Multiple Sclerosis Society

First edition
December 2010

Supportive Adjustment for Multiple Sclerosis (saMS)

An eight-week CBT programme manual

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This information is the result of
MS Society-funded research at

University of Southampton and King's College London

About this manual

- It was written to guide an eight-week CBT programme – for people with MS working with a health care professional trained in cognitive behavioural therapy (CBT).
- CBT is a type of therapy that involves looking at how thoughts, actions and feelings relate to each other.
- It was created as part of an MS Society-funded research trial run by the University of Southampton and King's College London.
- Download free of charge from **www.mssociety.org.uk**
- A complementary booklet for friends, families and partners, *Coping when somebody close to you has MS*, is also available to download from www.mssociety.org.uk

MS Society research

The MS Society funds a programme of independent research that has revolutionised the diagnosis and treatment of MS over the past 25 years. This has helped establish the UK's global reputation in this area.

The Society's research agenda is led by people with MS, working alongside independent panels of experts. We continue to search out advances in symptom management, developing better services, identifying the causes of MS as well as breaking new ground for better treatments. Our ultimate aim is a world free of MS.

The MS Society has invested over £133 million in MS research since 1956, and it will continue to be a key priority in our aim to beat MS.

Find out more at www.mssociety.org.uk/research or call 020 8438 0799 (weekdays 9am-4pm).

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Supportive Adjustment for Multiple Sclerosis (saMS)

Contents

INTRODUCTION:

This manual and your treatment sessions

What is in this manual?

This manual has information and exercises to support an eight-week treatment programme, designed to help you adjust to the challenges of living with multiple sclerosis (MS). It is based around a therapy called CBT, which you will learn about in your first session.

Who should use this manual?

This manual was designed for a randomised controlled trial of CBT for adjustment to early stage MS (within 10 years of diagnosis) funded by the MS Society. Our trial was called the saMS trial (Supportive Adjustment for MS). The manual can be read by people with MS and health professionals, but in order for it to be used as an effective therapy, it should act as a guide for a client with MS to work with a qualified therapist. It is written for both the person with MS and the therapist. Therapists should be people skilled in the use of CBT.

The saMS trial found that CBT based on this manual with a trained nurse therapist was effective in reducing distress in people with MS up to one year from the start of treatment. The therapy was particularly helpful for people with MS who felt dissatisfied with their current levels of social support and for those who completed all eight sessions of therapy. Some of the gains obtained at the end of therapy were lost at one year follow-up, suggesting that for some people more than eight sessions or more follow-up sessions would be useful. CBT sessions in the trial included two face-to-face and six on the telephone.

Developing this manual

This manual was designed by psychologists working at Southampton University and King's College London who have a lot of experience using CBT to help people manage long-term conditions.

To make sure that issues relevant to people with MS were covered, we used many different sources of information to develop it.

We interviewed 30 people with MS and 15 of their partners. We chose people from a wide range of circumstances: different ages, genders, family circumstances, work status, MS type and symptoms.

We asked them about what it was like to live with MS, what problems and issues they had encountered, how they dealt with them, and what they found helpful and unhelpful.

Throughout the manual you will find quotes from these interviews to illustrate some of the points we are making. We chose quotes that give clear examples of the ways people manage to cope effectively and the ways in which people struggle. Names have been changed to maintain confidentiality.

You may see similarities between yourself and some of the examples. Don't worry if you are like the examples we use to illustrate unhelpful responses! These are common responses – that's why we included them as examples. We found that most people do well at coping with MS, but it is a huge challenge for everyone and there are bound to be aspects that are difficult for you.

You may see similarities between yourself and some of the examples

Don’t worry if you are like the examples we use to illustrate unhelpful responses!

We also gathered information by:

- consulting with neurologists and MS nurses
- studying the research on things associated with better adjustment in MS
- looking at what has worked before with different conditions
- getting feedback from people with MS on our draft versions of the manual

We have used some materials from previous manuals we developed for CBT for people with other long-term conditions, including:

- *Managing your MS fatigue: a practical approach*. Van Kessel, K. and Moss-Morris, R. The University of Auckland.
- *Overcoming chronic fatigue: a self help guide using cognitive behavioural techniques*. Burgess, M. and Chalder, T. Constable and Robinson.
- *Managing your IBS symptoms: a practical approach*. Moss-Morris, R. and Didsbury, L. P. The University of Auckland.
- *Coping with chronic fatigue*. Chalder, T. Sheldon Press.
- *Adapting to living with diabetes*. Chalder, T. *et al* King’s College London.

Why is the manual so long?

The therapy manual might look a bit daunting. There is a lot to read and to work through. However, don't forget that you will be having eight sessions of therapy over three months. Most of the information will be discussed during your sessions with the therapist.

You might also find that some parts of the manual apply to you more than other parts. This is to be expected because your experience of MS is individual and unique. Together with your therapist you will identify areas you think are important and relevant and others that you may prefer to leave out.

As you go through the sessions, you might like to read some of the material before your sessions. You might also find you want to read chapters again afterwards. It is up to you.

The treatment sessions

- CBT treatment sessions are structured and take place over eight sessions. Sessions should be around 50 to 60 minutes long.
- You will need to have this manual handy during all of the sessions, so you can write on it if you want to, answer any questions that have arisen, and review your goals and tasks.
- It is important that if you have sessions on the telephone you are in a quiet area where you will not be disturbed. Make sure you set aside an hour for the session.

Regular attendance is very important, to be sure that the momentum and consistency of treatment is maintained. In the saMS trial, the researchers found that people who completed all eight sessions showed significantly greater improvements than those who did not.

- CBT sessions are collaborative – you and the therapist work together as a team. At each session, you will set targets for the week ahead. At the beginning of the session the therapist will review your progress so far, and discuss any difficulties which may have arisen. During the session you will decide what areas you want to work on during the coming week, what 'homework' tasks you want to set, and how you will achieve them.
- To help you and your therapist work effectively together and keep track of your progress, you will be asked to record your homework on progress sheets and bring them to each session.

What is CBT?

CBT stands for cognitive behavioural therapy. It is a practical form of therapy. It is based on the idea that feelings, thoughts, behaviours and physical responses are interconnected. All of these can affect adjustment to MS including your levels of distress and your quality of life. Using a range of CBT techniques, the therapist will help you address things that you may currently find challenging or that may be challenges for you in the future.

You will already have developed a number of ways of coping with your MS. The aim of CBT is to:
a) build on your own coping techniques
b) offer you new techniques to improve your quality of life
c) offer you new techniques to deal with distressing emotions

What does this programme of CBT involve?

The sessions will be tailored to your individual needs. The first step is to build up a detailed picture of the things you feel might help or hinder your adjustment to MS. This ‘assessment process’ carries on throughout the programme. It will help you and your therapist decide which of the modules covered in this manual will be best for you to focus on afterwards.

What happens when the programme ends?

One of the most important aims of CBT is for you to become your own coach, and to continue with a ‘self-directed’ treatment programme once the regular treatment course ends. This is very important, so you can build on the improvements you have made. It can also help when you have natural ups and downs or changes to your MS in the years to come.

Don’t forget that your neurologist, MS nurse and GP will still be available throughout this programme, and afterwards for advice, support, and treatment for MS-related issues.

The role of family and friends

This is largely a self-directed treatment, in which you do most of the work, so many people find it helpful to involve a close friend or relative as a support person. Really, all this means is that you have someone available who understands what you are doing in the treatment programme and who you can talk things over with.

They are mainly there to be supportive, and this can be very important – CBT can require quite a lot of determination. There may be times when you feel like giving up, or when you feel as though you are making no progress. The presence of someone who can encourage you and reinforce your achievements can be invaluable at these times.

Although you may not want to involve other people in your treatment directly, it can be useful for people close to you to know what it involves, so that they do not worry about whether the treatment is likely to be harmful.

You might choose to give your support person(s) part of the manual to read to help them understand what you are trying to achieve.

We have also produced a booklet specifically for partners or significant others *(Coping when somebody close to you has MS)* and suggest that you hand this on to your key support person.

If you feel it is appropriate, you can invite this person to join you and the therapist for a session or sessions.

CHAPTER ONE:

An introduction to adjusting to multiple sclerosis

What is multiple sclerosis (MS)?

MS is a long-term condition which affects the central nervous system (CNS). At the moment, there is no cure. It is called a long-term condition because once you have it, you have it for life.

No one knows exactly why MS develops in certain people. We know that the immune system goes wrong, but we don't know exactly why. In a healthy immune system, the immune cells of the body attack foreign bodies such as viruses or germs that enter the body to protect the person against harm. In MS, the body's immune system attacks its own nervous system tissue in the mistaken belief it is a foreign body. The immune system attacks the 'myelin' – the material which protects the nerves in the brain and spinal cord. This causes the messages from the body to the brain and vice versa to be slowed down, changed or blocked.

The damage to these cells of the nervous system causes the symptoms of MS. Because damage can happen in any part of the CNS they can vary from person to person. Common symptoms include:

- numbness or tingling in the hands and feet
- problems with vision
- fatigue
- dizziness
- pain
- loss of muscle strength
- problems with walking and balance
- muscle stiffness and spasms
- bladder and bowel problems
- problems with memory and concentration
- sexual problems

Many people experience only a few of these symptoms and it's unlikely that you will have to be concerned with all of them.

Other sources of information on MS

During CBT you may learn some new things about your MS and about managing its effect on your day-to-day life. However, CBT is not intended to offer any specific advice on medical treatment.

Your MS nurse, neurologist and other health care professionals such as a neuro-physiotherapist are best placed to answer medical questions about MS.

There are also lots of books and websites available about various aspects of MS, but unfortunately not all information is good quality!

Good sources of information you might want to refer to are:

The MS Society	www.mssociety.org.uk	0808 800 8000
The MS Trust	www.mstrust.org.uk	0800 032 38 39

The particular challenges of MS

Adapting to any long-term condition is challenging. Many of us take our health for granted. When we are faced with a situation where we will have an illness for the rest of our lives this may challenge the very essence of who we feel we are.

MS brings its own unique challenges:

- People are usually diagnosed in their 20's and 30's – a time of life when they are often developing careers, working towards financial security, and thinking about having a family.
- MS is unpredictable. Some people have relapses and remissions. For others it is progressive. No one can say when relapses will occur or how progression might affect them. However, we do know that 20 years after diagnosis approximately 60 per cent of people with MS are still able to walk without aids and fewer than 15 per cent require care in a home.
- Planning for the future can be difficult.

What do we mean by 'adjusting to MS'?

Having MS is going to cause a range of negative emotions at different times and will present ongoing challenges. Part of adjusting is acknowledging these negative emotions but not being overwhelmed by them. For instance, in describing how it feels to have lost some of her vision, Rene explains:

> "I can't read books any longer, because I can't see properly. So, my one love, the one thing that I really, really want to do, is the one thing that obviously I can't do and that is just so frustrating. I am learning to adjust to this, and in fact I do get large print books out of the library and spoken tapes and CDs out, and I am getting much better at listening to them. But it does take an awful long while to actually learn to listen rather than to read."

