible for you to learn how to work towards restoring ease within yourself so you can enjoy an enhanced quality of life. I hope you will discover, through following the plan I have devised, how to make good things happen throughout your life.

# Chronic illness – a global problem, a personal challenge

## **A global problem**

Chronic illness is a malady that persists for a long time. It is commonly accepted in the medical profession that any illness that lasts for over three months can be described as chronic. Many of us have experienced acute illnesses that, in spite of causing discomfort, inconvenience and anxiety, come and go quickly. Such illnesses are chest infections, stomach infections, colds and influenza. To put the subject of chronic illness in perspective I turned to the publications of the World Health Organization (WHO), which monitors health trends throughout the world and from time to time makes recommendations for the guidance of the countries that make up its membership. I must admit I was taken aback when I read the statistics about the extent and profound effects of chronic illness.

The WHO reported that in 2005 chronic conditions such as heart disease, diabetes, stroke, cancer and chronic respiratory diseases were by far the leading cause of mortality in the world, representing 60 per cent of all deaths. Of the 35 million who died from chronic disease in that year, half were under 70. The WHO describes this as an ‘invisible epidemic, an underappreciated cause of poverty and a hindrance to the economic development of many countries’.

In a document entitled ‘Facing the Facts: The impact of chronic disease in the United Kingdom’, the WHO reports that chronic diseases are projected to account for 85 per cent of all deaths between 2005 and 2015, in numerical terms five million people. In the same period, although it is estimated that the overall percentage dying from chronic illness will fall by 0.8 per cent, deaths from some chronic illnesses will increase. The report draws attention specifically to diabetes where the estimated increase is said to be 25 per cent.

## 2 Chronic illness

The WHO report also points out that being overweight and obese is a major cause of chronic disease. In the ten years from 2005 to 2015 the number of overweight and obese men in the population will increase from 76 per cent to 80 per cent, with the percentage for women projected to rise from 69 to 73 per cent.

In economic terms, in 2005 alone premature deaths from heart disease, stroke and diabetes lost the UK \$2 billion in national income (the WHO uses the dollar as a common reference point in order to compare costs from one country to another). In the years 2005 to 2015 the loss to the UK economy is projected to increase to \$33 billion as a result of premature deaths from heart disease, stroke and diabetes.

The WHO suggests that a healthy diet, regular physical activity and avoidance of tobacco products would make major inroads into the prevalence of these diseases and also cancer.

The WHO report refers only to the obviously life-threatening illnesses but there are many other chronic illnesses that need to be taken into account. These, in their turn, are known to have a major economic impact. Chronic pain alone affects more than eight and a half million people in the UK and costs the economy £18 billion in lost working days each year. The charity Arthritis Care carried out research in 2012 that predicts the number of people with osteoarthritis will double over the next few years, mainly as a result of obesity and the growing number of aged people in the community.

### A personal challenge

Other conditions that fall under the definition of chronic illness and which may be making your life miserable or stressful and preventing you from living life to the full may include:

- one of the many forms of arthritis and joint problems
- osteoporosis
- spondylitis and spondylosis
- spinal stenosis
- fibromyalgia
- myalgic encephalopathy (ME), also known as chronic fatigue syndrome (CFS)
- multiple sclerosis (MS)
- neuralgia – for example trigeminal neuralgia, post-herpetic neuralgia (pain after shingles), post-operative adhesions and adhesions following injury

- cancer and cancer pain following treatment
- stress, anxiety and depression
- high blood pressure and chronic heart disease
- insomnia
- migraine
- digestive problems
- irritable bowel syndrome (IBS)
- dermatitis, eczema, psoriasis
- chest complaints and asthma and other chronic conditions.

While not always directly life-threatening, any of these conditions can take away our zest for life, sap our energy and virtually extinguish that inner flame that we call 'spirit'. Some people suggest that it is the weakening of the spirit that is the root cause of many illnesses; however, this is not the place to get into a chicken-or-egg debate as the main purpose of this book is to help you to heal, to strengthen your spirit and your body and to use your mind to help your personal transformation.

The weakening of the spirit can make it difficult to take action to help yourself overcome problems arising from the illness, and these can be legion. There may be unpleasant symptoms to deal with which get progressively worse in spite of medication or treatment, resulting in feelings of frustration, helplessness and hopelessness. You may see aspects of your life just melting away as it becomes more difficult to hold down a job or do everyday tasks about the home. Hobbies and social life and – even worse – relationships may fall victim to your illness and you may feel isolated and alone as you are unable to share your fears and worries with friends or loved ones. You may indulge in self-blame or feel unable to follow through a rigid programme of treatment.

Getting back to living an enjoyable life in spite of your illness presents a real challenge. You may find it easier to sit back and do nothing rather than face making changes that are an essential prelude to following a programme that will help you get better. You may believe you are beyond help or you may feel it is a sign of inadequacy or failure to seek help; you may not want to trouble your doctor – it might seem you are complaining that the treatment you are receiving is no good. After all, Doctor knows best! You may already have exhausted the treatment options provided by conventional medicine. You might feel that you are to blame for the inactivity resulting from your illness that has culminated in substantial weight gain, and be afraid to have someone sit in

## Author's note to the reader

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