Managing Chronic Widespread Pain

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MUSICIAN STUDY

Acknowledgements

We would like to thank all the people who have helped us produce this book. In particular we would like to thank the members of the MUSICIAN research team at the Universities of Manchester and Aberdeen.

Dr Ashraf El-Metwally, Dr John McBeth, Professor Philip Hannaford, Professor Gary Macfarlane, Dr Paul McNamee, Dr John Norrie, Professor Jackie Oldham, Dr Richard Potter, Dr Gordon Prescott, Professor Deborah Symmons, Dr Steve Woby

We would also like to thank all the people with widespread chronic pain that we have talked to and treated over the years. The insights shared with us by these 'experts by experience' have been invaluable in shaping the way we have written the book. This book is much better for what we have learnt by talking to people who actually know what it is like to suffer from pain. Thank you all.

This book was developed as part of a clinical trial funded by the Arthritis Research Campaign.

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Recovery Stories

Step one: What is this managing my chronic pain programme all about

Our world can be a hectic and challenging place. Despite modern conveniences and advances, many of us find it a difficult place to be. For people with chronic pain it can be even more challenging and we can become overwhelmed by our world. Paul and Carol feel overwhelmed with their pain and how it affects their lives and their worlds. These are their stories.

Paul

"I am only 48 but feel 88. I live with my wife and 2 teenage sons. My doctor said I am depressed, now there is a surprise - who wouldn't be depressed with this terrible pain. I have chronic widespread pain and my doctor has also told me I have joint hypermobility syndrome. I have read up on this and looked them up on the internet but knowing the ins and outs of these conditions does not take the pain away. I have pain all the time all over my body.

The worst part of it is that I feel like a different man than I was 7 years ago. I was working and doing the normal things like enjoying a pint and a game of darts down the pub. But since this started I am not even sure I feel like a man anymore. I have lost all my confidence and self esteem. I have 2 teenage sons and I should be guiding be them but how can I when I am like this? My family have suffered so much as well, I used to be happy go lucky, now I am irritable and angry all of the time. They are frightened of me and how I will react – and that makes me feel even more worthless.

I don't feel I have much of a life, I get up at 10am every day (my wife works and the boys go to school and college) and I don't do anything. I do try sometimes but I get so frustrated so I just don't do much anymore. I can't bear family or friends seeing me like this so we never go out. I don't sleep well either because of the pain, but also because I worry. I feel stressed all the time, mainly about money. I worry about my wife she has to do everything and work full time- if anything ever happened to her then I don't know what will happen.

I have read that you can manage the pain better but I don't know where to start and I am not sure I believe in all this psychological stuff – if they had this level of pain they would think differently. I would like to manage it better but I just don't know how to".

Carol

"I am 56 and live on my own, I have a daughter but she is now grown up and has a family of her own. As well as chronic widespread pain, the doctors have told me that I have Cervical Spondylosis and low back pain, I don't care what it is called, what I do know is that the pain is terrible. I have pain all over my body but my neck, shoulder and back pain are my biggest problems. The pain started about 10 years ago and it was manageable with pain killers until a couple of years ago when it got so much worse. I am in pain for most of the day. Having this has affected my life so much. I shouldn't grumble as there are so many good things in my life but this pain is there 24 hours a day. It has affected my life so much, I used to work, not a great job but I had so many good friends there and the money was handy. I have been off sick for 2 years now and am not sure that I will ever be able to go back.

I don't know what I would do without my daughter; she rings me every day and visits me once a week. She helps me bath and wash my hair, and does my shopping for me because I can't do them because of the pain. I really look forward to her visits as I don't get out much and although I want to I can't be doing with contacting friends. I don't really do anything anymore. I have stopped gardening because I am worried that this will damage my back more and may make my pain worse. Most days I spend my time watching the TV. I often cry and have been feeling so miserable. I try to pull myself together but it is very difficult. My sleep is bad and that just makes me feel worse, I can't sleep because of the pain. , I usually get to sleep at about 3am and wake up again at 6am. The doctor told me that sleeping in the day won't help me – but I don't know what to do – I just fall asleep on the sofa most days.

I feel bad in myself and don't know what I have done to deserve this. I take lots of painkillers (Ibuprofen, Co-Codamol and Anadin Extra) which do take the edge off the pain... What I want to be able to do is to manage my pain better, I would love to go back to work but if not meet my friends again. I also would like my sleep to be better and get out of this rut I think I am in. I just don't know where to start."

How could we describe Paul and Carol's problems?

If anything about the way Paul or Carol is feeling sounds like some of your own feelings, this book could help you. In fact, we have tried to write this book so that people learn how to deal with these kinds of feelings. Of course, everyone is an individual. Everyone is different. Even if you share some of Paul or Carol's feelings, you will also have very different experiences of your own.

In this book, we have included advice about using cognitive behavioural therapy (CBT) techniques that have been developed from medical research. However, we have also included things that people who have experienced chronic pain themselves have told us they have found useful. We believe that the combination of both sides will produce the most informative and practical guide to help people manage their pain. We hope you will find all the information helpful. Most of all, we hope you will be able to put some of these suggestions into practice.

At this point we want to reassure you that you are not on your own. We don't want you to use the book without support from other people. Managing your chronic pain is a team effort – a partnership. So first of all, let's meet the team. The team includes you, this book, your therapist and your friends and family.

Step one:

Meet your team

You: you are the most important person in this team. Only you know what you feel like at the moment. And only you can take the steps that are needed to get back to the way you want to be. Actually, you are the only person that really knows what this feels like. You are the expert in how you feel.

Asking for help is hard to do. There is no shame in doing so and you must have had real courage to seek assistance. It's a tough decision to admit you need help. We all like to think that we are invincible but the bravest people are those that know when to call for help. Well done for getting this far. Nothing in this book will take your strength away. In fact, we have designed this book to support you as you take steps to help you to manage your pain better. Although you might not feel it at the moment, they are the same courageous step that you took when you asked for help.

However, as we said earlier, this is a team effort. Although you are the person in charge of your own recovery, you are not alone. The next important member of the team is this book.

This book: this book will help you manage situations which you are finding difficult at the moment. When you are in pain concentration can be affected so we have tried to make the book as friendly as possible. The book is based on Cognitive Behaviour Therapy (CBT). Before we explain more about the book let us explain what CBT is.

Cognitive behaviour therapy (CBT) is a treatment which helps people to manage a wide range of difficulties. It was first used to help people who were experiencing depression and anxiety, but over the last few years it has been successfully used in many other areas for example obesity, sleep problems, chronic pain and other medical conditions.

CBT is a 'talking therapy' based on a view that the way we act (behaviour) and our thoughts (cognitions) and our physical sensations (feelings) are all interlinked and change what we do. CBT helps to identify the unhelpful and helpful feelings, behaviour and thinking that you have. It can help you to change the way they think and act and in doing so reduce the impact that a problem has on your life. CBT is about working in partnership with you and together looking at and trying the best solutions. CBT is an umbrella term and there are many interventions that can be used. With a therapist you choose the intervention that you think best suits you.

Some people feel that having therapy means that their pain or condition is not believed by health professionals or that they believe the pain is psychological in origin. But this is simply not true, pain is very real and there are many reasons why pain occurs, but what therapy can help with is learning techniques that help to manage the pain and importantly to reduce the impact it has on your life.

This book is divided into steps.

- Step 1: "What is this managing my chronic pain all about?" (This section).
- Step 2: "Understanding how this pain is affecting me."
- Step 3: "My programme." We describe ways to help you better manage your pain based on CBT.
- Step 4: "Continuing to manage my pain." Finally, we have written a step about continuing to manage your pain when you have completed your programme.

Steps one and two are important for everyone to read through. Step three is different. In it, we describe ways to manage your pain. In this step you can make choices between the different things described to help you. When you are managing your pain better, step four looks at things you can do to continue to manage your pain when the programme has finished.

The book is available in a written form or audio CD and you can choose which form you would prefer.

We have used stories to illustrate how you can use the different techniques we describe in the book. These stories are about ordinary people, not supermen or women. They show how real people with real problems can manage their chronic pain. Before we wrote these stories, we talked to a lot of people who have experienced chronic pain about what should go in this book. We also asked doctors and other health professionals for their advice.

The people who actually wrote this book are a team of researchers working in the NHS and universities. Our group includes nurses, psychologists, doctors and health researchers. All of us are committed to making life better for the many people who struggle daily with their pain. Everything we suggest in this book is something that we know someone else has found useful or something we ourselves have found personally helpful. All the techniques are things we would do ourselves. We would feel very happy recommending them to our own friends and relatives.

Your therapist: Your therapist will be someone who is an expert in Cognitive Behaviour Therapy (CBT). All the therapists are trained and experienced health professionals (nurses, psychologists, or doctors) and they are also trained and experienced in CBT. In addition to this they have had extra training by our team about chronic widespread pain and delivering therapy on the telephone. Each therapist has made a short DVD of themselves, which will be sent to you before you they contact you. Their role is to support you as you learn to manage your pain. They will help you understand your feelings and the impact it has on you. Most importantly, they will help you to choose the most useful exercises for you in the book. Managing chronic pain can be tough. So when you feel discouraged, your therapist will give you advice and offer you support through any difficult times. If you wish, they can also speak to a friend or relative with you.