Rene openly acknowledges how frustrating and difficult it is but she doesn't appear to be completely overwhelmed. In contrast, Mary says about her MS:

> "I feel absolutely powerless, because I can't do anything about this and they can't do anything about this."

Adjustment to MS is also maintaining a reasonable quality of life in the face of the illness. Where possible, it is about reducing the impact that the illness has on day-to-day living. Fiona illustrates this very nicely:

> "I feel, not in control of my MS, but I am managing it. In that way, MS is not in control of me. I know it's going on, but it's not disrupting, terribly, what I am doing. I manage my life now, so that I can do what I want to do, and do what I need to do, despite my MS. There are some days that are worse than others, but I now know how to manage those days. But it is a series of strategies for management."

Adjusting might also include the flexibility to change the way things have been done in the past if necessary. If the illness progresses, this may mean altering or adapting life goals or values. Jim explains:

> "I had to give up work because my work required quite a bit of physical effort. So now I do other things that I never had time to do before. I am very involved in the MS Society and help out with projects where I can. I have also set up a local support group. I feel like I am still able to give things back."

In contrast, Susan felt less valued in a similar situation and found adapting to giving up work more challenging:

> "I do volunteering work for the MS Society. I also volunteer for the local health authority on the local patients' thing. So I don't feel quite so guilty about doing nothing, but it's not the same as working and it's not the same as earning real money. It's… you just don't feel as valued. I feel it's like you aren't worth the same…"

In summary, adapting to MS includes maintaining a flexible approach to life, being able to express negative emotions openly but not being overwhelmed by these emotions, and maintaining a reasonable quality of life in the face of the condition.

But of course none of this is easy when you have a condition which is unpredictable, often uncontrollable and associated with a range of unpleasant symptoms. At the beginning there is adjusting to the diagnosis, along the way it may be adjusting to relapses and, for some, progression of the condition. At times, people find they cope extremely well, whereas at others they feel completely overwhelmed by it all.

Getting help with adjusting to MS does not mean you are not a coping person or that you should be able to do it on your own. Rather, it acknowledges that MS poses a number of difficulties that anyone would find challenging.

The purpose of CBT is to work alongside people to help them manage their illness to the best of their ability.

Even if people currently feel they are coping well, CBT can help them manage the illness in the future.

Getting help with adjusting to MS does not mean you are not a coping person

Factors which affect people's ability to adjust to MS

A number of researchers have tried to find out what factors help people adjust better to MS and factors which are related to poorer adjustment. We have provided a brief summary of some of these findings below.

Stress

Stressful events in life have been shown to be related to poorer adjustment to MS. However, more importantly, the way people think about and respond to these events is also associated with adjustment. The more threatening people perceive stressful events to be, the greater their distress. This suggests that altering one's thinking might help lessen the impact of stress. Managing stress better could also be of benefit.

Thoughts and behaviours

Thoughts and beliefs about one's MS and symptoms have also been associated with adjustment. For instance, people who feel hopeless in the face of the illness, and believe that the long-term consequences of their illness will be very severe, don't adjust so well.

People who are embarrassed about doing things because of their symptoms, or tend to avoid using assistance when it may help, also don't adjust so well.

Two other behaviours appear to be unhelpful for people with MS. These include avoiding activity because they fear it will be bad for symptoms, or trying to do too much in the face of the illness.

Coping strategies... are associated with greater well-being and better quality of life

Finally, some people have a tendency to be inward looking by nature. This may mean they focus more on their illness, which can make them feel worse, as well as increase the severity of the symptoms experienced.

Coping strategies

Coping strategies, such as being able to see positive aspects of situations, use of humour and acceptance of the changes that MS may bring, are associated with greater well-being and better quality of life.

Avoiding situations because of MS or avoiding dealing with MS-related issues are generally related to higher levels of depression, anxiety and disability.

Optimism

Having an optimistic disposition or a natural inclination to have positive expectations of the future appear to make the adjustment process easier. People with MS who are naturally more optimistic tend to have lower levels of depression and greater social and psychosocial adjustment than those who don't. This may be because these individuals are able to find some positives even in difficult or challenging situations.

Social support

People with MS who feel they have high levels of social support experience a better quality of life and are less distressed. Helping people to find better ways of accessing or using available support might therefore assist the adjustment process.

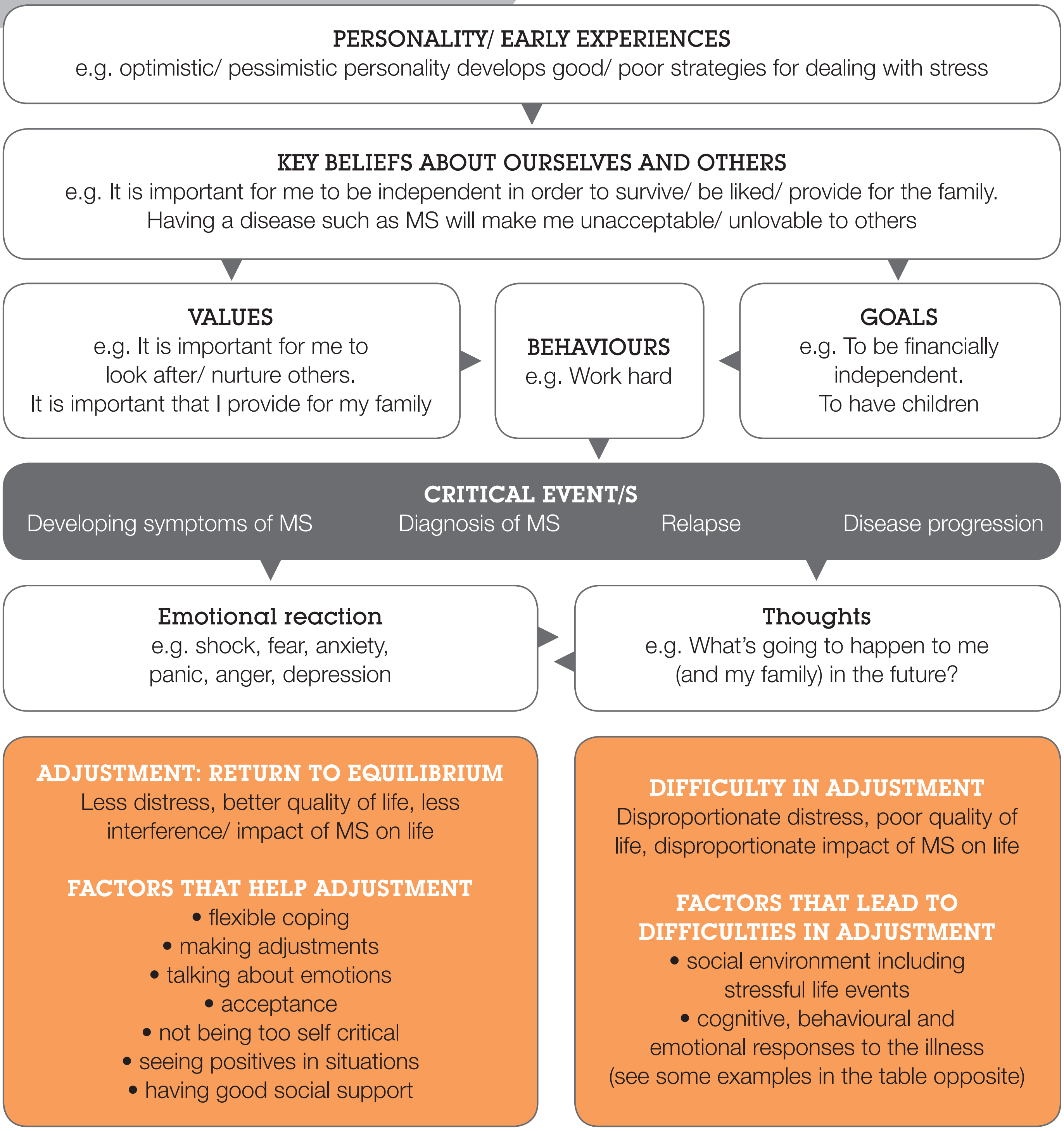
Healthy behaviours

Behaviours such as regular exercise, good sleeping patterns, eating a healthy diet, not smoking, and making time for enjoyable activities are known as 'healthy behaviours'. People with MS who report a high level of healthy behaviours experience better quality of life.

These findings suggest there are a number of factors which contribute to the adjustment process. In addition to these, our early life experiences, innate personality and basic values and beliefs will all determine how we cope with traumatic or difficult life experiences such as having MS. Rebecca illustrates this very nicely:

> "I'm not very good at accepting help anyway. Although that is nothing to do with having MS. That's just me. And so when people say 'Is there anything I can do?', I would say 'No, no. I'm absolutely perfectly fine. No problem at all.'"

In the diagram on the next page, we have attempted to pull these various factors together to provide an overall model of adjustment to MS.



PERSONALITY/ EARLY EXPERIENCES
e.g. optimistic/ pessimistic personality develops good/ poor strategies for dealing with stress

KEY BELIEFS ABOUT OURSELVES AND OTHERS
e.g. It is important for me to be independent in order to survive/ be liked/ provide for the family.
Having a disease such as MS will make me unacceptable/ unlovable to others

VALUES
e.g. It is important for me to look after/ nurture others.
It is important that I provide for my family

BEHAVIOURS
e.g. Work hard

GOALS
e.g. To be financially independent.
To have children

CRITICAL EVENT/S
Developing symptoms of MS
Diagnosis of MS
Relapse
Disease progression

Emotional reaction
e.g. shock, fear, anxiety, panic, anger, depression

Thoughts
e.g. What's going to happen to me (and my family) in the future?

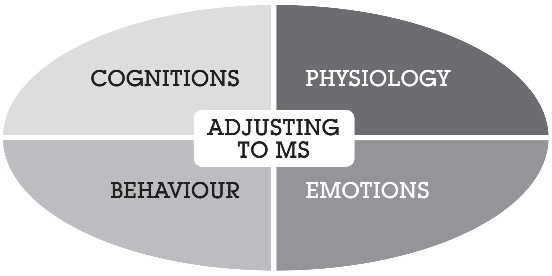
ADJUSTMENT: RETURN TO EQUILIBRIUM
Less distress, better quality of life, less interference/ impact of MS on life

FACTORS THAT HELP ADJUSTMENT
- flexible coping
- making adjustments
- talking about emotions
- acceptance
- not being too self critical
- seeing positives in situations
- having good social support

DIFFICULTY IN ADJUSTMENT
Disproportionate distress, poor quality of life, disproportionate impact of MS on life

FACTORS THAT LEAD TO DIFFICULTIES IN ADJUSTMENT
- social environment including stressful life events
- cognitive, behavioural and emotional responses to the illness (see some examples in the table opposite)

EMOTIONS



Social/ environmental context

Use 'Homework task – Adjustment strengths and difficulties' sheet, opposite, to write down factors which may be relevant to your personal adjustment to MS, both in terms of strengths and difficulties you may have.

