

overcoming

functional neurological symptoms

a five areas approach

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- Step-by-step success
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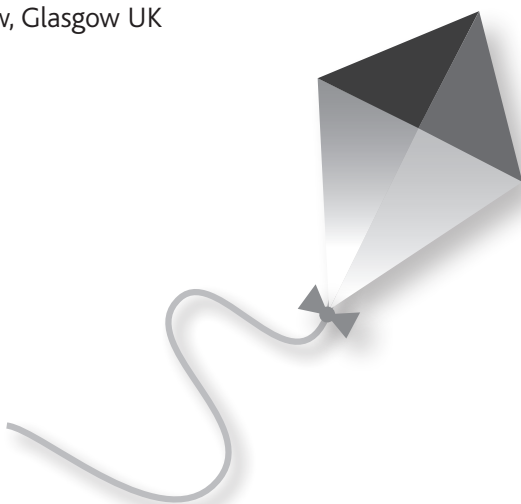
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Introduction

Welcome to *Overcoming Unexplained Neurological Symptoms: A Five Areas Approach*. Facing the challenge of how to cope with chronic illness can be difficult, confusing and distressing. Symptoms themselves may interfere and prevent people living life as they wish to. These may include symptoms such as paralysis or weakness, seizures, numbness, slurred speech or altered vision, hearing or speech. There may be symptoms such as pain, tiredness, anxiety or low mood. Sometimes there is a clear cause for symptoms, however sometimes the cause may be unexplained – and so the symptoms are described as *functional* in nature.

A diagnosis of functional neurological symptoms is much more common than you might think. Research in four major neurological centres suggests that about one in three people attending neurology outpatient clinics have this diagnosis. The diagnosis of functional neurological symptoms can be made as accurately as any other diagnosis. The diagnosis usually means that further tests are not required.

Functional symptoms significantly affect how the sufferer lives their life. We now know a lot more than before about the causes of such symptoms, and how to help tackle them. The treatment package described in these workbooks, and the accompanying toolbox, is designed to help you overcome your symptoms. A research study funded by the Medical Research Council has found that the content of this course can be an effective treatment for people with functional neurological symptoms.

This book is designed to actively help you to:

- Learn important information about how functional neurological symptoms can affect your life.
- Work out why you are feeling as you do.
- Learn and practise some practical skills to help change how you feel.

By following the clearly described tools in these workbooks, and the accompanying toolbox, you can make helpful changes to your life.

Who are the workbooks and toolbox for?

You may be using the workbooks for yourself, or perhaps you are a close friend or family member wanting to know more about functional neurological symptoms and

how to help. Many healthcare practitioners also use the workbooks in this series to support those they work with.

Self-help approaches can be used by people with problems ranging from mild distress through to more severe symptoms. The key thing is that you feel *able* to use the materials and *want* to use this approach.

Using the workbooks and toolbox

The course involves *reading* the course workbooks and also *working* on problems by putting into practice the things you are learning. Picking the right time to do the course is important. For example, if your concentration, energy or motivation levels are far lower than usual, you may find it very hard to keep your mind on things or to make changes. Other approaches may be more appropriate first – allowing you to come back to use the workbooks and toolbox at a time when you are able to get the most from them. If you find that you are struggling to use the workbooks, or you feel worse as you work through them, please discuss this with your doctor or other healthcare practitioner. The course is not meant to replace getting the right level of support for more severe health problems.

Which workbook should you use first?

There is no right or wrong way to use the workbooks. Many people find it helpful to first read the workbooks in Part 1 (Workbook 1: Introduction. Understanding how people respond to symptoms and Workbook 2: Your brain and body, and how these link to symptoms).

These workbooks will give you a good overview of the approach and will also help you to then move onto the 'Making changes' workbooks in Part 2 of the book. You can use as many or as few workbooks in the course as you wish. You will feel most motivated to try to make changes if you use the workbooks that tackle problems you have noticed in your life and that you want to change.

The third part of the book is the Toolbox, which will help you put all that you have learned in the previous workbooks into practice.



KEY POINT

The key to creating change in your life is *using* the workbooks and *putting what you learn into practice*.