Your therapist will telephone you every week for 8 weeks then again after 3 months and a final telephone call at 6 months. Telephone calls will generally last between 30-45 minutes. Your therapist will always try to contact you at a time that is most convenient to you.

You therapist is a really important part of your programme. Think of them like a personal fitness trainer. If you go to the gym or play sports, personal fitness trainers don't do the actual physical work of getting you fit. That's up to you. However, the trainer will help devise a fitness plan, monitor your progress and keep encouraging you when the going gets tough. Your therapist will act in the same way. They are there to support you.

Your friends and family: for many of us, our friends and families are usually the people we are closest to. They see when a person they know is acting differently. Sometimes of course, we try to hide how we feel from those closest to us. We feel embarrassed or we might want to protect them from how we feel.

Often, we try and hide our feelings and put on a brave face. Sooner or later however, people that know us well do see changes in us. They see the pain and tiredness. They may experience the results of our irritability. Many of us don't want to admit to how we are really feeling because we are embarrassed or worry that people will not understand. However, if we do talk about how we are feeling with those closest to us then we usually find they are concerned and supportive. The old saying that a "problem shared is a problem halved" may not be exactly true - but telling others about our feelings can feel very supportive.

We believe that families and friends are very important to helping to manage chronic pain. Everyone must make their own choices about what they say to whom. In general, however, we would encourage you to discuss both the way you are feeling and the programme in this book with at least one person you are close to.

Step one:

Tips for helping you manage your pain

To help you with your programme, here are some tips that have helped many people manage their pain.

Good and bad days: you are going to have some good days and some bad days. On bad days you will avoid looking at the book. You might even avoid speaking to your therapist. You will probably feel guilty about this. However, remember that this is what it feels like to be down. Sometimes we just want to avoid important things. If you have put the book down for a while or if you have missed a session with your therapist, don't feel guilty about it. Contact your therapist again. If you really don't feel able to make an appointment, just ring them and rearrange. They will understand and support you.

Keeping notes: because having chronic pain affects our concentration it is a really good idea to write things down. Keep a record of what you are doing, the exercises and plans you have made. When you begin to manage your pain you can look back at these and see just what progress you are making.

Make a step by step plan: at first it can seem very daunting to work on your problems. Step by step plans break down your recovery into manageable chunks. Doing little and often is the way to manage your pain.

Do something every day: just like trying to get physically fit, the best programmes involve regular activity. Try to do something from your recovery programme each day, even if it is just one thing. But remember, if you have a bad day it is not the end of the world. Tomorrow is an opportunity to try again.

Talk to friends, family and your therapist: support from friends, family and your therapist is vital. Keep talking to them. Let them know how you are doing.

If something is not working, try another thing: the book is full of different ideas and exercises. Some may not work for you. If this is the case, try another one. Make sure you discuss this with your therapist. She or he will help you make the right choices.

There are a number of ways that we know can help people with chronic pain – what you need to do is to look through the different techniques ns (your therapist will help you do this) and then work on this with you. But perhaps the best way to start is to ensure that you understand what you pain means to you and how it affects your life.

Step two:

Understanding how my pain is affecting me

How is your pain affecting you?

When people with chronic pain are asked how their pain is affecting them, the most common answer they give is how much the pain impacts on their daily lives. For example people say that some of the most enjoyable aspects of their lives are being avoided or curtailed because of the pain. This was highlighted in Paul and Carol's stories in the first section of this book. Being unable to deal with the pain usually means that people stop doing things they were doing before the pain started. This can be things that are part of their daily routine like not being able to do household activities such as shopping, cooking, vacuuming, working, socialising etc. Chronic pain often means that we stop working or that working becomes a struggle and it also affects our social lives and the things that we enjoyed doing. Chronic pain can have an impact on all areas of people's lives.

Before you choose some of the exercises that you will work through with your therapist, we need you to do two things. You and your therapist need to understand the impact that your pain is having on your life and also you may need to know a bit more about chronic widespread pain.

What is the impact of my pain on your life?

Many people with chronic widespread pain find that writing down the impact of their problems on their life is the first step towards helping them manage their chronic pain better. Although it may be quite distressing to list all these things, writing them down can give us something to aim for.

Your pain may affect your home life, your social life, your work and your personal relationships with partners, family and friends. The things you identify now are the things you really want to change. Use the questions below and discuss with your therapist how you pain is affecting you and then write them down on the sheet below.

- What exactly do you find difficult?
- Where and when is this difficult?
- Are the difficulties associated with specific situations or people?

Here is a copy of the IMPACT SHEET to help you decide what to write. Your therapist will help you to use this sheet to choose exercises to help manage your pain.

IMPACT SHEET	
Home – things around your house such as housework, cooking etc	The things to do with home that I find difficult because of my low mood are:
Work – paid, self-employment, home working or caring for others	The things to do with my working that I find difficult because of my low mood are:
Relationships – family and close relationships with others	Things to do with relationships with others that I find difficult because of my low mood are:
Social activities – being with other people	Things to do with being with other people that I find difficult because of my low mood are:
Personal activities – doing things alone which you enjoy such as reading	The things to do with personal activities that I find difficult because of my low mood are:

Step two:
Some Information about Chronic Widespread Pain

There is no way of knowing whether one person's experience of pain is the same as another's, however most people report their pain as unpleasant – leading to loss of function. Pain is the most common reason for people going to their GP.

Sometimes there are obvious reasons for a person presenting to their GP with pain, for example in the case of a fractured arm, however sometimes the cause is unclear. This is more often the case with chronic conditions, for example chronic widespread pain. Often people with chronic widespread pain are frustrated that exhaustive tests have been unable to find the cause of their problem.

Fibromyalgia is a name for chronic widespread pain affecting muscles and tendons. People with fibromyalgia may feel pain throughout their body and report having "tender points". The condition may last for several months or years.

A person suffering from chronic widespread pain may look well to other people who may not understand your pain and tiredness – this may be frustrating to you.

In the case of chronic widespread pain, the pain does not cause long term damage – however muscle weakness, stiffness and loss of function may occur if the experience of pain leads to avoidance of activity.

Living with chronic widespread pain is challenging and can lead to emotional problems (anger, low mood), avoidance of activity (work, social life) and lead to negative thoughts about the future.

We do not know exactly what causes chronic widespread pain and there are no known cures at the present time.

What most people with chronic widespread pain want is to decrease the impact that the pain has on their everyday life. An important first step in better managing pain is to have knowledge about what is happening to us. There is no single way a person who is in pain feels. It is an individual experience. However, there are many similar feelings which people have. The following section describes a model that many people use to help them understand and better manage their pain.

Pain has an effect on three different parts on us:

- Things we feel physically (the physical symptoms/feelings of pain)
- Things we do or stop doing
- Things we think

Things we feel physically include the physical symptoms you experience with pain. These may include sensations such as shooting, nagging, dull aching types of pain, but may also include difficulty sleeping, sleeping too much, exhaustion, fatigue, poor concentration, tearfulness, or poor appetite.

Things we do or stop doing include avoiding things because we feel they might be too difficult or because we fear they will cause more pain. We end up not doing things that we previously enjoyed and often our daily routine becomes disrupted.

Things we think include worthless or angry thoughts which make us feel less confident. People might have thoughts that the pain will get worse and end up in a wheelchair or dependent upon others. Some people have thoughts that life is not worth living, whilst others may have definite thoughts of killing themselves.

Step two:
The 'Vicious Circle' of Chronic Widespread Pain

Things we feel do and think are all related to each other. For example, our physical feelings can lead to changes in the way we do things and the way we think. If we stop doing things we can feel worse physically and have very negative thoughts. These thoughts can mean that we stop doing things and make our physical feelings worse.

This 'vicious circle' of unhelpful thoughts, changes in behaviour and physical symptoms can make the pain less manageable. Here is an example:

June

June has been experiencing chronic widespread pain for 3 years. She has pain in different parts of her body which she describes as 'aching…stiffness…dull…stabbing pins and needles…tingling…tightness…' and this is associated with fatigue and at times with 'blinding headaches'

On a bad day (usually about 3-4 times a week) she has total bed rest even though lying for long periods aggravates the pain. June is unable to do many of the household jobs and worries that they may make her back worse. June feels she can't do anything and does not go out or get any pleasure from her previously enjoyed activities. She has stopped meeting friends and has become withdrawn and isolated. She worries that her pain will become worse and will become more dependent on others for everything. She also feels she has "let herself go" in terms of her personal appearance. She feels guilty and angry that she can not do more for herself and suffers from lack of confidence. The more June has these thoughts, physical symptoms and behaviours the worse her pain is and the less control she has over her pain. This 'vicious circle' of thoughts, physical symptoms and changes in behaviour is making the pain worse.

For example, because June has total bed rest 3-4 times a week, this increases her physical experience of pain (lying down aggravates the pain), which evokes more thoughts of dependency on others, frustration and guilt. This leads to her becoming more and more withdrawn and isolated. This and other vicious circles are keeping June feeling less and less in control of her pain.

Step two:
Your own physical symptoms, behaviours and thoughts

Now let's think about you. What are your physical symptoms, behaviours and thoughts? Below is a copy of a sheet that you can use to write down how your pain is affecting you. Just jot down the main areas where your physical feelings, the things you do and they way you think are a problem for you.

It can be quite difficult to write these things down. It is like bringing everything out into the open. Your therapist will help you with this during in the first or second session.