Homework task – Adjustment strengths and difficulties sheet

Using the material covered in this chapter for reference, write down factors which may be relevant to your personal adjustment to MS, in terms of both strengths and difficulties you may have.

My strengths	
Example	I have a family who are supportive and helpful
1	
2	
3	

My difficulties	
Example	I don't go out very much any more because I'm worried about what people I don't know very well will think of me
1	
2	
3	

CHAPTER TWO:
Adapting to living with MS

The diagnosis

Before being diagnosed, people with MS say they felt a mixture of fear and anxiety. After this period of uncertainty, the diagnosis of MS is then confirmed. This brings about its own difficulties. Understandably, a range of emotions are triggered. We asked people how they felt about having been told they had MS. Some said they felt fear of the unknown, others were afraid of losing their independence. Some went into denial and were unable to accept they had MS. Some were afraid of what would happen to their family. Most people reported a strong emotional response, while others went into practical problem solving, seeking more information. The responses below give some examples of these:

> “My initial reaction was quite relieved really that I wasn’t making it up, but it soon changed to ‘Oh my God. What does this mean?’ and total panic and lots of tears; things like that for quite a long time.”

"The main worry for me is the wheelchair. The thought of it! No disrespect to anybody else that's in a wheelchair, but just the thought of being in a wheelchair. I feels like my life will end."

"I didn't feel that I asked enough questions, but I think it's probably because, you know, I was in denial. I didn't really want to know."

"I was just worried that I'd end up in a wheelchair and not being able to do anything, but then I sort of read about it and realised it was not the case."

Most people at some time fear the worst. It is normal to worry about the future and it is likely that people's ability to cope will change over time.

We know that having had MS for longer is linked to greater acceptance, so for many people it is a process that occurs over time. But we also know that some people find acceptance more difficult than others, and we know that acceptance is associated with better adjustment, so we would like to explore the concept in more detail.

Acceptance

What do we mean by acceptance?

Acceptance literally means living in the present moment, engaging fully in what you are doing or able to do, rather than getting lost in your thoughts. It also means sometimes accepting symptoms and distress.

Joan's experience illustrates this perfectly:

> "My dad had a stroke and I read that you have to grieve for the person you were. And I kind of adapted that to my illness. I thought, 'Well I have to grieve for that person'. So you go through the process of grieving and you then realise what you have and carry on. It's a kind of inner strength you get after a while. I don't know if everyone has it. You've gotta find something inside and… cherish what you have… little things…"

For others, acceptance of internal feelings is very hard and all sorts of strategies are used in order to avoid the unpleasant feeling or symptom:

> "It actually took me two years before I could say the words multiple sclerosis and tell anybody. I know I have this kind of avoidance issue about it, because I guess that's the way that I know how best to deal with something like that. I realise it's probably not the best thing to do. I think I am just learning how to cope."

Acceptance for some people might involve making changes that make living with MS easier. Not everybody will need to use mobility aids, but for some it makes life a lot easier. Mary talks about how she felt when she first starting using her scooter to help her get around:

> "I kind of felt a bit embarrassed. I was worried about what people are going to think. Are they going to think I shouldn't be in it? The embarrassment didn't last very long. I think after one day I was fine. I kind of accepted using it. I accepted using my chair, as well. I didn't feel too bad about it and it helps a great deal when you've got a problem…"

In contrast, Beverly found adapting to using a stick a lot harder even when she developed some difficulties walking on her own:

> "About three weeks later, I got a stick. It's a hiking stick. It's not a walking stick. And I don't need it and I don't take it with me every time I go out. I probably should but I don't and I won't."

Some people have more difficulty accepting negative emotions, symptoms, and the illness than others, and we'd like to emphasise that we are not confusing acceptance with giving up. Adaptations and adjustments are an unavoidable part of living with MS. The aim of this CBT programme is to help you improve your quality of life, by engaging in life as best you can, while accepting the symptoms, distress and disability that can go with having MS.

The more we try to control certain things the more uncontrollable they may become

In a condition such as MS it will certainly be impossible to control symptoms all of the time

Becoming accepting

So how do you become accepting in a way that is going to be helpful if you are having difficulty?

The idea of acceptance is often associated with Eastern philosophies. This is in stark contrast to Western philosophies. In the West we tend to see things rationally and we often hold the view that we should be able to get rid of symptoms or unpleasant experiences. In fact, the medical profession and other health professionals reinforce this view by seeing illness in terms of pathology (something that has gone wrong in the body) which they are attempting to treat or cure. They see their role as one of reducing suffering, by reducing the severity of symptoms and distress. What is interesting is that although occasionally we manage to control things, control is often difficult or even impossible to obtain. In practice the more we try to control certain things the more uncontrollable they may become. In a condition such as MS it will certainly be impossible to control symptoms all of the time.

Strategies

Sometimes people get stuck using a particular strategy to manage symptoms, distress or disability, despite the fact that it is not working. Ask yourself some questions and reflect on whether what you are doing is helping.

1. Am I accepting the reality of the situation?
2. Am I wishing things were different?
3. What do I want in life, given my current level of ability?
4. Am I making some changes that will help me work towards these life goals?
5. What do the coping strategies that I am using cost me in terms of energy or relationships?
6. Are some of the things I am doing to control the situation actually keeping it going?
7. Am I asking for help when I need it?
8. Am I talking to someone about how I feel?
9. Am I being too self critical?
10. Am I recognising that other people cannot know what I want unless I tell them?
11. Have I stopped doing enjoyable things altogether?
12. Am I seeing things in black and white terms and failing to compromise or be flexible?
13. Am I forgetting the things that I can do and focusing on the things I can't?
14. Sometimes we avoid things because we feel it is the best thing to do in the short term. Am I avoiding anything as a way of coping with an aspect of my MS? Is it helping in the long term?

Some of the issues that might arise from your answers to these questions will hopefully give you some idea of what you would like to work on. Reflecting on these questions might also help you assess your current level of acceptance.

Dealing with negative emotions

Sometimes people avoid acceptance because part of it involves experiencing difficult, negative emotions and fearful thoughts. In the rest of this chapter we focus on the process of accepting and dealing with negative emotions.

At the beginning of this manual we introduced you to a model for explaining adjustment to MS, and this included an emotion/ feeling component. People who have an unpredictable, long-term condition like MS will normally experience a range of emotions. These might include sadness and grief, frustration and anger, depression, fear and anxiety, embarrassment and shame.

Strong feelings are usually a signal that something important is going on in your life. Ignoring and/ or pushing away your emotions might sometimes help in the short term. But in the long term, avoiding emotion gets in the way of adapting and could make symptoms worse.

Feeling tense, angry, stressed, anxious or low in mood produces physiological changes such as increased fatigue and muscle pain, impaired memory and concentration, and poor sleep. Even if we try to shut out these emotions or ignore them by keeping very busy, we usually still suffer the physiological effects. Allowing yourself to feel the emotions and to process them will ultimately ease the discomfort the emotions cause.

What negative moods do you experience frequently?

How have you coped with feelings like these in the past?

Do you try to avoid them?

Do you vent or ever take them out on other people?

What has been helpful and what has been less helpful?

Helpful strategies

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Unhelpful strategies

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In the following section we suggest some helpful strategies for processing different feelings. Other methods are also included in different sections of the manual.

Feelings of sadness, grief and loss

It is perfectly understandable that a person who has MS will experience times of sadness and grief. This is a sign that you are adjusting to changes and loss. Helpful strategies to use when you feel this way include telling people how you feel and getting support from family and friends.

People often say, “I don’t want to talk about how I feel because it burdens other people.” But many people feel flattered when you confide in them. It is a sign that you trust them enough to talk about your feelings. Research shows that when you confide in people you usually feel more connected to them and less alone.

When you are feeling down it can make you feel bad about yourself and less likely to do pleasurable and nice things for yourself. It may sound strange, but it is possible to feel very sad and still enjoy things at the same time. So it is worthwhile treating yourself when you are down – allowing yourself to believe that you deserve to have something nice – not as a way of avoiding your sadness, but as a way of allowing yourself some positives at the same time.

For some people, treats may involve a bit of pampering – going out for a nice meal, having a massage or perhaps nibbling on some chocolate while watching an enjoyable DVD.

For others it’s letting yourself enjoy the small pleasures of life, as Gary describes:

> “I do enjoy being outside and do enjoy observing the wildlife. There is a lot of green space around me and if all the birds are out I enjoy watching what they are doing and I go down to the beach and usually there’s some seagulls or something down there to be looking at.”

Feelings of frustration or anger

Feeling angry and frustrated is a common experience with any long-term condition. People have to adjust to limitations imposed by their symptoms. For example, a person might no longer be able to attend after-work activities they previously enjoyed. This can result in them feeling frustrated or angry. Two people with MS explain:

> "I can be very angry with it, because it – the MS – makes me lose certain things in life. So that causes loss sometimes, and that can be upsetting and make me angry."

> "You get frustrated and angry sometimes. Oh, I throw things around 'cos I can't get out and do the things I used to be able to do. Really, my social life has gone, and my working life. Well I'm not sure about the working life side of it – I think I can do something about that later. But I think at the moment, my social life has gone right out the window, 'cos I can't do the things I used to be able to do."

Talking about your anger and frustration is helpful, although venting your feelings in an aggressive manner can make both you and the other person uncomfortable. In chapter eight we talk about assertiveness training. Expressing anger to someone in an assertive rather than aggressive way is usually more helpful.

If you feel unable to talk about your angry feelings because they feel so powerful and overwhelming at first, physical exercise can be helpful. Exercise uses up some of the unpleasant physical energy generated by anger and you may then feel more able talk to someone about how you feel in a less aggressive way.

What if I can’t talk about my feelings?

Some people find talking to others about the way they feel very hard. Some also have difficulty identifying what they are feeling. In the examples above, people were obviously able to talk about their anger, but some people find it very hard to allow themselves to be angry. If this is the case, it can help to write about your feelings first.

A researcher in Texas, Jamie Pennebaker, has shown that writing about how you feel about traumatic experiences can help relieve distress and improve health. Straight after writing, people are usually more distressed – this is normal and to be expected. But the process of writing does help people come to terms with how they feel and/ or understand their feelings better. So, over time, the benefits are felt. Writing worked very well for Jim:

> “I worked on finding a way of expressing what I felt and I did a lot of that on paper. And not typing it or writing it, because that was too difficult, but I found a way of getting it on to the computer without having to write and just to have a place that was private enough to be able to say what I felt, and to say it articulately, and to say it clearly, and to be able to reflect on what that meant for me, and what that meant for my personal growth, and how it fitted into my life.”