Getting help from others

It can be hard making changes when you feel ground down or stressed. Many people start off trying to improve things with lots of motivation. But feeling ill can sometimes make us quickly give up on change. That's entirely normal and is very human (think how hard people find it keeping New Year resolutions even when they aren't feeling worried about things).

Time and time again, people using resources like this have found the benefits of working with someone else to support and encourage them when things feel hard. We therefore suggest that you partner with someone to help you as you use the course. For example, a health or social services worker, your doctor, a voluntary sector worker or a trusted family member or friend.



The important thing is to have someone else there, helping you, discussing problems that seem hard – and to say well done when things move forwards.

A word of encouragement

The content of these workbooks and toolbox is based on the cognitive behavioural therapy (CBT; a kind of talking treatment) approach. The developers of CBT have found many effective ways of tackling the common symptoms and problems people face when feeling low.

This course is written in a way that clearly explains what to do, so that you can test the effect of these different suggestions in your own life. The workbooks aim to help you to **regain a sense of control** over how you feel.

The self-help approach can really work

Research has been done on people who use books like this one based on CBT. A research study on this book has shown that when offered with support it can help people experiencing functional neurological symptoms. The course can make a big difference if you can commit to using it.

Making a commitment

Sometimes making changes is easier said (or written) than done. All of us feel discouraged and overwhelmed from time to time. This is even more likely when you feel distressed, anxious, tense or low.

Therefore, **try to make a commitment to use this course** and to keep at it even if you feel discouraged or stuck for some time. To do this you will need to **pace yourself** by using a step-by-step approach. Having someone else to encourage you is also important. The research on these approaches shows just how helpful this can be. Also, be realistic. Bear in mind your motivation and energy levels so that you don't try to do more than you can at one time. This will help you to get as much from the course as you can.



New online resources

An online resource is available to support users of the course: **www.livinglifetothefull.com**. This free website contains short talks that help you to build upon the course workbooks. There is also a moderated chat room where people can swap ideas, hints and tips, as well as offering and receiving mutual support. If you don't have a computer, try to use one in an internet café, or in a public library. Sign up for the free reminder letters there to help you keep on track. You can also freely access TV-based versions of the course from the website. Some people like to see and hear how other people have applied what they have learned. Again, using the site with support and encouragement from someone can be a big help to getting the most out of the approach.



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Please note: in a clinical service each practitioner using the workbooks must have their own personal copy of *Overcoming Unexplained Neurological Symptoms: A Five Areas Approach*.

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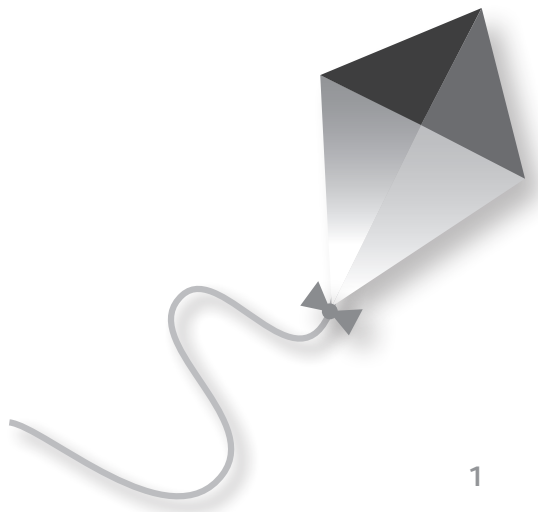
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Part 1

Understanding how people respond to symptoms



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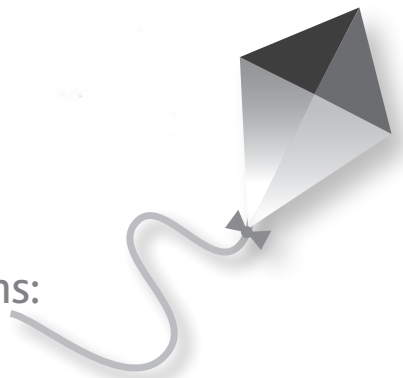
Workbook 1: Introduction

Understanding how people
respond to symptoms



overcoming

functional neurological symptoms:
A Five Areas Approach



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SECTION 1: Introduction

A diagnosis of functional neurological symptoms is much more common than you might think. Research in four major neurological centres suggests that about one in three people attending neurology outpatient clinics have this diagnosis.

What are functional neurological symptoms?