MY OWN PHYSICAL FEELINGS	THINGS I DO OR HAVE STOPPED DOING	MY THOUGHTS

Have a look at your lists above. Can you identify how the three areas are linked? Write this in the space below. Once again, your therapist will help you with this.

MY PHYSICAL SYMPTOMS, BEHAVIOURS AND THOUGHTS ARE LINKED IN THE FOLLOWING WAYS:

Step two:
Setting some goals

Now you understand how your physical symptoms, behaviours and thoughts fit together you can use your knowledge and your therapist's knowledge and skill to choose some treatments and activities from this book. You already know how your pain affects you life; you wrote this down a few pages ago on the impact sheet.

Many people find it a really good idea to set themselves some goals to start managing their pain better. You should base these goals around the areas where your life is affected by your pain. That way you can do something really positive to overcome the impact of your pain on your life. Remember that your therapist will help you with this.

Goals in Detail

You are the person who can decide what you want out of your treatment. These will be your goals. Goals will help you to:

- keep focussed on your recovery
- be clear about what you want to achieve
- give you feedback on your progress

A goal is what you want to be able to do at the end of your treatment. You should be as clear as you can. You may want 'to feel better' or 'to feel less pain' but ask yourself what 'feeling better' means you will be able to do.

Examples of a person's specific goals:

To go to sleep in 30 minutes 6 nights a week

To meet friends for lunch once a week

To go for a 20minute walk every day

Your goals

What are your goals? We have provided some sheets for you to write them down. Your therapist will help you with this. Working with too many goals can be confusing. We would advise you to work with between one and three goals. Here is some advice for setting your goals:

- Ask yourself what you want to be able to do
- Be as specific as you can by stating how often you want to do something
- Set realistic goals, things you want to do in the future or used to do in the past
- State goals positively, start with 'to be able to …' rather than 'to stop ……' e.g. 'to be able to stay awake in the day' rather than 'to stop falling asleep in the day'

Goals are things to aim for. Choose things that your pain is getting in the way of. Because of this, they should be things that you are struggling with at the moment. The techniques in this book are designed to help you reach your goals. So that you know how you are doing, we have written down a simple scale underneath each goal. Circle one of the numbers for each one. This will tell you how difficult you find each goal.

At the moment, you should choose goals that are difficult. As time goes by, however, we hope that the techniques you try will help you to mange your pain better. As you do this, your goals will be easier to achieve. Re-rating them every now and then using the same scale is an excellent way to monitor your own personal progress. Aim to do this at least monthly with your therapist.

MY GOALS

Today's date______________

Goal number 1

I can do this now (circle a number):

0	1	2	3	4	5	6
Not at all		Occasionally		Often		Anytime

Goal number 2

I can do this now (circle a number):

0	1	2	3	4	5	6
Not at all		Occasionally		Often		Anytime

Goal number 3

I can do this now (circle a number):

0	1	2	3	4	5	6
Not at all		Occasionally		Often		Anytime

Step three

Your own physical symptoms, behaviours and thoughts

Ways of managing your pain

There are a lot of different things you can do to try to manage your pain and reduce the impact it is having on your life. Probably the last thing you want to do right now is make a choice from a great long list of options. This is where your therapist comes in. Your therapist will work in partnership with you and will help you make the best choice with you.

A few pages ago you looked at your problems in terms of your own physical symptoms, behaviours and thoughts. You saw the way June experienced her pain (pg). You also looked at the vicious circle of your physical feelings, behaviours and thoughts. There was a very good reason for this.

Treatments for chronic widespread pain can be divided into techniques designed to improve our physical symptoms (feelings), strategies to alter our behaviours and ways to help us think differently. The idea is to get the vicious circle working in reverse. If our physical symptoms improve, our behaviours and thoughts can also change for the better. If we choose a technique to change our behaviours, thoughts and physical symptoms can change. Changing thoughts can lead to different behaviours and improved physical symptoms. Your vicious circle can be turned into a 'recovery circle'.

Now is the time to step into your recovery circle. In the following pages we describe a number of very useful ways of improving the way you feel. They are not in any particular order of helpfulness. Some people use one intervention; other people like to try a number of them.

Your therapist will help you decide which of these techniques might be the best place to start. However, to help you make a choice, we have collected some stories for you to read. They are stories about ordinary people who have used some of the ideas in this book to cope with their chronic pain. You may wish to read some or all of these stories first. You can find them on pages

Improving the way I feel physically

In the next few pages we have listed the common physical symptoms experienced by many people with chronic widespread pain. These are the symptoms that can really interfere with your daily lives. We have written down some ideas which you could use to help you improve these symptoms. If they sound like the kind of things that you would like to try, you should discuss them with your therapist.

Poor Sleep

Our sleep is often disturbed when we have pain. Sleep problems can take many forms. Some people have difficulty getting off to sleep. Some people wake early in the morning and are unable to get back to sleep. Some people wake frequently in the night whilst others sleep but wake up without feeling rested. Some people sleep too much, sleeping throughout the day. This can be because they feel so much pain and they think sleep will help the pain or at least give them some respite from it. Other people sleep a lot because they feel tired and have lost energy.

If your sleep is disturbed here are some useful dos and don'ts about sleep which you could find helpful.

- Try not to sleep in the day. The problem with not sleeping at night is that we then feel down, tired and washed out. This tempts us to nap in the day. Unfortunately napping in the day just creates another vicious circle. The more we take daily naps, the harder it becomes to sleep at night.
- Ensure that you prepare yourself for sleep before going to bed. Try to relax for an hour or so before going to bed. Some people find it useful to have a warm bath or a milky drink.
- Eating a large meal in the evening may prevent sleep, so try to eat earlier.
- Don't drink tea or coffee before going to bed. Both tea and coffee contain caffeine. Caffeine is a stimulant and will keep you awake.
- If you cannot get to sleep, try to relax your body and mind. Focus on resting rather than sleeping. For some people doing some mental relaxation exercises can help.
- Try to go to bed and get up at the same time each day. Keeping to the same routine every day is more likely to restore your sleeping pattern.
- Try to do some exercise every day. This could just be a brief walk, swimming or some exercise alone. 'Little and often' and 'start small' are good pieces of advice. A ten minute walk every day is a great start.

Problems with Eating

When some people are in a lot of pain they can lose their appetite. For other people, they find that they eat more to comfort themselves. Cooking a meal can be a problem when we are in a lot of pain, this may be because the pain or fatigue mean it is just too much effort. We stop bothering to cook shop or prepare a meal. If our appetite is poor it can seem like there is little point in making the effort. Even if we are tempted to eat, we tend to choose convenience or 'junk' foods. This kind of food makes us feel temporarily better but quickly leaves us craving for more.

If your chronic pain is causing you a problem with eating here are some useful dos and don'ts which you may find helpful.

- Try to eat small meals regularly. It is often easier to face small amounts of food often rather than a huge meal all at once.
- If you don't want to make a lot of effort to prepare food, try to buy healthy food that doesn't need much preparation. Fruit, yoghurts, salad and fish are examples of foods which are easy to prepare.
- Try to avoid too much comfort eating – it rarely feels comforting in the end. It is easier not to buy it at all when you go shopping than to resist eating it when it is in the cupboard.

Feeling Irritable

Irritability, frustration and anger are a common experience for many people when they are in pain. We can become intolerant of people and snap at them. We do this with our loved ones, our work colleagues and even people we don't know. In turn, this can make us feel guilty about the way we are behaving. Guilty thoughts are very common when we are in pain. They can make us feel even worse.

If irritability is one of your symptoms here are some useful dos and don'ts which you could find very helpful indeed.

- Try reminding yourself that the way you are feeling is because of your pain.
- Explain to your family and friends how chronic pain affects people. You could ask them to read this book, particularly the stories. It is also possible to get your therapist to talk to your family. The main idea is for you to help your family and friends understand that your irritability is a symptom of your pain.
- Many people find they need help to relax. Some simple relaxation exercises might help here. Listening to your favourite music is another good way to relax.
- From time to time, even the most placid person needs to take time out. Many people experiencing chronic pain find that one thing that helps is to have some respite from their day to day lives. Respite can be anything. Mostly it will include something that you find pleasurable, something just for you. This could involve a simple activity such as having a relaxing bath or listening to some favourite music. Other people find that telephoning a friend or going out with friends or family a good way to distract themselves.

Lack of concentration

Experiencing difficulties with concentration can be a very distressing symptom of chronic pain. Many people find that they cannot pick up and read a book or newspaper anymore. Even the thought of reading can be very difficult. Our memories seem to deteriorate and we forget what we have just read or heard. This can happen in conversation with people, not just when reading or watching the TV.

Actually, our concentration may not be as bad as we fear. In fact, when we are in a lot of pain we tend not to listen as carefully as we normally do. Because we don't listen clearly, we don't remember information properly. We then end up worrying about our concentration. Once we start to worry, our concentration gets even worse. It's another vicious circle.

If concentration is a problem for you here are a couple of useful ideas which you may find helpful to try.

- One useful suggestion is to write things down. It can be very helpful to keep a list of important things to do. Sometimes repeating what somebody has said either out loud or in our head can help with remembering things.
- Because our concentration can be affected when we are in pain we often simply stop doing things like reading. One solution is to read regularly but for small periods of time only. Alternatively, we could read something that is slightly easier to digest than the material we are used to.