Anxiety, depression, embarrassment and shame

With all these feelings, telling others about how you feel and getting their support can be helpful. Like all feelings, at times they may seem too overwhelming. In the next chapters we provide other strategies for lessening the impact of these emotions. These strategies may include changing any unhelpful thinking that contributes to your feelings, and not always avoiding situations that evoke these emotions.

Homework task – strategies for dealing with emotions

Identify any difficult emotions currently experienced. Decide on a strategy or strategies to work on to deal with these emotions.

Strategies for dealing with emotions

	Emotion	Current strategy/ strategies	Alternative strategy/ strategies
Example	Anger	Ignore it Keep it inside Take it out on my wife	Make use of the physical energy – do half an hour on the excercycle Take some time out in the evenings to write about what is making me angry Once I have worked out why I am so angry – talk to my wife about what makes me feel this way
1			
2			
3			

CHAPTER THREE:

Setting goals and problem solving

Setting goals

Setting goals is an important step in helping you to cope with and manage your MS. Goals will help you to think about what you would like to work towards in the coming months. The process of setting goals will help you to think through and reflect on what adjustments you have already made and what adjustments you would still like to make.

It may be useful to think about them in relation to your values. Some examples of values are:

- it is important for me to have a family and be a good mother
- it is important for me to succeed at work
- it is important for me to have a good social network and offer support to my friends

Important facts about targets and goals

- Long-term goals are things that you would like to be doing in the longer term, rather than something you want to achieve immediately. This is taking into consideration the severity of your symptoms and any associated disability.
- It can be helpful to have *different* goals to work towards, to make your life as balanced as possible. Rather than working on one particular area of your life, such as work, ensure that your long-term goals have a *mixture* of activities.
- It is important to remember that activities for pleasure are as important as work and chores.
- It is important that you set yourself *realistic* and *achievable* goals.
- Be wary of being too ‘driven’ or ‘ambition orientated’ when setting your goals.
- It is important to make your goals *specific* in terms of:
    - the *activity* that you wish to perform (activity)
    - how *often* you would like to carry out the activity (frequency)
    - the *length of time* to be spent on the activity (duration)
- Although you may feel that your choice of goals is very restricted due to your level of symptoms or disability, setting goals will provide you with a clear direction and focus. We acknowledge that your targets may have to be modified in the event of a relapse or a worsening of your MS.

Examples of target areas

A) Leisure time

You may find that your time at home is taken up with chores. Think about planning regular time for pleasurable activities (whether that’s reading, playing a musical instrument, painting, writing letters, quality time with children…). You might have neglected hobbies or have always had a burning desire to try something new!

B) Work/ education

If you are *not* working, you might consider (if suitable) doing part-time work, or doing some voluntary work. If you *are* working, you might feel that you are working too much, and would benefit from reducing your hours.

You might consider some type of educational course to enable you to find work or change direction in your career, or simply because you have an interest in a particular subject.

C) Social activities

You might find that you have reduced or lost contact with some friends and family. Consider a regular time for talking to or meeting up with those people. Or you might want to look at ways of meeting new people.

D) Exercise

In the past you might have exercised regularly. On the other hand you might never have been particularly fit and might have had exercise on a 'to do list' for many years. You might want to find time for a particular type of exercise.

E) Chores/ DIY/ gardening

If you are overwhelmed by a 'to do list' of things that have to be done, plan a regular, realistic time to do them.

F) Sleep

If getting a good night's sleep is a major problem, you might target a specific getting up/ going to bed time.

How to set goals

To give you some ideas, look at the examples of clearly defined goals below.

1. Write a list of things that you would like to work towards over the coming months. Discuss this with your therapist during your next appointment.
2. Prioritise your list into four areas, such as work, social, exercise, leisure.
3. Ensure that your goals are clearly defined and specific.

Examples of clearly defined goals

- to go shopping twice a week for half an hour
- to have a friend for coffee once a week for half an hour
- to walk for 15 minutes daily (if able)
- to do voluntary work three times a week for at least two hours each time
- to go out with friends once a week, for up to three hours
- to swim twice a week, for half an hour each time
- to do a course at college for three hours a week
- to do gardening three times a week for half an hour each time
- to spend an hour every day on my hobby (specify the hobby)
- to do an hour of chores every day (such as ironing, washing, cleaning)
- to work part-time in my trained profession
- to have two breaks at work of at least 15 minutes each
- to sit and read the paper/ magazine for half an hour every day
- to get up by 9am each day

Examples of not clearly defined goals (and why)

- to go to work (no frequency or duration specified)
- to go out more socially (no frequency or duration specified)
- to be more active (no activity, frequency or duration specified)
- to feel better (no activity, frequency or duration specified)

How to break down your goals into manageable steps

1 Look at the examples of goals that have been broken down into manageable steps.

2 Think of ways to break each of your goals down into manageable steps.

3 Make each step small and grade it from easy to difficult.

Examples of breaking down goals into manageable steps

Target 1

To go out with friends once a week, for up to three hours

Steps to achieving Target 1

- talk to a friend on the phone for 15 minutes, three times a week
- go to a friend who lives nearby, for an hour every week
- go out with a friend to a local venue for an hour every week
- go out with friend(s) for an hour and a half every week
- go out with friend(s) twice a week for two hours

Target 2

To read for 30 minutes twice a day

Steps to achieving Target 2

- read for 15 minutes twice a day
- read for 20 minutes twice a day
- read for 30 minutes twice a day

Target 3

To do voluntary work three times a week for at least two hours each time

Steps to achieving Target 3

- write a list of voluntary work in which you might be interested
- contact the appropriate association(s) for information
- plan steps which will help you to sustain the activity in which you will be involved: for example, standing for longer periods – if working in a charity shop – or reading/ computer work – if doing administrative work
- arrange informal visit(s) to the work place
- arrange a graded work schedule if possible

Target 4

To do something relaxing for myself for an hour every day

Steps to achieving Target 4

- leave work on time each day
- ask other family members to help with the chores
- leave non-urgent activities for another day
- plan a list of pleasurable things that I would like to do each day

Homework task – Goals sheet

The 'Goals sheet' provides space for you to plan out steps towards achieving long-term goals. You may only need two or three steps to achieve your goals, or you may need a lot more. Use extra paper if necessary.

Goals sheet

Long-term goal	Steps to achieving long-term goal
	1. 2. 3. 4. 5. 6. 7. 8.
	1. 2. 3. 4. 5. 6. 7. 8.
	1. 2. 3. 4. 5. 6. 7. 8.

Problem solving

Problem solving is based on a common observation – that emotional symptoms are associated with problems of living. Problem-solving techniques can enable you to sort out issues when you feel particularly stuck.

We all get stuck sometimes, and being aware of the problem-solving process can help move things along a bit quicker. Problems should be tackled in a planned and structured way.

Although some problems may not be completely solvable, in starting to tackle problems you can re-assert control over your life. It is probably this regaining of control that lifts mood. Problem solving focuses on the here and now rather than on mistakes of the past.

Problem solving can be divided into five stages. Like any new skill, it takes a while to be able to do it automatically. At first, you might find it helpful to write down the various stages. Until you've mastered the art of problem solving, it can be useful to go into detail at each stage. But once you have practised it several times and have become more confident, you will be able to skip some of the steps. It is always helpful to evaluate how effective your strategy has been. This will guide you with future difficulties.

Stage 1

a) identify your problem(s)
b) recognise your emotional symptoms – anxiety, low mood, worry associated with the problem

Stage 2:

a) break down the problem(s) into smaller chunks

Stage 3:

a) consider your strengths and assets
b) consider support available from relatives, friends and health professionals

Stage 4:

a) consider alternative solutions to each problem
b) try not to discount possible options too soon
c) examine the pros and cons for each solution
d) choose a preferred solution
e) identify steps to be taken to achieve the solution (long-term goal)
f) specify exactly what you are going to do and when (put it in your diary)

Stage 5:

a) implement your steps
b) evaluate your degree of success
c) don't be put off if your first solution doesn't work
d) consider common reasons for failure – being too ambitious, lack of consistency or practice, giving up too soon
e) reward yourself for your success
f) try not to focus on failures – focus on what you've achieved

We will now focus on one specific problem to illustrate the approach. You can follow the same principles in relation to a problem you have encountered in the past. In the future you will then find this process more helpful.

MS-specific problems

Stage 1

a) Identify the problem
For example – I can't get out as much as I used to.

b) Identify your emotion
For example – worry/ anxiety/ stress about not wanting to put friends out, or worry about going somewhere without wheelchair access.

c) Recognise the link between the anxiety/ worry and the problem. Be aware of your own emotional response to this situation. This will help you solve the problem.

Stage 2

a) Break down the problem into smaller chunks
For example – find out about wheelchair access (call the restaurant); talk to friend about concerns

Stage 3

a) Consider your own strengths and assets. How would you consider helping others in a similar situation? Now apply the same rules to yourself.

b) Consider support available from friends, relatives, health professionals. Do you need practical or emotional support? Who would provide the type of support you need?

Stages 4 & 5

a) Consider alternative solutions.

b) You might also want to consider what sort of support you need. Is it practical or emotional support? You might consider asking a friend for help.

These courses of action then help you to put the situation in perspective, realise that your problem is not unusual, and help you deal with the situation realistically. Don't be put off if occasionally things don't work out as you had intended – go back to the drawing board and think again.

Other examples

Below is a good example of how Ben got around the problem of missing his old hobbies – by adapting his leisure activities to accommodate the fact that he could no longer be active in quite the same way as before:

> "I used to ride motorbikes a lot but I've had to give that up recently. That made me feel pretty upset because that's something I've done all my life since I was 16. For many years I've been riding motorbikes and it was my sort of true love. But I found other things to replace it with. I filled in the gaps by doing other things. I've taken up things which I would never have thought of doing beforehand, like I go sailing now, horse riding and carriage driving and go to a gym, which I would never have done before. So that sort of fills in the gaps, where I would have been riding a motorbike."

Pete also demonstrated good problem solving skills. He knew that if he wanted to go to the party, he had to plan for it by pacing himself beforehand:

> "If it's something I really, really want to do – for instance, if I'm going to a party or going out or something – I am very careful about not overdoing it that day, or even two days before. Because I'm not going to be stopped from doing anything..."