The diagnosis of functional neurological symptoms covers a wide range of difficulties in how your body works. These include:

Paralysis or weakness of an arm or leg	Pain in your arms, legs or joints (knees, hips, etc.)
Double or blurred vision	Chest pain
Partial or total loss of vision	Feeling your heart pound or race
Partial or total loss of hearing	Problems with your memory or concentration
Difficulty swallowing or a lump in the throat	Shortness of breath
Difficulty speaking or slurred speech	Stomach pain
Lack of co-ordination or balance	Constipation, loose bowels or diarrhoea
Seizure or fit	Nausea, gas or indigestion
An anxiety attack (suddenly feeling fear or panic)	Feeling tired or having low energy
Shaking or tremor	Trouble sleeping
Headaches	Little interest or pleasure in doing things
Dizziness	Feeling down, depressed or hopeless
Fainting spells	'Nerves' or feeling anxious or on edge
Loss of sensation, numbness or tingling	Worrying about a lot of different things
Back pain	Having flashbacks to stressful events

Functional neurological symptoms can affect anybody no matter how old, what gender or race. It affects people from all parts of society. It doesn't matter whether you are working, retired, a student or unemployed – anyone can develop this problem. Half of those people with these symptoms are still working.

How is the diagnosis of functional neurological symptoms made?

Your neurologist will make the diagnosis based on two key factors:

- Your *clinical history* (what you tell them) – how your symptoms have developed and how they affect you.
- Your *physical examination*: especially an expert neurological examination.

Sometimes, based on your assessment, specialist investigations may be recommended. You can find out more about these in Workbook 2. Please note that these investigations may well have been previously completed by your GP.



KEY POINT

The diagnosis of functional neurological symptoms can be made as accurately as any other diagnosis. The diagnosis usually means that further tests are not required. The treatment package described in these workbooks is designed to help you overcome your symptoms.

The overcoming functional neurological symptoms treatment package

This first workbook contains an overview of the treatment approaches people can use to help overcome problems caused by functional neurological symptoms. It covers:

- How to use the workbook.
- The diagnosis of functional neurological symptoms.
- Understanding the impact of these symptoms by looking at the effect **on five key areas** of your life. These are:
 - Your physical symptoms/feelings in your body
 - Your thoughts
 - Your feelings or emotions
 - The impact of all these on your activity levels and life
 - The situations, relationship and practical problems you face.
- How to use this approach to improve things. By using the different workbooks in the course you can slowly put things back to normal in your life.
- A brief description of the workbooks that make up the rest of this course. This will help you to choose which workbooks will be most helpful for you.

You can use the workbooks by yourself or with your healthcare practitioner. You may find that it is also helpful going through them with a friend or family member (see Practical toolbox E – Illness, symptoms and other people).



KEY POINT

Many people notice that they feel slightly worse to begin with as they use this approach. This is usually only temporary and is an important part of the process of recovery.

How to use the workbooks

We recommend that any workbook you use is completed over a period of a week or two. Completing the entire course of workbooks is therefore likely to take more than a month. But putting the techniques into practice might take longer than you think. It does take an investment of your time for these approaches to work.

- ★ There is a lot of information in each workbook, so the workbooks are divided into clear sections covering each topic.
- ★ You might find it helpful to read one section at a time.
- ★ Try to **answer all the questions** asked. The process of having to **stop, think and reflect** on how the questions might be relevant to you is an important part of getting better.
- ★ You will probably find that some aspects of each workbook are more useful to you at the moment than others. **Write down** your own notes of key points in the margins or in the *My notes* area at the back of the workbook to help you remember information that has been helpful. Plan to **review** your notes regularly to help you apply what you have learned.
- ★ Once you have read through an entire workbook once, **put it to one side** and then **re-read it** again a few days later. It may be that different parts of it become clearer, or seem more useful on second reading.
- ★ Within each workbook, important areas are labelled as **key points**. Certain areas that are covered may not be relevant for everyone. Such areas will be clearly identified so that you can choose to skip optional material if you wish.



KEY POINT

There is no right or wrong way to use this manual. Some people like to fill in a lot of detail but others prefer brief notes. Do whatever you feel helps you reflect on your situation. The information you record is simply to help you.