Fatigue and exhaustion

Fatigue and exhaustion are very common for people who experience chronic pain. People experience a loss of energy. Loss of energy is a key symptom of pain and is closely linked to tiredness and fatigue. Energy loss is another vicious circle. The less we do, the less we want to do. However, for some people with pain – when the pain is less severe they have spurts of energy and tend to overdo it and consequently feel much worse the next day. Some people become fatigued because of 'booms and busts' which is when people do lots on one day but then feel exhausted for the next 2-3 days (the best way of managing this is explained in the next section).

If fatigue and exhaustion are a problem for you here is a useful idea which you may find helpful to try.

- Although it sounds very difficult to do at first, taking some exercise will actually help with loss of energy. The idea is to break the vicious circle of tiredness followed by inactivity and more tiredness. Try to plan some exercise into your day every day. Set yourself small goals – this might be a walk, a slow swim or anything that involves even a small amount of movement. An important thing to remember is that exercise is unlikely to make you any more tired than you already feel. We have suggested some techniques in the next section which might help you plan some exercise into your daily routine.
- Pacing your activity is very helpful for people who alternate between resting some days and overdoing it on others. Pacing yourself means structuring your day so that it is balanced by activity periods followed by rest periods.

Step three
Changing the things I do

Behavioural Activation

So far in this book we have discussed how pain often consists of feeling physically unwell, thinking unhelpful thoughts and changes in the way we behave. As we have shown, these feelings, thoughts and behaviours are all linked. We can end up in a vicious circle where we withdraw or avoid doing the normal things that we do.

Your therapist will discuss behavioural activation in more detail for you but basically it means planning, structuring and pacing your activities as well as incorporating planned rest periods and gradually building them up to a level that is right for you.

When we have chronic widespread pain, it is often the pain that controls what we do or don't do. Generally we do one of two things, either we stop/avoid or greatly reduce all of the things we used to do, or we wait for the pain to become more tolerable and rush around to get as much done as possible (but this often results in feeling much worse later on). This is often referred to as 'boom and bust' behaviour. Although it is understandable why we do this it is problematic in that the level of pain determines our activities and life. Our lack of control can make us feel hopeless, unhappy, anxious etc.

Behavioural activation is a technique which aims to help you to be in more control of your pain by planning, pacing and structuring your activities differently, and making sure that there are planned rest periods. Research into pacing has shown that this technique makes you feel more in control of your pain, can help reduce the amount of medication that you take but most importantly helps to increase the things you want to do.

- Some of the things that are disrupted when we experience chronic pain are regular, routine activities such as cleaning the house or car, washing up, cooking a meal, gardening etc. Our sleeping and eating routines also become disrupted. We change the time we go to bed or get up, when we eat and how we cook and care for ourselves.
- Other activities that get disrupted are the things we do for pleasure. These can include seeing friends, enjoying a day out with our families, reading or doing whatever interests we have.
- The third area where our lives can become disrupted are important necessary things such as paying bills or confronting difficult situations at work, home or in our close relationships. Although the consequences of not doing these things can be quite serious, when we are in pain we often avoid doing them.

Behavioural activation is a technique where we focus on re-establishing our daily routines, (or for some people develop new routines), increase our pleasurable activities and do the things that are necessary for us. It also makes sure that our activities are paced by ensuring that there are structured rest periods.

How do I start to do this?

There are four stages to behavioural activation. If you choose to try it, your therapist will help you to make a start.

- Stage 1 is to fill in a weekly diary of what you are doing now
- Stage 2 is to think about activities that you would like to do or that you wish to start doing again. Some of these things will be routine things. Other things will be pleasurable activities such as going out and meeting people and some things will be important activities that may need to be dealt with quickly
- Stage 3 is to make a list of many of these different activities. You write the most difficult things at the top of the list and the easiest activities at the bottom. When making these lists it is a good idea to make sure that you have some routine, some pleasurable and some necessary activities evenly spread throughout.
- Stage 4 is using the behavioural activation diary to plan out how to start doing these things. You can do this by starting with the easiest activities first and adding activities which are more difficult as time goes on. It is important that you build in regular rest periods.

At each stage you will be able to discuss your plans and activities with your therapist. If you wish to read a story of someone who has chosen behavioural activation as part of their programme then go to page???

Step three
Behavioural Activation - stage one

Take a blank behavioural activation diary. Each day, write down what you do. Try to be specific and try to fill in each square. Even if you think that you have done nothing, make a note. This is all helpful information. When you record your activities write down some details about what exactly you have done. It can be helpful to record details such as where you were when you did things and if you were with anyone.

BEHAVIOURAL ACTIVATION DIARY

		Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
Morn	What Where When Who							
	What Where When Who							
Aft	What Where When Who							
	What Where When Who							
Eve	What Where When Who							
	What Where When Who							

Step three
Behavioural Activation - stage two

Think about the things that you want to do. Some of these things will be activities that you have stopped doing since you have started to feel pain, but may well include new activities. This will be discussed in detail with your therapist. Remember to include routine activities which need to be done such as housework and cooking. Also include pleasurable activities that you would normally enjoy. Finally try to think of things that are necessary such as paying bills, dealing with conflict or activities associated with home.

Use the Behavioural Activation Worksheet A below to list all these activities. Put them down in any order you like.

BEHAVIOURAL ACTIVATION WORKSHEET A

Write down your routine activities here:
e.g. cleaning, cooking, shopping etc

Write down your pleasurable activities here: e.g. going out/visiting friends or family	Write down your necessary activities here: e.g. paying bills etc

Step three
Behavioural Activation - stage three

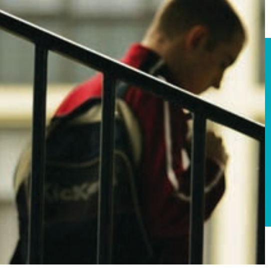
Use Behavioural Activation Worksheet B below to organise all these different things into a list, with the most difficult activities at the top of the list and some easier activities at the bottom. Try to make sure that you mix up routine, pleasurable and necessary activities in the bottom, middle and top of the list.

BEHAVIOURAL ACTIVATION WORKSHEET B

Now try to put your lists in order of difficulty.

MOST DIFFICULT

MEDIUM DIFFICULT	**EASIEST**



Step three
Behavioural Activation - stage four

In this last stage you should take a blank diary sheet to plan out how to start doing some of your activities. Take some routine, pleasurable and necessary activities from near the bottom of your list and write in your diary when you would like to do them. Try to make sure that you include sufficient rest periods.

Once again, being specific is helpful. Write down what the activity is where it will be done, when it will be done, how it will be done and if it includes other people who it will be done with. Writing things down this clearly will help you when you actually come to do the activity.

Try to schedule an activity at least once a day, more if you wish, but for most people it is best if you start with something fairly easy and for a short period of time.

When you have tried to do some of the activities you have listed, discuss your progress with your therapist. Over time, you can move up your list to do other things. You can go at your own pace and your therapist will support and encourage you.

For many people even doing what were once pleasurable activities may not bring immediate pleasure. To start with, people often feel a sense of achievement rather than actual pleasure. As the weeks go on you should find that you develop a routine. The main thing with behavioural activation is to plan carefully and keep going.

BEHAVIOURAL ACTIVATION DIARY

		Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
Morn	What Where When Who							
	What Where When Who							
Aft	What Where When Who							
	What Where When Who							
Eve	What Where When Who							
	What Where When Who							

Step four
Changing the way I think

Cognitive restructuring

Cognitive restructuring is a way of changing our unhelpful thoughts by looking at them and challenging them. When we have chronic pain we have many thoughts. Some of these thoughts may be about the impact the pain is having e.g. "I can't do any of the things that I did before", or "my body feels like a prison of pain". They may be thoughts about the stigma of the pain e.g. "People don't really understand what it is like to have this pain" or "I can't tell people how bad it is because they will feel sorry for me". They may be thoughts about to control the pain such as "when I have a good day I do loads but always pay for it the next. I know it is not the right thing to do, but I just want to make the most of the opportunity of painlessness when I can", or "resting will help me recover". Other thoughts are linked to emotions such as anger "Why me" or guilt "I feel I am a burden on others and terrified of becoming dependent" or anxiety/worry "If I do anything physical it will make the pain worse".

Some of these thoughts may be unhelpful and often stop us doing things that we want to. The more unhelpful thoughts that we have, the more we believe them, the less confident we become, the less we do which increases the physical the pain we experience. We can then have even more unhelpful thoughts. It is yet another vicious circle.

The features of unhelpful thoughts are:

- they are automatic. We don't think them on purpose, they just appear in our heads
- they seem believable and real at the time they appear.
- they are the kind of thoughts that would upset anybody

You can use cognitive restructuring to help you to put your thoughts in perspective. A helpful example is given in one of the recovery stories on page???? of this book. If you want to use this technique your therapist will support you.

The stages of Cognitive Restructuring

There are three stages to cognitive restructuring.

- Firstly, you need to identify exactly what the content of your unhelpful thoughts are.
- Secondly, you do something to help you examine the thought more objectively. Sometimes this includes collecting 'evidence' as to how accurate the thought really is.
- Finally, you reconsider the thought in light of the evidence you have collected. You can then put the thought into perspective.

How do I do cognitive restructuring?

If you want to do some cognitive restructuring you can use a thought diary to collect and write down your thoughts.