Paula explained how being unemployed after leaving a job because of MS was making her feel quite down. She had thought about different ways of getting round the problem, using her assets and her support network, and had come up with potential solutions:

> "I've given up the work partly because I'm not driving. I don't have transport at the moment. Also, the company I worked for has moved out of the area. I was doing shift work so there's no way I can do that anymore. But having said that, tomorrow I'm going to see an Employment Adviser in the Job Centre. I'm hoping to turn things round, and try and get a bit of a life back. I decided to try and do something. I'm in receipt of DLA and I listened to other people – what they do with the money – and they put it into transport (whether it be a motor, a buggy, a wheelchair) and they get around this. And I've got lots of booklets and pamphlets and things, so I decided that I'd send off for some information. And I contacted the employment office. I made an appointment to see an adviser, which I shall do tomorrow, and see where we go from there."

Homework task – Problem solving sheet

You might want to use the 'Problem solving sheet' to practise working through the five stages of problem solving.

Problem solving sheet

This sheet can be used to work through the five stages of problem solving

Stage 1 Identify problem. Recognise emotional symptoms of problem.	
Stage 2 Break problem into smaller chunks.	

Problem solving sheet continued

Stage 3 Consider your strengths, assets and support available.	
Stage 4 Consider different solutions. Think about pros and cons. Choose a solution. Identify steps towards solution.	
Stage 5 Implement solution. Evaluate. Focus on what has been achieved, not what has not!	

CHAPTER FOUR:
Symptom management

Behavioural strategies

People who experience prolonged and/ or severe symptoms, often try to manage it by:

- resting more and reducing activity in the hope of feeling better and to prevent symptoms from getting worse
- pushing themselves to do as much as possible when they can, and rest more when symptoms get worse (‘all or nothing’ behaviour).

Many people use both of these strategies. They are natural, understandable ways to try to manage symptoms.

However, as you will see below, sometimes the very thing we do in order to feel better actually makes us feel worse in the long run (they perpetuate the problem, or keep it going).

Reasons why extremes of rest and activity are counterproductive in the long run:

a) Too much rest and the body becomes physically de-conditioned or unfit. Following periods of rest and reduced activity, the cardiovascular system becomes less fit. This can result in a number of symptoms including palpitations, sweating, breathlessness and fatigue. Inactivity also leads to loss of muscle tone or strength in the legs, resulting in less blood returning to the heart. This can lead to a drop in blood pressure when you stand up, with less blood going to the brain, causing unpleasant symptoms including dizziness and fatigue.

b) In contrast, a reasonably consistent approach to activity allows the body to get used to a regular routine. Too much rest results in more tiredness, reduced motivation and poor quality of sleep.

c) When a person over-exerts him/ herself, symptoms – such as fatigue – often get worse. This may then lead to slowing down or resting completely. Before long, a vicious cycle develops, in which fatigue follows on from over-activity but is then followed by too much rest. This is a habit which can be difficult to break.

‘All or nothing’ people often focus on the things they feel they have to get done, such as work assignments and/ or care-giving for children, and they cut out enjoyable or relaxing activities. In this way they miss out on activities which are ‘for them’. If this goes on for too long, they will start to feel depressed or overly stressed and anxious.

How to avoid perpetuating symptoms such as fatigue

One way of both preventing fatigue and managing fatigue once it’s started is to adopt a consistent approach to activity, sleep and rest. In a recent treatment trial of MS fatigue, this was shown to be very effective.

Homework task – Activity diary

For each day, write a summary of your periods of activity, rest and sleep. Try to write what the activity is, so that you have a sense of how much time you spend on work and chores and how much on more pleasurable activities.

	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
Morning							
Midday							
Afternoon							
Evening							

Below is an example of what someone has written:

	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
Morning	Breakfast, take kids to school	In bed	Breakfast, housework	Breakfast, take kids to school	Breakfast, visit friend	Asleep	Watch TV
Midday	Prepare lunch, housework	Walking, watch TV	Resting	Lunch, shopping	Walking, lunch	Gardening, reading	Shower
Afternoon	Resting	Housework	Visit friend	Resting	Housework	Visit friends	Prepare dinner
Evening	Dinner, watch TV	Dinner, reading	Pick up kids, dinner	Get takeaways	Dinner, watch TV	Rest	Walking, dinner

Keeping a record such as this one will allow you to see any problems in your pattern of activities. Look out for a tendency to do a lot one day and then having to rest up another. Some people will notice they are too busy, others will notice they are resting a lot and others will feel they have the balance more or less right.

Developing a more consistent pattern of activity

If possible, try to adopt a consistent approach to activities – even if at first you feel you are doing slightly less. You will then be in a better position to either increase or reduce what you are doing, if you need to. Be sure to schedule in plenty of fun things and try to balance chores and enjoyable activities.

It will be more of a challenge to carry out your activities on bad days. But by sticking to a routine you will start to gain control over your life and symptoms rather than allowing your symptoms to gain control over you. It is important to remember that resting is not always the best of way of dealing with symptoms, and often by distracting ourselves with activity we can lessen the impact of the symptoms.

Try not to be too hard on yourself. People's activity patterns have often been developed over a long time and it will take time and effort to change. It is important that you notice and acknowledge any small changes you make.

It is important that you make changes slowly and steadily over the next weeks, rather than changing activity patterns too suddenly or too quickly.

Chapter three describes in detail how to set goals for yourself and chapter six describes ways of improving your sleep. It might be worth re-reading chapter three and if you have sleep problems jumping to chapter six.

As well as having natural rhythms in terms of activity, people also tend to cope with symptoms in different ways. We will now turn our attention towards other ways people cope with symptoms that may not be all that helpful.

Homework task – Activity and rest goal sheet

You might want to use the 'Activity and rest goal sheet' to set some targets to help you develop a consistent daily routine.

Write your goals in the column provided for each section. If a section does not apply to you, leave it out. In the columns marked Monday-Sunday tick if you achieved the goals or cross if you did not manage to meet your target. If a goal is set for only a few days a week, leave the other days blank and tick or cross on the chosen day(s).

Activity goals

Goals	M	Tu	W	Th	F	Sa	Su
1.							
2.							
3.							

Resting goals

Goals	M	Tu	W	Th	F	Sa	Su
1.							
2.							
3.							

Symptom focusing

One of the key factors which makes symptoms worse is focusing unnecessarily on symptoms. It is natural in a chronic, unpredictable illness such as MS to become worried when experiencing symptoms, and as a consequence, to focus more on the symptoms than is perhaps helpful. This can lead to a vicious cycle where focusing on symptoms leads to experiencing more symptoms and more worry about symptoms.

For example:

Judy is busy at work when she notices she has a headache. Although she has managed to ignore it up until now, once she notices it she focuses on it and the headache gets worse. She starts to worry about how she will get her work done with this pounding headache. Her body tenses up because she is worried, which in itself makes the headache worse.

When people identify the fact that they are focusing on symptoms, their initial response is often an attempt not to think about their symptoms. However, trying not to think about something often makes it worse. The more you say to yourself, "I must not think about my symptoms," the harder it is to ignore them.

What can you do about 'symptom focusing'?

There are a number of different strategies you can experiment with to reduce the amount you focus on your symptoms. But the first step is to become aware of when you are actually 'symptom focusing'.

1) Increasing your awareness

Most people notice a change in how they are feeling (for example, feeling anxious) or a change in their body (for example, being more tense) when they are focusing on their symptoms.

What happens for you when you focus on your symptoms? How would you notice you were doing this?

....

....

....

2) Redirecting your attention

Once you are aware you are focusing your attention on your symptoms, you can choose to redirect your attention somewhere else. This might be a helpful strategy when you are in a situation which requires your full attention, and where you do not have the time or space to find alternatives to your thoughts (this is the next strategy).

For example, you might be at work trying to finish a job when you notice a tingling in your legs. Your usual response might be to start scanning your body for other symptoms and to think that it is a symptom of MS. Instead, you could observe that you are focusing on your symptoms, remind yourself that this is not helpful and that the symptom may well go away, and then refocus your attention on the task you were doing.

There are lots of different ways you can redirect your attention away from symptoms:

- you can focus on the sounds around you
- you can look at the pictures on the wall
- you can do some quick stretches
- you can smell your favourite soap/ perfume
- you can focus on the taste of your coffee/ lunch

The main idea is to redirect your attention away from symptoms onto other things

Understanding symptoms

When you have a chronic condition like MS it is easy to assume that all symptoms are caused by your illness. In fact, it is just as likely that common symptoms could be due to a wide range of other factors, such as tiredness, anxiety, or the common cold.

In the next sections, we explore these alternative explanations for symptoms.

Developing alternative explanations

One way to reduce the amount you focus on your symptoms is to be aware of the thoughts you have about the onset of a symptom, and to explore alternatives to these thoughts.

For example, Jane has a thought such as, “My energy level has dropped and that means I am about to have another relapse and I won’t cope.” This may make her scan her body for other symptoms, which might suggest a relapse. This will make her even more sensitive to any bodily changes which might have occurred anyway, make her more likely to think she won’t cope, and make it more likely that her symptoms increase.

The reality is that not all your symptoms are necessarily related to your illness. They could be a physical response to anxiety or depression, or be due to a change in routine, or simply be a common symptom which is part of everyday life and not a reflection of your MS.

So it may be helpful to replace the thought:

> “My energy level has dropped, that means I am about to have another relapse and I won’t cope.”

with an alternative like:

> “I sometimes experience a drop in energy when I have been really busy, but it does not necessarily mean I am going to relapse. In fact, it is much more likely to be part of the normal ups and downs of MS.”

In order to reduce the amount you focus on your symptoms and to develop more helpful explanations for your symptoms, it is important to have a good understanding of the exact nature of MS symptoms.

The first step in developing alternative thoughts is to understand your individual MS symptoms as well as becoming aware of other possible explanations for experiencing certain symptoms. By being able to develop alternative explanations you might be able to reduce the amount you focus on your symptoms.

Different explanations for symptoms:

A) Normal fluctuations in MS symptoms

Symptoms which linger after you've otherwise improved from an MS relapse are unpredictable. These 'residual' symptoms often vary at different times for the same person. In addition, not everyone has the same residual symptoms and they can vary in duration and severity. A person with MS will usually experience more than one symptom, and not everyone experiences every symptom.

Common residual symptoms include: visual disturbances, changes in sensation, weakness, stiffness or spasms, impaired balance and coordination, pain, bladder and bowel problems.

MS symptoms vary according to where in the brain or spinal cord there is inflammation (swelling) and demyelination (damage to the 'myelin' protection around nerve fibres).

Inflammation and demyelination both affect the way electrical messages pass along the nerve fibres. When messages are disrupted, it causes symptoms.

Inflammation and demyelination cause symptoms during a relapse. As inflammation dies down, the symptoms of a relapse fade away. If demyelination has happened, there might be lasting, residual symptoms.

The nerve can repair after demyelination, but it is never as good at doing its job as it was before.

Most of the time, changes in symptoms are due to natural fluctuations in how well nerve fibres work, rather than new areas of inflammation or demeylination. Nerve fibres that have been demyelinated in the past are liable to have faults.