Every person has a different experience. In the workbooks we will use some specific examples but some will seem more relevant to you than others. The object of the workbooks is to allow your own experience to form the basis for treatment.

When times are difficult ...

Functional neurological symptoms can make life seem like a real struggle. This is why choosing to commit yourself to the approach is important, and why we recommend using the workbooks together with someone else who can encourage and support you. Taking small steps can make a really big difference to how you feel.



KEY POINT

Adjusting just a few small things in your life can result in big benefits.

How the workbook will help you

Symptoms have an effect on **every** aspect of your life. Think about the experience of having flu. The flu virus causes symptoms such as a runny nose, temperature and aching muscles. But it also affects other key parts of our lives. You can have:

- *Altered thinking:* you may not think as clearly as usual and may find it difficult to make decisions.
- *Altered feelings:* you may not enjoy things as much as usual – and not feel very cheerful.
- *Altered behaviour:* you may have to go to bed, take medicines such as throat lozenges and paracetamol, and rest. You may not feel like going about your usual life activities such as meeting friends or going out.
- Symptoms that also have *an impact on those around you*. For example, others may make your meals and bring you drinks. If there is no one around to do these things, people might feel increasingly isolated.

In flu, these symptoms resolve over a week or so. What happens when symptoms last for far longer than this or are more severe?

Illness doesn't just affect our physical health. It affects our work, family, social life and hobbies, and all our relationships. This can sometimes feel like having a mountain to climb. You might feel that your symptoms have taken over your life and you'll never be yourself again.



The workbooks all use an approach to help you work out how your problems are affecting you in different areas of your life. This treatment approach is based on a cognitive behavioural therapy (CBT or talking therapy) approach. This therapy can help people cope with a wide range of health problems such as heart disease, diabetes, cancer, tiredness, pain and anxiety. It teaches you skills to cope with your symptoms.

SECTION 2: Starting your own self-assessment

It can be useful to start by reflecting on what has been happening to you since you first began to notice your symptoms. This workbook will help you do this in two ways:

- 1 Considering how your problems have developed to where they are now.
- 2 Summarising the impact of your symptoms on key areas of your life.

How my symptoms have developed

One way of considering how your symptoms have developed is to use a **time line**. This can help you think about how things have progressed. An example is shown below.



Example time line

★ Beginning

Paul (age 35), works as a civil servant.

July 2002. Car accident

October 2002. Started getting bad headaches

Next 6 months tried on lots of medications by my GP

May 2003. Started to get tingling in my right hand

Summer 2003. On holiday, felt right leg give way

Had medical tests while on holiday

Autumn/Winter 2003. Tingling comes and goes

January 2004. Wife gives birth to our daughter

March 2004. Right hand very weak and sometimes 'won't work'

My GP suggests referral to neurology

May 2004. Sick leave from work because of pain tingling and occasional paralysis

October 2004. Seen by neurologist, no specific disease found

★ Today

Told by neurologist I have a functional disorder





Task

Write in your own time line of the progress of your current problem in the space below. Give a general overview of key changes that have happened since the symptoms became a major problem for you.

Time line

Beginning (a time when I last was well)