Step three

Cognitive restructuring - stage one

Each time you feel sad, depressed or irritable, anxious, worried, frustrated or guilty:

- Write down in the first column of your thought diary a brief description of the situation where the thought occurred. You should write down where you were and what you were doing.
- In the second column write down the actual feeling you had. This may be sad, anxious or angry. Also record how bad that feeling was on a scale of 0–100%. 0% is not at all, 100% is the worst it could be.
- In the third column write down exactly what your thought was and how much you believe that thought to be true. Here 0% is "I do not believe this at all", 100% is I totally believe this thought". An example can be found on the thought diary
- For the time being, ignore the last two columns as you start the diary.

THOUGHT DIARY

SITUATION	FEELING Rate how bad it was (0-100%)	THOUGHT Rate how much you believe this thought (0-100%)	REVISED THOUGHT Rate how much you believe this thought (0-100%)	FEELING How bad was it? (0-100%)
Eg. Sitting doing nothing	Sad (70%)	Things will nver get better (90%)		

We suggest that you should collect your thoughts for two weeks in this way. You will be regularly discussing with your therapist about what you have written in your thought diaries. Often these thoughts might be all about a similar topic, such as guilt or feeling a failure. Such thoughts are very common when we are experiencing chronic widespread pain.

Step three

Cognitive restructuring - stage two

Stage two is all about collecting some kind of evidence to see if you're thought is accurate or not. There are many ways to collect evidence. Some are more difficult than others. In this book we have described one of the most common ways and straight forward ways to do this. It is also one of the most straightforward to use yourself.

We suggest that you examine a frequent thought in more detail from the ones you have collected. To do this, take one thought that you have rated yourself as believing in at least 60% and which is causing you distress.

Write the thought down on top of the 'evidence table'. Add in your percentage rating of how much you believe it. In the evidence table, one column is labelled evidence for and one is labelled evidence against.

Next, imagine that you are the judge in a court where the evidence for and against the truth of your thought is being examined. Write down the evidence for and against the thought being true. Remember that you are the judge and you need to present the full picture so that a fair decision can be made.

EVIDENCE TABLE

MY THOUGHTS	MY BELIEF (%)
Evidence for	Evidence against

Sometimes people find this quite difficult. People particularly find it difficult to come up with evidence that the thought is not true. To help you to give your thought a 'fair trial' uses some of the following questions:

- If my best friend or partner were giving evidence, what would they say for and against this thought?
- If you rate the belief in your thought as 75%, then there is 25% of the thought you do not believe to be true. Ask yourself what makes up that 25%.

Do remember that you therapist will help you with challenging your thoughts.

Step three
Cognitive restructuring - stage three and four

Stage three

Now you need to reconsider the thought in light of the evidence you have collected. You should be able to come up with a revised thought. Use the fourth column of the thought diary to write down this new thought. You should also rate how much you believe the revised thought.

In the final column rate your feelings again using the same 0-100% scale. Notice how by changing your thought, your mood has also changed. This is the way cognitive restructuring can really work to change the way you feel.

Here are some tips to make cognitive restructuring easier

- Unhelpful thinking takes time to change. Often you will need to challenge your thoughts several times before change takes place.
- Ask a friend you trust to help you look for evidence for and against your unhelpful thoughts
- Practise cognitive restructuring with other thoughts. Use your evidence table to judge them.
- As you become more expert in this, try to catch the thoughts and judge them as they actually occur.
- Carry your diary with you so that you can catch and challenge your thoughts straight away.
- Your therapist will also show you other techniques to help you. He/she will show you how to carry out some 'experiments' to test out whether your beliefs are valid. For example the person who feels that they are not able to do anything might with support from their therapist test this thought out by trying something new.

Stage four

How to continue with my progress

Many people ask what happens when their programme has finished. We would suggest that it is your programme and you should continue with it, including keeping your diaries until you feel that your new routines have become fully incorporated into your lifestyle.

Your therapist will discuss in detail with you before the end of the sessions how to keep your routine going and how to cope with 'bad days'. With your therapist you will devise a plan of how to help you continue with your progress.

There are two ways to increase the chances of you staying well.

- Keeping a healthy lifestyle
- Continuing to build on the progress you have made

A Healthy Lifestyle

We know that the things we do in our lives have an important effect on managing chronic pain. Lifestyle activities such as regular exercise, positive relationships with other people and making sure we allow time in our lives for things that give us pleasure all help to keep our mood stable. A balanced diet is another important factor in keeping well.

We suggest that towards the end of this programme you have a look at your overall lifestyle. See if you wish to identify any changes that could help. Pay attention to exercise, scheduled rest periods, diet, sleep, having a balance between duties and pleasures and your close relationships. Is there anything that you could do to make any of these aspects of your life more positive? If there is, it could be a really good idea to make some positive changes in the next few weeks.

Continuing to build on the progress that you have made

During your programme, you will have discussed what to do if you start to fall back into your unhelpful routines. With your therapist, you will have written down a plan in case this happens. This plan will be individual to you. It will include monitoring your pain, recognising if problems are happening again, and dealing with setbacks. However, we have outlined the basic principles below.

- During this recovery programme you have probably learnt a lot about the way you feel about your pain. You will have understood your pain in terms of the way you feel, the physical symptoms, the things you do or have stopped doing and the things you think. We suggest that you pay attention to these aspects of yourself on a regular basis. Notice if you begin to experience any of these feelings again. These could be potential early warning signs that you having stopped managing your pain as well as you had been.

Recovery stories
Haifa

Haifa's story is about someone who used a technique from the book which is aimed at improving some of the physical symptoms of chronic pain.

Haifa is 39 years and works as a supply teacher. He was diagnosed with chronic widespread pain 5 years ago, but like many people he realised there was something wrong long before it was diagnosed. He described pain all over his body but severe pain in his back and neck which varied from day to day but was made worse by stress and cold weather. Haifa also described 'tender points' in his back and neck which were painful to touch.

Haifa is married with young children and although his family are supportive he feels he misses out a lot on family life. He has large extended families who offer to help him in any way they can and he appreciates their support, but he thinks that they don't really understand how he feels. He feels very frustrated and angry and does not understand why this condition has happened to him or what he has done to deserve this illness.

His pain has had a major impact on his life; he has changed his employment from full time teaching to working as a supply teacher. He left his permanent full time post as Head of Maths because of long periods of sickness and absence. Although he continues to work when he can (usually 1-2 days a week) he finds it much less rewarding than his previous job. Haifa also feels that fatigue is a major problem. He feels too tired to do anything and has lost interest in activities that he used to enjoy. He said "I am so tired all the time. I just can't be bothered to do anything anymore. Everything feels like a struggle". He used to enjoy having large family meals but now finds it hard to cope with and usually avoids going. This has caused some friction between him and his wife and family. He also describes his concentration as poor. His sleep is disrupted because of the pain and he feels that things would be much better if he could sleep better. He tried sleeping tablets a few years ago and they helped a lot but then they stopped working after a few months.

He has difficulty getting off to sleep and wakes often. He describes having about 2-3 hours sleep a night. Haifa describes feeling exhausted when he wakes in the morning. He often does not bother going to bed and falls asleep on the sofa. He said that he often drops off to sleep in the day because he is so tired. He is too tired to make love with his wife and this is also causing a strain on their relationship. All the problems have led to lack of confidence and low self esteem. In many ways Haifa finds the exhaustion more difficult to cope with than the pain.

With the help of his therapist Haifa decided on the following goals

HAIFA'S GOALS

Goal number 1

To sleep for 6 hours a night

I can do this now (circle a number):

[✓ 0]	1	2	3	4	5	6
Not at all		Occasionally		Often		Anytime

Goal number 2

To enjoy a large family meal once a week

I can do this now (circle a number):

0	[✓ 1]	2	3	4	5	6
Not at all		Occasionally		Often		Anytime

Goal number 3

To work 3 days every week

I can do this now (circle a number):

0	1	[✓ 2]	3	4	5	6
Not at all		Occasionally		Often		Anytime

Recovery stories
Haifa

Haifa read through some of the techniques in his book and decided that he would like to do something to improve his sleep. His therapist suggested that he kept a sleep diary. Haifa recorded the following:

- what time he went to bed
- what time he fell asleep
- what time he woke up
- details of other times of the day that he slept and for how long

Haifa kept the diary below for a week

At the next session with his therapist Haifa discussed the sleep diary. He was able to see clearly that his sleep pattern was probably not helpful. He was surprised at how infrequently he even tried going to bed (except when he was working the following day).

Haifa decided to try and change his sleeping routine. With the help of his therapist they agreed that for the first week Haifa would go to bed every night rather than sleeping on the sofa. He agreed that he would go to bed at midnight every night. He was also encouraged to try not to sleep during the day. At the next telephone appointment with his therapist Haifa had managed to do this every night. It was still taking him an hour to get off sleep and he woke at 5.00am. For Haifa this was a great improvement as he rarely slept for a 4 hour stretch. His sleeping had reduced in the day but he still found himself sleeping for about 2 hours. Over the next few weeks Haifa developed a sleep pattern that allowed him to structure his days better. Although he still woke at 5.00am he would get up, walk around to ease his stiffness and sleep from 6.00am to 8.00am. This meant he was sleeping about 6 hours every night. He stopped sleeping in the day and found that he was much less tired than he had been previously. As he was less exhausted he started to be more active in the day. Haifa also felt he was less irritable with his family. At the end of 8 weeks of his sessions Haifa felt that the impact of his exhaustion had reduced a lot. The tension in his relationship with his wife had reduced and he was able to work 2 days a week consistently and was thinking of increasing this to 3 days a week. His pain levels continued to fluctuate but he felt that overall his pain had reduced and felt that he could manage the pain much better now that he was less exhausted.