Changes in body temperature (often because of infection or increased physical activity) can affect how well these repaired nerve fibres pass their messages. This leads to increased symptoms, which might last minutes or hours depending on the cause. But the symptoms do not indicate further nerve damage.

One of the best strategies for dealing with these common fluctuations in symptoms is to learn to tolerate the different levels of discomfort rather than worry about them.

It is important to be clear about the symptoms that are part of your individual experience of MS, as well as what you experience when you have normal fluctuations.

Let's review what you believe your individual MS symptoms are and the change in symptoms you might experience as part of normal fluctuations:

………

………

………

Symptoms of a relapse are also individual, and depend on where the patch of inflammation occurs

B) Symptoms related to relapse in MS symptoms

An acute relapse is due to a new area of inflammation causing a new neurological symptom or the re-appearance of a previous symptom. A relapse can be confirmed by objective neurological signs from a neurological examination.

New symptoms of this sort are usually fairly clearly separate from fluctuating residual symptoms. They usually get worse over several days and persist for a week or more (often several weeks).

Symptoms of a relapse are also individual, and depend on where the patch of inflammation occurs. Common examples are blurring of vision in one eye, often with pain on moving the eye (optic neuritis); double vision, particularly on looking to one side; weakness and clumsiness in the limbs on one side; or numbness with tingling on one side or in both legs up to a level on the trunk.

It is extremely hard in MS not to get too worried about new onset symptoms, or change in symptoms. Having some knowledge of what is likely to represent a relapse or what are normal fluctuations of the illness can prevent you focusing too much on your symptoms and reduce your anxiety about the symptoms.

If you are concerned that you might be having a relapse, it is important that you consult your doctor. Serious new bouts of inflammation are commonly treated with anti-inflammatory medication, but such treatment is often not necessary for minor relapses.

C) Symptoms related to medication side effects

A lot of people with MS take medication for various symptoms, and some medications have side effects, particularly in the initial stages of taking them.

Because there are so many different medications that people could be taking we cannot review them all here. It is important, however, that your therapist knows exactly what medication you are prescribed, how long you have been taking it, and whether there are any relevant side effects.

What medications are you currently being prescribed?

....

....

....

When did you start taking them?

....

....

....

What are the known side effects of these medications, and how long do they typically last?

....

....

....

D) Symptoms related to poor routine and deconditioning

Earlier in this chapter, we explained that people with long-term conditions and fatigue often try to manage it by changing their routine. For example, people may increase rest and decrease activity. As a consequence, the body can become ‘deconditioned’, resulting in symptoms such as an increase in fatigue, lethargy, poor muscle tone and exercise intolerance.

Symptoms related to poor routine and deconditioning are very individual.

Do you have any symptoms which might be related to your level of rest and activity?

....

....

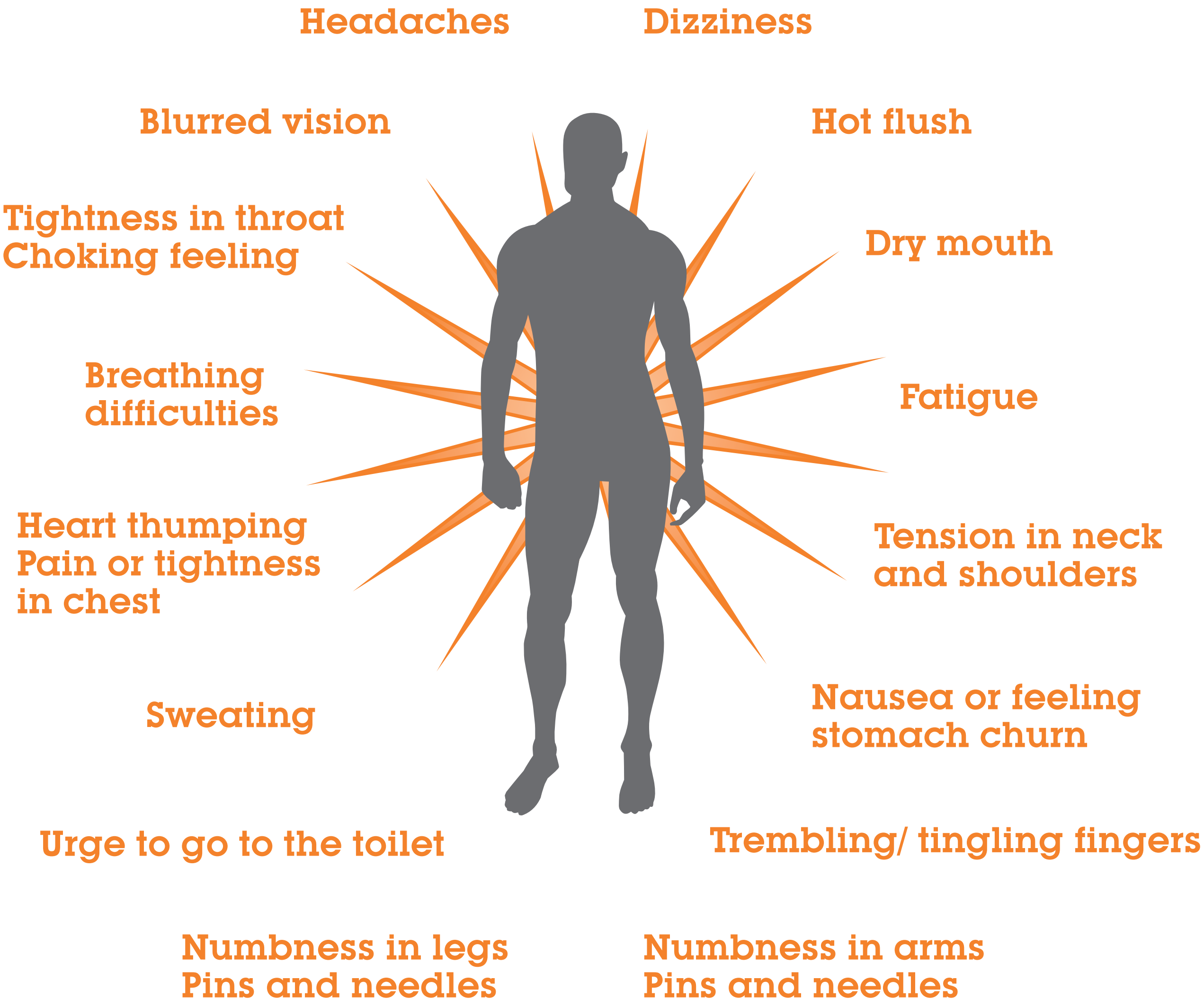
....

Symptoms related to poor routine and deconditioning are very individual

E) Symptoms related to stress and anxiety

In the chapter on stress management we talk in more detail about our body's natural physical response to stress, worry or anxiety. This response produces a number of symptoms, which are shown in the diagram below.

Common physical signs of extreme worry and anxiety



Some of the feelings shown opposite may come on when you are extremely worried or anxious. Some may last a short time (for example, heart thumping or breathlessness). Others may persist when you no longer feel anxious (for example, headaches, tension in the neck and shoulders).

What physical reactions have you noticed in yourself when you get stressed and/ or anxious?

....

....

....

F) Symptoms related to depression

People who feel low in mood or depressed experience physical symptoms. These can include tiredness or loss of energy; problems sleeping; tension; loss of interest in sex; loss of appetite or increased appetite; problems thinking or concentrating; feeling slowed down. In turn, some of these symptoms can lead to other physical sensations. For example, someone who feels depressed and eats less may feel more fatigued.

What physical sensations have you noticed when you get depressed or low in mood?

....

....

....

As you can see, there are numerous reasons for experiencing symptoms. The aim of this session is to help you develop a range of possible explanations for symptoms you might be experiencing – in order to reduce symptom focusing and 'symptom attribution' and help you manage your fatigue better.

CHAPTER FIVE:

How to tackle negative or unhelpful thoughts

In this chapter, we will focus on tackling unhelpful thoughts.

PART 1 – First of all we introduce the characteristics of unhelpful thoughts and why they can be a problem.

PART 2 – Next we will look at how to identify unhelpful thoughts.

PART 3 – Finally we will look at ways to challenge unhelpful thoughts and develop alternatives.

Part 1:

About unhelpful thoughts

When living with a condition such as MS, it might be difficult at times to keep a positive attitude, especially when you feel so unwell, your life has become restricted and your future appears uncertain. As discussed in chapter two you may feel frustrated, angry, demoralised, worried, anxious or depressed at times.

Negative emotions are usually associated with specific unhelpful thoughts and behaviours. Changing these thoughts and behaviours to more helpful ones tends to have a positive impact on how you feel emotionally – and sometimes physically too.

Here are some examples:

1. Fears about illness and the future

Example of how a situation triggered off a low mood and an unhelpful thought (what we might call a catastrophic thought)

Situation:	Relapse; worsening of physical symptoms; legs gave way.
Thought:	Here we go again. I will be bedridden before you know it.
Emotions:	Feeling very anxious.
Behaviour:	Excessive focusing on body and possible symptoms.
Physical:	Conscious of any small change in body sensation.

Can you think of any personal examples of how thoughts about MS may have influenced how you felt and how you coped with the situation? If so, write them in the spaces provided below.

Situation:

....

Thought:

....

Emotions:

....

Behaviour:

....

Physical:

....

2. Having high personal standards and self-expectations

Some people will naturally have high self-expectations. This might be accompanied by striving to achieve, either at work or in their personal life. Having MS means that goals people set for themselves might have to be modified and personal standards reduced (see chapter three). For some people, this goes against the grain and might result in them:

- becoming overly self-critical
- worrying about starting new things and/ or fearing not being able to do them well enough
- doubting their own judgement, making it hard to complete tasks
- focusing on things that haven’t been done
- feeling guilty about relaxing when you haven’t completed a task
- feeling frustrated about doing so much less than you used to be able to do

The quote below from Sue illustrates this point:

> "There's always about three times the jobs I need to do in a day, compared to what I actually get done. So I never actually feel satisfied that I've done what I need to do. I always find that. It gets to picking up time at school, so I pick my son up from school and then it's basically making tea, and then by the time I've actually cooked tea and prepared tea, I'm tired so it's bedtime. So I haven't really achieved a great deal."

Example of how unhelpful thoughts relate to high standards

Situation: Didn't achieve all that I planned to do today.

Thought: I'm useless! I should be able to do more.

Emotions: 'Frustrated' about not completing the tasks that I set myself.

Behaviour: Unable to relax or concentrate on any one thing.

Physical: Feel more fatigued.

Can you think of any personal examples of how high standards have influenced aspects of your life since you developed MS? If so, please write them in the spaces provided below.

Situation:

Thought:

Emotions:

Behaviour:

Physical:

As well as the unhelpful thoughts mentioned above, you might from time to time have unhelpful thoughts about a variety of things related or unrelated to your MS.