Today

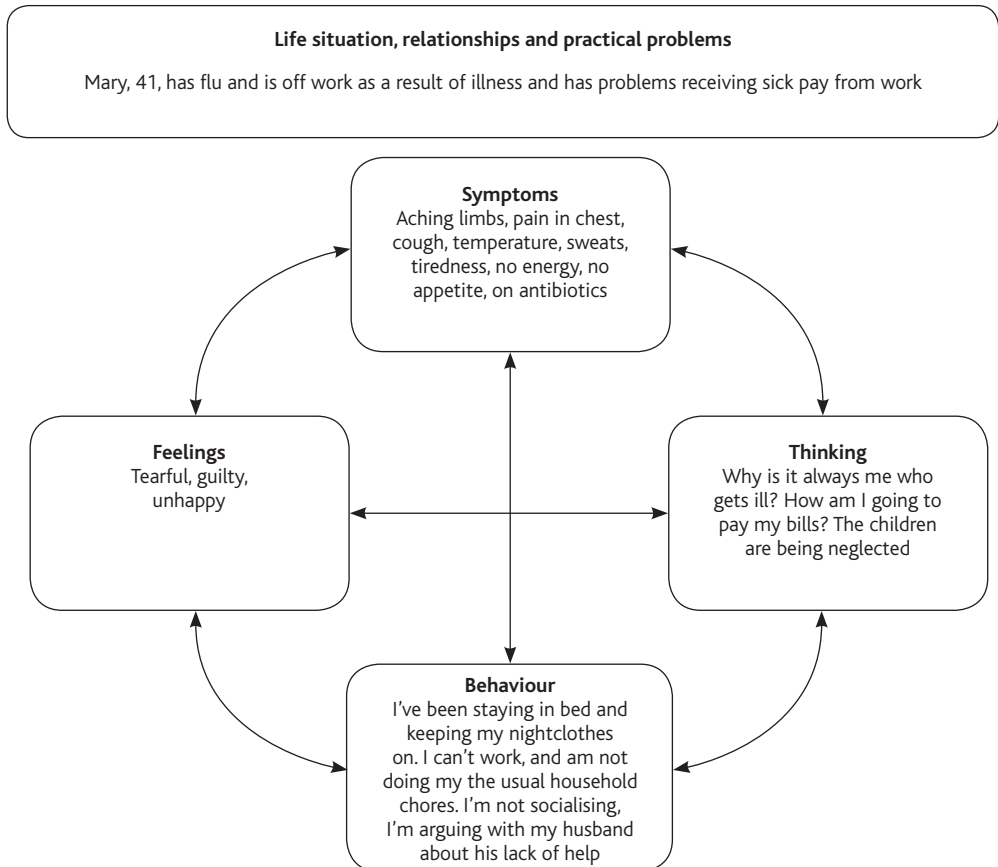


The Five Areas assessment

We already know from our own experiences that health problems are very complex and affect us in many ways. A *Five Areas assessment* will provide you with a clear summary of the difficulties you are facing in each of the following areas:

- 1 Symptoms/feelings in your body.
- 2 Altered thinking.
- 3 Altered feelings (also called moods or emotions).
- 4 Altered behaviour or activity levels (with reduced activity, avoidance or unhelpful behaviours).
- 5 Your life situation, relationships, practical problems (i.e. the people and events around you).

Below is an example of how Mary, who has a common illness, responds to being unwell and the impact it has on all five aspects of her life.



The Five Areas assessment model of Mary.

Look at the arrows in the diagram. Each of these five areas affects each other and offers possible areas of change to improve how Mary feels. Because of the links between the areas, the physical impact of Mary's illness influences many other important aspects of her life. It also shows how much illness can affect people. For example, being ill can have emotional consequences. This is especially the case where symptoms stop you living your life as you would wish, or when illness lasts for many months or years. Living with uncertainty, and with long-term illness, can grind people down.

Mary's example shows how much even a short-term (sometimes called 'acute') illness and very common problem with health can affect people. **How you think about your illness can also play an important part.** The Five Areas assessment shows that what a person thinks about a situation or problem may affect how they feel emotionally and physically, and also alters what they do. Finally, other important things going on in your life – such as relationships, jobs (or lack of a job) – can all affect how you are.

Don't worry if this approach seems hard to understand at first. In the next section of the workbook you'll have the chance to complete your own Five Areas assessment. This will make the approach clearer to you.

SECTION 3: Carrying out your own Five Areas assessment

A **Five Areas assessment** can be helpful in understanding how your symptoms are affecting you.



REMINDER

The five areas are: symptoms; thinking; feelings/emotions/mood; behaviour or activity levels in the face of illness; and your situation, relationship or practical problems. Think about how your health problems have affected you in the past few weeks.

Area 1: Symptoms

An important point to think about with functional neurological symptoms is the symptoms themselves.

Listing your symptoms

Symptom	First started	How often do you have it?	What helps?	What makes it worse?
<i>Fatigue</i>	<i>December 2009</i>	<i>Every day</i>	<i>Resting</i>	<i>Exercise or activity</i>

Physical symptoms can be made worse by uncertainty, frustration, stress or demoralisation. For example, when you feel tense, you might also notice feeling restless and unable to relax. Feelings of mental tension can also cause physical tension in our muscles and joints. This may cause shakiness, pain, weakness or tiredness.