Six months later Haifa had made further progress, he was working 3 days a week, and regularly enjoying family gatherings.

Haifa scored his goal sheet again several times during his programme. His ratings went up as he started to feel better and achieve his goals. These are detailed in Haifa's goal summaries.

HAIFA'S DIARY

Mon	Tues	Weds	Thurs	Fri	Sat	Sun
Did not bother going to bed. Fell asleep on the sofa at 4.00am Woke at 7.00 am Fell asleep from 10.00am till 12.00 and again from 3.00 till 4.00pm	Went to bed at 11.00pm (work tomorrow) Woke at 2.00am and again at 4.00am. Got up at 5.00am (worked from 9.00am till 4.00pm) Fell asleep when I got home from 4.00pm till 8.00pm	Went to bed at 11.00pm Did not sleep at all (supposed to be working but rang in sick) Fell asleep from 10.00pm until 2.00pm	Did not bother going to bed. Fell asleep at 4.30am Woke at 7.30 am. Slept on sofa from 3.00pm until 6.00pm	Did not bother going to bed. Fell asleep at 3.30am Woke at 7.00 am Slept from 12.00 till 2.00pm and again from 8.00pm until 10.00 pm	Did not bother going to bed. Fell asleep at 4.30am Woke at 7.00 am Slept from 11.00 to 2.00pm and again from 9.00 till 11.00pm	Went to bed at 2.00am Slept from 3.00am till 5.00am Slept on sofa from 11.00am until 3.00pm and from 8.00pm to 9.30pm

HAIFA'S GOAL SUMMARIES

Goal number 1

To sleep for 6 hours a night

I can do this now (circle a number):

0	1	2	3	4	[✓ 5]	6
Not at all		Occasionally		Often		Anytime

Goal number 2

To enjoy a large family meal once a week

I can do this now (circle a number):

0	1	2	3	[✓ 4]	5	6
Not at all		Occasionally		Often		Anytime

Goal number 3

To work 3 days every week

I can do this now (circle a number):

0	1	2	3	4	[✓ 5]	6
Not at all		Occasionally		Often		Anytime

Recovery stories
Patricia

Patricia's story is about someone who used behavioural activation, a technique from this book which is aimed at increasing the things people have stopped doing because of their chronic pain by helping them to pace their activities and including planned rest periods.

Patricia is 48, divorced with 3 grown up children and lives with her youngest daughter who is 24. She has been in pain for 2 years and was diagnosed with chronic widespread pain. Doctors have told her that she has mechanical neck and low back pain, sciatica in her left leg and fibromyalgia. The pain became much worse 9 months ago and her movement has become increasingly restricted and she uses a stick to help her walk. She has been off sick from her job as an office manager for the last year. More recently she has become depressed and is taking anti-depressants as well as a number of painkillers. She has had problems with her mood in the past but now feels that because of the pain it has spiralled out of control.

Patricia uses a stick to help her walk and feels that everything she does is controlled by her pain. On 'good days' she is able to do some things but on 'bad days' feels that she does nothing. Patricia states "I try and make the most of my good days by catching up on lost time and cramming things in. This feels great at the time but the following day I am usually in agony and have to rest a lot more. She does not feel she has any routine in her life and is unable to plan anything because she cannot predict her pain levels. She had lots of thoughts such as "What if the symptoms get worse and I end up in a wheelchair" and "I want to manage better but I don't know how to". Since her pain had worsened and had stopped working she had lost contact with many of her friends because she felt ashamed of her illness and did not think her friends would understand. Her confidence and self esteem were low. She was walking much less than she used to. Patricia was dependent on her children to do the shopping, heavy housework like making beds and doing the washing because she felt these activities would damage her back and make the pain worse. She also picked up her granddaughter from school on 2 days each week whilst her daughter was working; often she was in too much pain and rang her daughter to say that she could not do it. This was causing some tension between her and her daughter. Although she slept reasonably well she often did not get up until lunchtime as she felt that there was nothing to get up for. Patricia had always enjoyed reading but because her concentration was poor she had stopped trying.

Patricia felt that these problems were having an impact on her life in many ways. She wrote on her Impact Sheet that a big problem was that she was lonely and wanted to meet with her friends again even though she felt too ashamed to. She also felt that she would like to do her own food shopping. Patricia felt that her lack of leisure activity was impacting her life as she did not do anything she used to enjoy like reading and going to the cinema. A big problem for Patricia was that she had got into debt, she had applied for a credit card in the previous year to help pay for her daughters wedding. She was getting letters from the credit card company and debt collection agencies but was ignoring them. This was causing her to worry and she had kept this a secret from her daughters.

With the help of her therapist Patricia decided on the following goals:

PATRICIA'S GOALS

Goal number 1

To meet a friend once a week

I can do this now (circle a number):

[✓ 0]	1	2	3	4	5	6
Not at all		Occasionally		Often		Anytime

Goal number 2

To read a book for at least 30 minutes a day

I can do this now (circle a number):

[✓ 0]	1	2	3	4	5	6
Not at all		Occasionally		Often		Anytime

Goal number 3

To sort out my debt

I can do this now (circle a number):

[✓ 0]	1	2	3	4	5	6
Not at all		Occasionally		Often		Anytime

Recovery stories
Patricia

Patricia read through some of the techniques in her book and decided that she would like to do something to help her get into a routine. She discussed this with her therapist and together they decided to try ‘Behavioural Activation’.

First of all, Patricia completed stage 1 of behavioural activation which involved completing a weekly diary of her current activities. She felt that it had been a typical week. As can be seen by the diary Wednesday had been a ‘good day’ but felt she had suffered for it the next day.

BEHAVIOURAL ACTIVATION DIARY

		Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
Morn	What Where When Who	Stayed in bed till 12.00	Stayed in bed till 12.00	Walked to Drs (5 mins away) at 10.30	Stayed in bed till 12.00	Stayed in bed till 11.00	Stayed in bed till 12.00	Stayed in bed till 12.00
	What Where When Who	Stayed in bed till 12.00	Stayed in bed till 12.00	Did a bit of tidying	Stayed in bed till 12.00	Up at 11.00 as Fran brought shopping	Stayed in bed till 12.00	Stayed in bed till 12.00
Aft	What Where When Who	Did a bit of housework (dusting)	Walked to local shop for milk	Cooked a casserole and made one for my daughter	Nothing, sat on sofa	Sat and did nothing	Daughter came to do the laundry	In pain – did nothing, sat on sofa
	What Where When Who	Sat and watched TV	Sat and watched TV	Picked up Tia (grandchild) from school	Supposed to pick up Tia but too much pain	Tired fell asleep on the sofa	Sat and talked to my daughter	Watched TV
Eve	What Where When Who	Made myself a ready meal	Looked through old photos and cried	Took Tia to the park	Overdid it yesterday – fell asleep on the sofa	Made self a sandwich	Watched TV Made self ready meal	Made self a ready meal
	What Where When Who	Nothing- sat and watched TV	In a lot of pain so went to bed early (9pm)	Did some housework and watched TV	Nothing – just sat and cried	Sat and watched TV	Watched TV	Watched TV

Patricia also completed the worksheets from stages 2 and 3 of behavioural activation. She made lists of routine, pleasurable and necessary things in her life. When she discussed these with her therapist it was clear that sorting out her debt was very important.

BEHAVIOURAL ACTIVATION WORKSHEET A

Write down your routine activities here:
e.g. cleaning, cooking, shopping etc

I don’t really have a routine, though would like to have a routine. I want to cook more as those ready meals are disgusting, but it is all I feel I can manage at the moment

Would like to get up at a regular time not lunch time

Daughter does my shopping and I clean my house (dust and tidy) when the pain is not too bad

Write down your pleasurable activities here: e.g. going out/visiting friends or family	Write down your necessary activities here: e.g. paying bills etc
Used to enjoy reading **Used to enjoy working (but not sure I am ever going to be able to go back)** **Enjoy picking my granddaughter up from school** **Used to enjoy going for a drink/out with my friends** **Used to enjoy going for walks**	**I feel so ashamed but I must sort my debt out as I am paying such a high rate of interest- I can’t even afford the minimum payment.**

Recovery stories
Patricia

BEHAVIOURAL ACTIVATION WORKSHEET B

Now try to put your lists in order of difficulty.

MOST DIFFICULT

Sorting out my debt

Meeting friends

Returning to work (but not sure if this is possible)

MEDIUM DIFFICULT

Picking Tia up from school

Going for a walk (think I could do this but only for a short distance)

Reading

Cooking a meal (a proper meal)

EASIEST

Dusting and tidying my flat

Cooking ready meals

Get up at a regular time and earlier

Patricia and her therapist discussed the Behavioural Activation Sheet 2 and planned some of the activities that she could do. One of the important things that the therapist discussed with her was to do the activities she had planned regardless of the level of pain. With routine activities she decided that she would do 30 minutes of dusting and tidying a day, followed by a 30 minute rest period. The therapist stressed that Patricia should only do 30 minutes even if she felt like continuing. Patricia also decided that she would get up at 11.00am every day instead of 12midday.