For example, relationship issues, finances or moving house. These thoughts might also make you feel a bit down and may in turn negatively affect your thoughts about your MS.

Characteristics of unhelpful thoughts

- *Automatic:* As with all thoughts, unhelpful ones tend to pop into our heads rapidly and unexpectedly, without any deliberate or conscious effort.
- *Distorted:* They may not be entirely accurate.
- *Plausible:* We accept them as facts, and do not question them.
- *They can be difficult to switch off.*
- It can be useful to view unhelpful thoughts as *prejudices* because they can be hard to change.

Common unhelpful thoughts

Here are some common unhelpful thoughts that people with MS have identified:

1. I am afraid I will make my symptoms worse if I exercise.
2. Symptoms signal I have overdone it.
3. If I push myself too hard I will relapse.
4. I can't cope with this.
5. My illness is awful and my symptoms are completely unpredictable and uncontrollable.
6. This pain is going to keep me up all night.
7. People must think I am really strange because I'm always turning down invitations.
8. I should pay close attention to how well or how badly I am feeling.

9. People will think badly of me because of my symptoms.
10. People will think I am drunk because of staggering gait.
11. If I use my stick when I go out people will stare at me.
12. If I'm not earning money I don't have much value.
13. If I end up in a wheelchair my world will come to an end.
14. If I ask for help then I am burdening others.

Are any of these familiar to you? In the following sections we look at some of the common biases that underlie thoughts such as these. See if you recognise some of these biases in your own ways of thinking.

Common unhelpful biases in thinking

A) 'Shoulds'

> I should be able to cope with my MS symptoms better.
>
> I should be able to complete all these tasks like I used to.

Many thoughts include the word 'should'. The word 'should' suggests that there is a standard or fixed rule that must be followed. It can apply to us or to others. We might continually feel that others 'should' act in a certain way. We might also spend quite a lot of time telling ourselves how we 'should' be acting.

This can get us into thinking problems as it fills us with expectations of others and ourselves that are: 1) probably not possible and 2) leave us feeling disappointed or upset. The problem with 'should' thoughts is that they are often not realistic and so they leave us constantly upset when things don't go the way we think they 'should'.

B) 'Black and white' thinking

I will never be able to exercise again.

My MS symptoms are completely unpredictable and uncontrollable.

The tendency to think in black and white or in absolutes is another common error. These thoughts often contain a never or always statement. As MS is an ongoing issue, it is not uncommon for people to start to think about their condition in terms of "always having it" or "never managing my symptoms".

Other examples could occur in your day-to-day life. You might think, "I am never on time". But chances are that you will be on time at least some of the time! You might have thoughts such as, "I always mess things up". This is not only highly unlikely, but there are also few absolutes in the world – the use of "never" or "always" is rarely appropriate.

You might also have these thoughts about other people, such as, "She never considers how I might be feeling". Realistically, never and always are rarely appropriate when thinking about others or ourselves.

C) 'Catastrophising'

I am going to overheat and have a complete relapse.

Being fatigued is the worst feeling in the world.

If I have another relapse I will end up in a wheelchair.

If I go out, I will be totally embarrassed by my symptoms.

As you can see from the long list of examples, 'catastrophising' is a common bias in thinking. It is the tendency to think the worst about things.

Catastrophisers tend to get things out of proportion which often leads to unnecessary feelings of anxiety, panic or distress. For instance, Sally starts to worry when her husband is five minutes late from work, convinced that he has been in a terrible accident. When he arrives home safe and sound thirty minutes later, she has made herself feel sick with worry.

Catastrophisers often jump to conclusions about future events and imagine the worst possible outcome. For example, John has been told that his MS is in the very early stages. However, he is convinced that the doctor is saying that because he doesn't want John to know how bad it really is.

D) Over generalising

> The last time I did too much, it set off my fatigue – so I'd better not ever overdo things.
>
> Oh no, I've started to lose the sensation in my legs. It's bound to get worse like the last time, and I will have a major relapse.

When we over generalise, we come to conclusions based on one experience or aspect of a situation. For example, Joan thinks, "I've tried changing my daily routine this week and since it did not make any difference there is no point, because it will never work."

E) Predicting the future

> I just know that if I keep up my exercise routine it will cause a relapse of my symptoms.
>
> I will end up incontinent and in a wheelchair.

Without realising it, many of us have gloomy thoughts about future events. If we think we are going to feel bad we often end up doing so. However, none of us can really predict what is going to happen in the future.

F) Eliminating the positive

I feel good today, but I usually have so many symptoms. It won't last.

It is often easy to dwell on the bad aspects of experiences and to ignore or forget about the good aspects. For instance, Jeremy's boss gives him some feedback about his work. Most of this is very positive, but he tells Jeremy that he needs to be a bit more assertive in meetings. Jeremy goes home thinking that he is doing a terrible job. In this situation, Jeremy has ignored the fact that most of the information is positive and has only focused on the negative.

G) Mind reading

People must think I am really strange because I need to use a crutch.

I am sure my partner thinks that I am exaggerating, and that my loss of sensation is all in my head.

We constantly make assumptions about what others are thinking about us. These assumptions are usually negative, such as, "Because my house is a mess, they must think I am a lazy housekeeper." The truth of the matter is, most people are too concerned about the impression they are making on you to have time to pass judgements. Some people are very critical, but it is worth thinking about whether these people's opinions need to matter that much to us.

H) Negative thoughts related to perfectionism

Even though I am feeling really tired, I need to get the house spotless before the visitors arrive.

I can't have a little nap because it means I am not a good mother.

Part 2:
How to identify and record unhelpful thoughts

1. Try to notice what goes through your mind when you have a strong feeling, a strong reaction to something, or a change in your mood.

2. Write down your unhelpful thoughts in your 'Unhelpful thoughts diary' (page 69) as soon as possible so that you remember the details.

    a) In the *situation* column
    Write down what you were doing or thinking about before having a strong feeling or change in your emotion/ mood.

    b) In the *emotion* column
    Write down the emotion or feeling that you had when you had unhelpful thought(s).
    Write down the intensity of your emotion on a 0 to 100 per cent scale.

    c) In the *unhelpful thought* column
    Write down the actual thoughts that went through your mind.

3. If you have more than one unhelpful thought connected with the situation, draw a line under the thought that you feel particularly provokes the emotion. Or break down your thoughts into separate ones.

4. Write down how much you believe each thought (on a 0 to 100 per cent scale). 0 per cent means that you do not believe it at all. 100 means that you believe the thought completely, without any doubts.

At first, it can be difficult to detect your unhelpful thoughts. After all, we are not used to focusing on what we are thinking about.

Sometimes people feel a bit uncertain about writing down their unhelpful thoughts, but look at it as the first step to overcoming them.

It is important to say at this stage that there is no right or wrong way of thinking. Everyone has negative thoughts from time to time. However, some thoughts are not as logical as we think they may be. Learning to recognise some of the illogical patterns in your thinking can be an important step towards managing symptoms in a more helpful manner.

It may feel a bit strange writing your thoughts down, at first. You might worry that you will make them worse by focusing on them, or you may feel that they are trivial or silly. Remember – no thought is too trivial to write down. You need to know what your thoughts are before you can address them.

Each day, you might want to go back to the list of common unhelpful biases in thinking (presented earlier in this chapter) and see if you can identify any of these in your thoughts. Once you feel that you can easily identify your thoughts, move on to the next section which gets you to challenge your unhelpful thoughts and come up with alternatives (alternative thought column).

Unhelpful thoughts diary – example

Date	**Situation** What was I doing at the time of the thoughts?	**Emotion** How did I feel?	**Unhelpful thought** What thoughts went through my mind just before I started to feel this way?
14 May	About to go out for dinner with a friend.	Anxious	There is no way I can go out with this fatigue. I will never enjoy myself **(black & white, predicting the future).**
14 May	Talking with my mother on the phone about my difficulties coping with MS.	Angry Frustrated	She doesn't understand me at all. She should listen to me when I try to explain my MS **(black & white, should).**
15 May	Trying to get the children ready for school and not having the energy.	Distressed	Here we go again. I am going to spend the whole day feeling unwell and tired and this is the first sign of a relapse **(catastrophising, predicting the future).**
16 May	Sitting in a meeting at work – losing sensation in one leg.	Anxious Embarrassed	This is a nightmare. What if someone notices? I will have to stumble out and people will think I am strange **(catastrophising, mind reading).**
17 May	Handing in report at work.	Depressed	I know she is going to think it's useless. I would have liked to have spent at least another day perfecting it **(perfectionist thoughts).**

Homework task – Unhelpful thoughts diary

A useful exercise is completing the 'Unhelpful thoughts diary'. The example opposite has been completed to help you get the idea of what to do.

Unhelpful thoughts diary

Date	**Situation** What was I doing at the time of the thoughts?	**Emotion** How did I feel? Rate intensity (0 to 100 per cent)	**Unhelpful thought** What thoughts went through my mind just before I started to feel this way? Rate belief in each thought (0 to 100 per cent)

Part 3:
Developing alternative thoughts

Once you have identified your patterns of unhelpful thinking, the next step is to evaluate your thoughts and to look for more helpful alternatives.

A) Weighing up the evidence

There are many different ways to look at any situation. An unhelpful thought more often than not ignores some of the key facts. Once you have identified an unhelpful thought, you can spend a bit more time looking at the evidence for your thought.

These are some of the questions to ask yourself when weighing up the evidence:

1. How else could I interpret what has happened?
2. Do some of the facts contradict what I am thinking?
3. Am I just focusing on the negative aspect of the situation?
4. Am I seeing the picture in black and white?
5. I am expecting the worst, or catastrophising?
6. What is truly the worst thing that can happen in this situation?
7. Am I trying to predict the future or read other people's minds?
8. Am I jumping to conclusions based on a previous experience?

You will probably find that some of your unhelpful thoughts have evidence for and against them. By looking for evidence, you are less likely to have completely negative thoughts. This will help you break the habit of automatically just focusing on the negative.

Coming up with alternatives does not mean you have to be positive all the time. It just means there are other ways of viewing the situation which might be more balanced and more helpful to you.

B) Coming up with alternatives

At first, it will be hard to identify helpful alternative thoughts. You might have some unhelpful thoughts that are overwhelming or strong. The best way to challenge your thoughts is to list all the evidence for and against your unhelpful thought. You can then review the evidence for and against, assess how accurate your original thought was, and develop an alternative, more helpful, thought.

Remember, thoughts are neither true nor false. It is a matter of weighing up the logic and the evidence in them. You may find it hard to be convinced by your alternative thoughts at first – but do not give up. Unhelpful thoughts are like any bad habit: they are hard to change and one needs to keep working on them.

One way to tackle alternative thoughts is to imagine you are giving advice to a good friend who is troubled by negative thoughts. We are often better at providing good advice to others than ourselves.