It can be surprising how tiring stress can be. Some people may feel completely exhausted when they have felt stressed for a time. Their muscles are so tense it can seem as if


they have run a marathon all day. This muscle tension can cause other problems, such as tension headaches, or stomach or chest pains. Anxiety can also cause other physical symptoms. A feeling of being hot or cold, sweaty or clammy is common. Your heart may seem to be racing, and you may feel fuzzy-headed or disconnected from things.

Low mood or depression can also lead to a number of symptoms.

<i>Symptoms that can be worsened by stress or low mood</i>	<i>Tick here if you notice this symptom</i>
Pain – especially pain that is worse in the mornings, and which is unaffected by painkillers. Examples are tension headaches, stomach pain, eyestrain or chest pain	<input type="checkbox"/>
Muscle tension/shakiness	<input type="checkbox"/>
Tiredness and low energy	<input type="checkbox"/>
Reduced or increased appetite (comfort eating)	<input type="checkbox"/>
Weight loss or gain (as a result of comfort eating and under-activity)	<input type="checkbox"/>
Reduced concentration – can't keep focused	<input type="checkbox"/>
Problems going off or staying asleep. You may wake up earlier than normal, feeling unrested and not be able to get off to sleep again	<input type="checkbox"/>
Feeling dizzy/fuzzy-headed or cut off from things	<input type="checkbox"/>
There may be anxiety about sex and avoidance of sex as a result. Loss of sex drive	<input type="checkbox"/>
Butterflies, loose bowels, sickness, churning stomach, going to the toilet frequently	<input type="checkbox"/>
Restless and tense. Rapid heart/palpitations. Sweaty, clammy, shaky	<input type="checkbox"/>
Dry mouth. Shallow rapid breathing	<input type="checkbox"/>
Constipation	<input type="checkbox"/>

Summary for Area 1: Symptoms

Having read about this area:

 Overall, do you think these symptoms affect you? Yes No

You will find out more about symptoms in Workbook 2.

Area 2: Thinking

When facing symptoms, people can often feel overwhelmed and uncertain about the future. You may not realise your strengths and ability to cope with your symptoms. Things can seem to be out of control.

How do you respond when you notice worrying thoughts about illness?

A common response from people around us when trying to cope with health problems is to say: 'Try not to think about it.'

Experiment

To see if trying not to think about worrying thoughts about illness is effective, do this practical experiment. Try very hard for the next 30 seconds not to think about a white polar bear.



After you have done this, think about what happened. Was it easy not to think about the polar bear, or did it take a lot of effort?

You may have noticed that trying hard not to think about the bear actually made it worse. Alternatively, you may have spent a lot of mental effort trying hard to think about something else such as a black polar bear? For many people, trying hard to ignore their worrying thoughts doesn't work and may actually worsen the problem.

- 1 Do I end up putting a lot of mental effort into trying hard not to think worrying thoughts? Yes No
- 2 If I try not to think the thoughts, does it work? Yes No

You will learn about *unhelpful thinking styles* that can affect anyone from time to time. During times of distress, especially when someone is struggling hard against their symptoms, they become more frequent and are harder to dismiss. Focusing on problems means they can often build up in your mind without actually being tackled. People may see their symptoms in catastrophic ways and predict that the very worst will occur.

However, such thinking styles can be unrealistic, extreme and unhelpful. When such thoughts dominate your thinking, they can make you feel worse.

Why are such thoughts so unhelpful?

The unhelpful thoughts can worsen how you feel emotionally and physically. This then can unhelpfully alter what you do in both the short and the longer term.

Unhelpful thinking causes



Unhelpful mood changes

You may feel more down, guilty, upset, anxious, ashamed, stressed or angry

Unhelpful behaviour changes

You may stop or reduce what you normally do, or start to avoid things that worry you or cause stress. Conversely, you may start to act in ways that seem to help but which end up backfiring and worsen how you feel in the longer term

Images and mental pictures – an important part of how people think

Some people notice *mental pictures or images* in their mind when they think about their illness. The images may be moving or still, or be in black and white or in colour. They may include mental pictures of painful parts of the body such as joints, or pictures of a brain tumour, multiple sclerosis or being in a wheelchair or alone. As with all thoughts, mental images can be inaccurate or **portray the very worst** outcome. They may sometimes worry about scary things happening and feel even more anxious or upset as a result.