As well as the routine activities, Patricia decided to do one pleasurable thing and one task from her necessary list. She agreed to pick up her granddaughter 2 days a week. For the necessary activity she agreed to open all the unopened letters and find out exactly how much her debt was. To ensure that Patricia paced her activities planned rest periods were built in. Patricia's first stage 4 behavioural activation diary is shown here. It has a range of activities including routine (red), pleasurable (purple), necessary (blue) and rest periods (yellow).

PATRICIA'S FIRST BEHAVIOURAL ACTIVATION STAGE 4 DIARY

		Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
Morn	What Where When Who	Get up at 11am 30 mins housework	Get up at 11am 30 mins housework	Get up at 11am 30 mins housework	Get up at 11am 30 mins housework	Get up at 11am 30 mins housework	Get up at 11am 30 mins housework	Get up at 11am 30 mins housework
	What Where When Who	30 mins rest	30 mins rest	30 mins rest	30 mins rest	30 mins rest	30 mins rest	30 mins rest
Aft	What Where When Who			Pick Tia up from school	Pick Tia up from school		Sort out letters from the bank and credit company (30 mins)	Sort out letters from the bank and credit company (30 mins)
	What Where When Who	30 mins rest	30 mins rest	30 mins rest	30 mins rest	30 mins rest	30 mins rest	30 mins rest
Eve	What Where When Who							
	What Where When Who	30 mins rest	30 mins rest	30 mins rest	30 mins rest	30 mins rest	30 mins rest	30 mins rest

Patricia told her therapist the following week that she had managed to do most of the things in the diary. On the Sunday she had been in pain and not got up until 12.30 but had got up at 11am the rest of the week. She had been in "bad pain" on the Tuesday when she picked Tia up from school but had completed the task. She had found going through the letters very difficult but had established that her debt was £2000. Despite a difficult week Patricia was pleased with what she had done. She enjoyed the rest periods and felt that they were more restful than before she started the intervention because they gave her 'permission' to rest.

With her therapist Patricia planned her next week's diary. As we can see, she agreed to continue to get up at 11.00 and do 30 minutes housework. Patricia agreed to pick Tia up like the previous week but to go the park for 30 minutes. Patricia also agreed to cook herself a meal on Saturday evening. With her therapist she planned the menu, so that she knew which ingredients she should ask her daughter to get. Patricia also planned to ring her bank to make an appointment about her debt.

PATRICIA'S SECOND BEHAVIOURAL ACTIVATION STAGE 4 DIARY

		Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
Morn	What Where When Who	Get up at 11am 30 mins housework	Get up at 11am 30 mins housework	Get up at 11am 30 mins housework	Get up at 11am 30 mins housework	Get up at 11am 30 mins housework	Get up at 11am 30 mins housework	Get up at 11am 30 mins housework
	What Where When Who	30 mins rest	30 mins rest	30 mins rest	30 mins rest	30 mins rest	30 mins rest	30 mins rest
Aft	What Where When Who	Ring Bank and make appointment		Pick Tia up from school	Pick Tia up from school			
	What Where When Who	30 mins rest	30 mins rest	Pick Tia up from school	30 mins rest	30 mins rest	30 mins rest	30 mins rest
Eve	What Where When Who			30 mins rest			Cook meal for myself	
	What Where When Who	30 mins rest	30 mins rest	30 mins rest	30 mins rest	30 mins rest	30 mins rest	30 mins rest

A week later, the therapist rang Patricia. On 6 of the 7 days Patricia had got up at 11.00am, and had made an appointment with the bank for the following week. She was delighted with her progress and felt that she had started to develop a routine. Although her pain levels were not any different she was not doing the 'booms and busts' and she felt her pain was more controllable. She still felt low but was pleased with what she was achieving. With her therapist Patricia decided on the plan for the next week. As can be seen by the diary below, Patricia decided to get up 30 minutes earlier, cook a meal twice a week, ring a friend from work and perhaps most importantly go to the bank for her appointment.

PATRICIA'S THIRD BEHAVIOURAL ACTIVATION STAGE 4 DIARY

		Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
Morn	What Where When Who	Get up at 11am 30 mins housework 30 mins rest	Get up at 11am 30 mins housework	Get up at 11am 30 mins housework	Get up at 11am 30 mins housework	Get up at 11am 30 mins housework	Get up at 11am 30 mins housework	Get up at 11am 30 mins housework
	What Where When Who	Appointment with Bank Manager	30 mins rest	30 mins rest	30 mins rest	30 mins rest	30 mins rest	30 mins rest
Aft	What Where When Who			Pick Tia up from school	Pick Tia up from school			
	What Where When Who	30 mins rest	30 mins rest	Pick Tia up from school	30 mins rest	30 mins rest	30 mins rest	30 mins rest
Eve	What Where When Who		Cook a meal for myself	30 mins rest	Pick Tia up from school		Cook a meal for myself	
	What Where When Who	30 mins rest	30 mins rest	30 mins rest	30 mins rest	30 mins rest	30 mins rest	30 mins rest

The following week Patricia discussed her progress with her therapist. Patricia had again been successful and had got up every day at 10.30, on one occasion she had not completed her housework. She had kept her appointment with the bank manager. Patricia said he had been very helpful and had suggested a bank loan with a much lower rate of interest and had agreed a repayment plan that was feasible. In addition she had told her daughter about the debt and was surprised to find that her daughter was not cross about the debt but was cross that she had been too ashamed to tell her. The most pleasurable thing had been ringing her friend, who had been delighted to hear from her. Her friend had agreed to visit Patricia the following week.

Over the next few sessions Patricia's routine became more established, she started seeing her friends more regularly and her mood improved. She also started to pick Tia up from school 3 days a week and always managed to do this which reduced the tension with her daughter and was cooking a meal for herself regularly. Although walking was painful she got rid of the stick and found that she was walking much more than she had previously. Patricia's final diary example below shows how much progress she had made in establishing a routine and doing more pleasurable activities with regularly planned rest periods. Patricia did not return to work as, following discussion with her therapist she felt that this was not a feasible option. Instead Patricia started some voluntary work – helping in a charity shop for one afternoon a week. Patricia still had days where her pain was severe but she felt much more in control of the pain and felt that her pain no longer controlled her activities.

Recovery stories
Patricia

PATRICIA'S FINAL BEHAVIOURAL ACTIVATION STAGE 4 DIARY

		Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
Morn	What Where When Who	Get up at 11am 30 mins housework	Get up at 11am 30 mins housework	Get up at 11am 30 mins housework	Get up at 11am 30 mins housework	Get up at 11am 30 mins housework	Get up at 11am 30 mins housework	Get up at 11am 30 mins housework
	What Where When Who	30 mins rest Work in charity shop	30 mins rest Walk to local shops	30 mins rest	30 mins rest	30 mins rest	30 mins rest	30 mins rest Go for lunch with a friend
Aft	What Where When Who		Work 30 mins rest	30 mins rest Pick Tia up from school	30 mins rest Pick Tia up from school	30 mins rest Pick Tia up from school	Read a book 30 mins rest	
	What Where When Who	30 mins rest	30 mins rest	Pick Tia up from school	Do an activity with Tia	Do an activity with Tia	30 mins rest	30 mins rest
Eve	What Where When Who	Cook meal for myself	Cook meal for myself	Cook meal for myself	Cook meal for myself	Cook meal for myself	Cook meal for myself Go out with a friend	Cook meal for myself
	What Where When Who	30 mins rest Read book	30 mins rest Read book	30 mins rest	30 mins rest	30 mins rest		30 mins rest

Patricia scored her goal sheet again several times during her programme. Her ratings went up as she started to do more but with scheduled rest periods. These are detailed in Patricia's goal summaries.

PATRICIA'S GOAL SUMMARIES

		TIME 1	TIME 2	TIME3
Goal number 1	To meet a friend once a week	0	4	5
Goal number 2	To read a book for 30 minutes a day	0	3	6
Goal number 3	To sort out my debt	0	6	6

Recovery stories
Martin

Martin's story is about someone who used a technique from the book which is aimed at changing the way we think. This technique is called cognitive restructuring.

Martin is a 54 year old man who had experienced chronic pain for some years. He had been married for 20 years and has a 30 year old son from a previous relationship. Although he had not seen his son very much during his early years (due to an acrimonious divorce) he re-established their relationship when his son was 16. About 8 years ago Martin had woken up with sharp shooting pains in his ankles which over a number of weeks developed into chronic widespread pain. Martin had seen his GP, who had referred him to Rheumatologist and a Neurologist, who all agreed that he had Fibromyalgia. Martin said that pain occurred in different parts of the body and described it as 'aching, stiffness, dull, stabbing, tingling, tightness and pins and needles. He also described being fatigued most days for most of the time.

Martin's pain started on waking in the morning. It was triggered by sitting for longer periods or most physical activity such as walking or going shopping or simply with the effort of dealing with people. Martin felt that the constant pain caused him to be irritable and angry with both himself and his partner. He also had difficulty getting off to sleep and often woke in the night. He spent most of the day sitting (even though this aggravated the pain) and believed that 'resting his body is the best thing he could do as this would give his body time to recover'. However, Martin also felt frustrated and angry that he could not 'function' as he had before. He had a good job but had taken long term sick leave and was terrified that he might become dependent on his wife. He felt ashamed of his illness and although he felt people believed how much pain he was in he did not feel they understood his illness. Martin also felt that he had lost his role as a 'man', and he saw himself as a poor role model for his son and a poor partner.

Martin felt that the pain impacted on every aspect of his life. Prior to the onset of his pain he had enjoyed working, socialising and had a number of hobbies including going to the gym, running, gardening, and going to auctions. He also had an interest in classic cars. For the past few years he had reduced all his activities and rarely did anything because he feared that he would cause more damage to his body and make his pain worse. He felt his relationship with his partner had deteriorated. He described how supportive she was, but felt he had withdrawn emotionally from her and was often angry with her. He felt he did this so that she would eventually leave because he felt he had nothing to offer her and she would have a good life without him. Although he had never discussed this with her he was convinced she only stayed with him because she would feel guilty if she left. He also felt that his contribution in the home was diminished as prior to the pain he had been responsible for the garden, paying bills, general repairs and he and his partner had shared the cooking. He no longer did any of these things. He wanted to manage his pain better, to feel more 'worthwhile' and to be less angry with his partner.

With the help of his therapist Martin decided on the following goals:

MARTIN'S GOALS

Goal number 1

To be able to have a conversation with my partner (without becoming angry towards her)

I can do this now (circle a number)

0	[✓ 1]	2	3	4	5	6
Not at all		Occasionally		Often		Anytime

Goal number 2

To become involved in an activity and spend at least 10 hours a week doing it

I can do this now (circle a number):

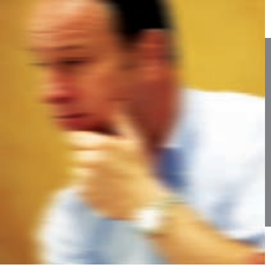
0	[✓ 1]	2	3	4	5	6
Not at all		Occasionally		Often		Anytime

Goal number 3

To be able to do some light gardening for 2 hours every week

I can do this now (circle a number):

0	[✓ 1]	2	3	4	5	6
Not at all		Occasionally		Often		Anytime



Recovery stories
Martin

Martin felt that dealing with his thoughts would help him most. He felt that if he could feel less angry and frustrated this would help him to do more things in his life. With the help of his therapist, Martin learnt how to complete some thought diaries. These helped him identify the exact type of thoughts he was having, the situations where these thoughts were occurring and how much he believed the thoughts to be true. To start with Martin filled in the first three columns. An example of one of Martin's diaries is shown below.

THOUGHT DIARY

SITUATION	FEELING Rate how bad it was (0-100%)	THOUGHT Rate how much you believe this thought (0-100%)	REVISED THOUGHT Rate how much you believe this thought (0-100%)	FEELING How bad was it? (0-100%)
Sitting at home in a lot of pain (my wife asked me if I wanted a newspaper and I shouted at her and said "Don't be so bloody stupid cant you see what pain I am in") Watching a TV programme on classic cars Light bulb goes in lounge and will have to wait for my wife to come home and ask her to replace it	Anger (90%) and guilt (95%) Sad and frustrated (85%) Anger (90%)	My wife feels that I am a burden on me and only stays with me because she pities me (90% I can't do anything; my life is nothing now (90%) I can't even change a light bulb – I can't do anything at all because of this pain (85%)		

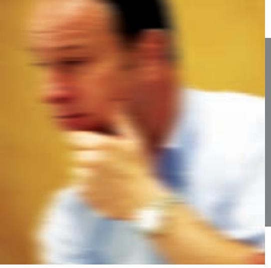
Martin collected a week of diaries and discussed these at the next session with his therapist. Through the diaries the main type of thought he could recognise was that he saw himself as "of no use to anyone and not being able to do anything because of his pain". He saw the link between his thoughts, his belief in how true they were and his mood and subsequent behaviour. He was able to clearly identify this link with his relationship with his wife – he understood that his guilt, anger and frustration from his chronic pain led him to believe that his wife was only with him because she felt pity. The more he believed this thought the more angry he become, so he withdraw from his wife (or became angry with her) which led him to believe more that his wife was fed up with him. He understood the link that these thoughts led to him feeling frustrated, which led to him doing less.

With help from his therapist, Martin worked on the thought that 'his wife was only still with him because she pitied him'. This was a distressing thought as he believed this to be 90% true. He looked at how true or how false this thought really was. The way he did this was to imagine that he was the judge in a court where the evidence for and against the truth of the thought was being examined. This is shown in Martin's evidence table.

EVIDENCE TABLE

MY THOUGHTS	MY BELIEF (%)
"My wife is only with me because she pities me"	**90%**
Evidence for	Evidence against
I get cross with her when she tries to help me	She has never said this to me – and says that she loves me
I can see how tired she gets because she has to do everything	She does not act as though she pities me – she asks me if she can help me but has never treated me as an invalid
Sometimes she tries to chivvy me along with comments like "I am sure it will get better soon and you will be back to your normal self"	My son tells me not to be daft when I have asked him if he thinks she only stays with me because she feels sorry for me
I can tell by the look in her eyes	She is not someone who would stay in a loveless relationship. This is her second marriage and she has always said if she was unhappy for a long time she would leave

When Martin completed this exercise, he reconsidered his belief in his thought that his wife only stayed with him because she pitied him. He could see that his evidence for believing the thought was fairly weak as it was based on assumptions and his feelings rather than facts. Instead of believing it to be 90% true, he decided that it was no more than 40% true. Because his belief was less, he felt less frustrated and angry when he had this thought. With his therapist he developed a new thought (called a revised thought) which was "I am sure that my wife does get frustrated but she does not stay with me out of pity". He rated this new thought as 80% and his anger and guilt had reduced considerably. This example is shown in Martin's second thought diary.



Recovery stories
Martin

Martin repeated this process a number of times with the same thought. He also tackled other thoughts, particularly about his belief that "Resting my body will give my body time to recover". With support and encouragement from his therapist Martin carried out some behavioural experiments. For example one experiment was to rest for an entire day and rate his pain levels, the next day he was asked to do some mild activity and again rate his pain. He did this for 6 days and at the end of the experiment he discovered that his pain levels were less on the days he did some mild activity. Over the course of a few weeks, with challenging his thoughts and carrying out some behavioural experiments, Martin reported that he felt far more in control of his pain. The more he challenged his thoughts, the more confident he became and the more his behaviour changed as he started to do more. He felt much more confident, importantly his mood improved, which led to him feeling less angry which helped improve his relationship with his partner. Instead of doing heavy gardening, Martin started growing tomatoes and bought a greenhouse where he grew herbs and vegetables which did not entail digging or lots of bending. His interest in classic cars and auctions returned.

As with the other recovery stories, Martin's improvement was not immediate and he continued to have days where he was in a pain. He knew that he needed to continue to challenge his thoughts and carry out experiments but he did feel that he managed his pain much better. He also recognised that he had been low in mood which had led to him feeling low in confidence, frustrated and angry. He felt that he could use the techniques he had learnt to manage these emotions.

Martin scored his goal sheet again several times during his therapy. His ratings went up as he started to feel better and achieve his goals. These are detailed in Martin's summaries.

MARTIN'S SECOND THOUGHT DIARY

SITUATION	FEELING Rate how bad it was (0-100%)	THOUGHT Rate how much you believe this thought (0-100%)	REVISED THOUGHT Rate how much you believe this thought (0-100%)	FEELING How bad was it? (0-100%)
Sitting at home	Anger (90%) guilt (95%)	"My wife is only with me because she pities me (90%)	"I am sure that my wife does get frustrated but she does not stay with me out of pity". (80%)	Anger 10% guilt 40%

MARTIN'S GOAL SUMMARY

Goal number 1

To be able to have a conversation with my partner (without becoming angry towards her)

I can do this now (circle a number)

0	1	2	3	4	[✓ 5]	6
Not at all		Occasionally		Often		Anytime

Goal number 2

To become involved in an activity and spend at least 10 hours a week doing it

I can do this now (circle a number):

0	1	2	3	4	5	[✓ 6]
Not at all		Occasionally		Often		Anytime

Goal number 3

To be able to do some light gardening for 2 hours every week

I can do this now (circle a number):

0	1	2	3	[✓ 4]	5	6
Not at all		Occasionally		Often		Anytime

Fianl thoughts

Recovering from depression can be a difficult journey:

it takes courage and often seems to involve quite a lot of hard work. We hope that this book has helped you in this journey. We particularly hope that the team approach made it easier.

We wish you well in your recovery programme.

As we said at the beginning we are committed to improving the information and help that people with depression receive so please do let us have any comments or changes that you would like to see. You can write to us at the following address:

The Guided Self-Help Research Team
c/o The School of Nursing Midwifery and Social Work
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Oxford Road
MANCHESTER
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K. Lovell
Karina Lovell

David Richards
David Richards

Biographies

Karina Lovell is a Professor of Mental Health at the University of Manchester. Much of her research is centred on developing accessible treatments for people with anxiety and depression. Karina works with people with anxiety and depression in various NHS settings and with the National Phobic Society. Unlike Professor Richards, Karina finds it much more difficult to follow government health guidelines but swims fairly regularly and has just purchased a trampoline!

David Richards is Professor of Mental Health at the University of York, UK. He runs a research programme which develops, measures and tests new ways of organising treatments for people with depression and low mood. He believes passionately that people with these and other common mental health problems are themselves the best managers of their own emotional difficulties. This book reflects his belief that the starting point for any effective treatment should always be the most user friendly approach possible. When not working, he tries to follow government health guidelines through swimming, walking and surfing and can occasionally be found ruminating about the state of the vegetables on his allotment.