The ultimate goal of this exercise is to be able to challenge your unhelpful thoughts automatically. Just as unhelpful thoughts can become automatic, challenging those thoughts can also become automatic.

Unhelpful thought:

This is a nightmare. What if someone notices? I will have to stumble out and people will think I am strange.

Alternative thought:

The worst thing that can happen if I look a little unsteady is that I may feel a bit embarrassed for a while. Most people will forget about it very quickly.

Homework task – Alternative thought record

Opposite are some possible alternatives to the example 'Unhelpful thoughts diary' on page 68. Once you have read through these, try coming up with alternative thoughts for the unhelpful thoughts you recorded in your own diary (page 69).

Then, for the rest of the week, try to record your unhelpful thoughts as they occur. Write possible alternatives to these thoughts on the 'Alternative thought record' on pages 74 and 75.

Once you feel you have a good grasp of this exercise, go back to your 'Alternative thought record' and rate how strongly you believe each of your thoughts (both the negative and alternate thoughts) out of 100. At the beginning, you might find that you rate your unhelpful thoughts higher than your alternate thoughts. However, over time this should change and you will become more convinced by the alternatives.

You might want to photocopy the 'Alternative thought record' for your own use.

Turn over for your 'Alternative thought record' sheets

Alternative thought record – example

Date	Situation	Feeling	Unhelpful automatic thought	Alternative thought
14 May	About to go out for dinner with a friend.	Anxious	There is no way I can go out with this fatigue. I will never enjoy myself **(black & white, predicting the future).**	If I don't focus on the fatigue it may not seem so bad and I might enjoy myself more.
14 May	Talking with my mother on phone about my difficulties coping with MS.	Angry Frustrated	She doesn't understand me at all. She should listen to me when I try to explain my MS **(black & white, should).**	She doesn't understand my MS but that doesn't mean she doesn't understand me at all. She does listen to other problems.
15 May	Trying to get the children ready for school and not having the energy.	Distressed	Here we go again. I am going to spend the whole day feeling unwell and tired and this is the first sign of a relapse **(catastrophising, predicting the future).**	I am going to stick to my planned routine and do some exercise. This way I may help to manage my fatigue and there are lots of other explanations for feeling fatigued.
16 May	Sitting in a meeting at work – losing sensation in one leg.	Anxious Embarrassed	This is a nightmare. What if someone notices? I will have to stumble out and people will think I am strange **(catastrophising, mind reading).**	The worst thing that can happen if I look a little unsteady is that I may feel a bit embarrassed for a while. Most people will forget about it very quickly.
17 May	Handing in report at work.	Depressed	I know she is going to think it's useless. I would have liked to have spent at least another day perfecting it **(perfectionist thoughts).**	There is never enough time to do things as perfectly as I would like. She has always been happy with my work in the past and if she wants me to change something it is easy to do it.

Alternative thought record

1. Situation	2. Feeling	3. Automatic thoughts (images)	4. Evidence that supports the thought	5. Evidence that does not support the thought	6. Alternative/ balanced thoughts	7. Rate moods now
Who were you with? What were you doing? When was it? Where were you?	Describe each mood in one word. Rate intensity of mood (0 to 100 per cent)	Answer some of the following questions: What was going through my mind just before I started to feel this way? What does this say about me? What does this mean about me? My life? My future? What am I afraid might happen? What is the worst thing that could happen if this is true? What does this mean about how the other person(s) feel(s)/think(s) about me? What does this mean about the other person(s) or people in general? What images or memories do I have in this situation?	Circle the thought in previous column for which you are looking for evidence. Write factual evidence to support this conclusion. (Try to avoid mind-reading and interpretation of facts.)	Ask yourself questions to help discover evidence which does not support your thought.	Ask yourself questions to generate alternative or balanced thoughts. Write an alternative or balanced thought. Rate how much you believe in each alternative or balanced thought (0 to 100 per cent)	Copy the feelings from column 2. Rerate the intensity of each feeling from 0 to 100 per cent as well as any new records.

Alternative thought record

1. Situation	2. Feeling	3. Automatic thoughts (images)	4. Evidence that supports the thought	5. Evidence that does not support the thought	6. Alternative/ balanced thoughts	7. Rate moods now
Who were you with? What were you doing? When was it? Where were you?	Describe each mood in one word. Rate intensity of mood (0 to 100 per cent)	Answer some of the following questions: What was going through my mind just before I started to feel this way? What does this say about me? What does this mean about me? My life? My future? What am I afraid might happen? What is the worst thing that could happen if this is true? What does this mean about how the other person(s) feel(s)/think(s) about me? What does this mean about the other person(s) or people in general? What images or memories do I have in this situation?	Circle the thought in previous column for which you are looking for evidence. Write factual evidence to support this conclusion. (Try to avoid mind-reading and interpretation of facts.)	Ask yourself questions to help discover evidence which does not support your thought.	Ask yourself questions to generate alternative or balanced thoughts. Write an alternative or balanced thought. Rate how much you believe in each alternative or balanced thought (0 to 100 per cent)	Copy the feelings from column 2. Rerate the intensity of each feeling from 0 to 100 per cent as well as any new records.

CHAPTER SIX:

Improving the quality of your sleep

Many people with MS have sleep problems. There can be a number of causes, including bladder dysfunction, spasticity, pain, anxiety, depression and fatigue. Quality of sleep can be affected by a number of other things, including irregular sleep patterns, daytime inactivity, caffeine, alcohol, an uncomfortable sleeping environment, an overly active mind or worrying and sleeping too much.

Keeping a sleep diary

To begin with, it would be helpful to get a more detailed picture of your sleep routine. This will give you a clearer picture of what to change if anything.

Homework task – Sleep diary

At the end of this chapter, you will find an example 'Sleep diary' (p86) and a blank 'Sleep diary' (p87) for you to fill in.

Things you will be asked to record

1. Bedtime. This is the time you go to bed and actually turn the lights off. If you go to bed at 10.45pm but turn the light off at 11.15pm you should write down both times in that space.
2. Length of time between turning off light and going to sleep.
3. Number of times you wake up during the night.
4. Number and length of waking-up times. Estimate the amount of time you spent awake for each awakening. If this is difficult, then estimate the amount of time you spent awake in total.
5. Time of last awakening. This is the time you wake up in the morning, that is, the last time you woke up.
6. Out-of-bed time. The time you actually got out of bed for the day.
7. Catnaps. This should include all naps, even if not intentional (e.g. dozing off in front of the TV for ten minutes).
8. How refreshed you feel on getting up.
   1=exhausted, 2=tired, 3=average, 4=rather refreshed, 5=very refreshed
9. Sleep quality.
   1=very restless, 2=restless, 3=average, 4=sound, 5=very sound

If you are a good sleeper you may not need to change anything. Good sleepers can break some of the rules we are going to discuss in this chapter. However, poor sleepers need to be more careful. If you are a poor sleeper, you will need to make more effort to be sure you are doing the things that are the most helpful for improving sleep. As we work through the following sections, you may find it helpful to write down the factors that you think might contribute to your sleep difficulties. You will find that some factors are relevant to you, but others are not. Use the information alongside your sleep diaries so that you can get a clear picture of your sleep patterns.

A) General tips for getting a good night’s sleep

- Only go to bed when you feel sleepy. If you try to fall asleep before your body is ready you will tend to lie in bed worrying.
- Your bedroom should be associated with sleep rather than wakefulness. Therefore, if you are unable to fall asleep or return to sleep within 20 minutes, get out of bed, go to another room and do something relaxing like reading a book, listening to music, or doing a relaxation exercise. Return to bed only after you feel sleepy. This might feel like a hassle, particularly if you are leaving a nice warm bed, but it does make a difference. If getting out of bed is physically difficult, leaving the bed for a while might not be practical. If you share a bed with a partner, disturbing them may be an issue. Other strategies could involve sitting up in bed with a small bedside light on and reading a book, or listening to some music through headphones. The key thing to remember is that it is not helpful to just lie in bed wide awake.
- Because the bedroom should be associated with sleep, with the exception of sex, try to avoid doing all other forms of activity in the bedroom such as watching TV, working or eating.
- Avoid stimulants such as coffee, tea, chocolate or chocolate drinks, fizzy drinks and cigarettes at least four hours before you go to bed. All of these can disrupt sleep.
- Many people think that alcohol helps them sleep because it relaxes them. It may help you to fall asleep, but it causes awakenings during the night. It is better, therefore, to avoid alcohol two hours or so before bedtime.
- Simple things, like a comfortable bed in a warm, quiet, darkened room, can all help facilitate sleep. Ear plugs and eye shades can help if you can’t get the environment the way you like it.
- Regular exercise will help you sleep better, but avoid vigorous exercise just before going to bed as it can create a ‘hyper aroused’ state which makes it difficult to sleep.

B) Erratic sleep patterns

If you have symptoms or worries that keep you up at night, you may well find that you have a sleep pattern which varies from day-to-day. People who have difficulty sleeping might go to bed earlier than usual on some days, sleep in later on others, or nap during the day to catch up on lost sleep.

Erratic sleep patterns such as these can confuse our internal body clock or natural bodily rhythm. This can create symptoms. Jetlag is a classic example of what happens when our body clock is disrupted. If you have ever experienced jetlag from long-haul flights you will be aware of the symptoms. These include a feeling of heaviness, waves of extreme tiredness, difficulties remembering and/ or concentrating on things, and difficulties sleeping. If you have consistently restless or disturbed sleep – particularly if this leads you to sleep at different times each day – you might experience similar symptoms.

The best solution for this is to **develop a consistent sleep routine**. The way to do this is to:

- Go to bed at more or less the same time and wake up at the same time each day. Even if you have had a really bad night's sleep, you should try to stick to this.
- Avoid daytime napping. Daytime sleep may help in the short term, but it is often responsible for sleep difficulties at night. If you like sleeping during the day, try taking your mind off the urge to sleep by doing some gentle exercise or doing something relaxing.
- Make sure you wake at the same time by setting an alarm clock. Even if you have woken several times during the night, get up regardless of how you are feeling. Over time, this approach will ensure that you sleep better.

It will be hard at first and you may feel more tired initially. As with all the changes you make, perseverance will soon result in an improved quality of sleep.

Note: Some people can't sleep at regular times each night – for example, if they do shift work or are up in the night with children. If you have children, still try to have a set sleep time and wake-up time as far as possible. If you are getting woken a number of times during the night, try to schedule a relatively consistent time every day to have a daytime nap. If you do shift work, try to have the same sleep/ wake times when you are on night duty, even during daylight hours.

Apart from erratic sleep patterns affecting our natural body clock, stress can also affect the way we sleep.

C) Sleeping too little due to stress

Some people find that the stress of having MS means they have a hard time getting to sleep. Stress can cause an increase in adrenaline release in your body. Adrenaline tends to make you alert even when you are very tired, and it is possible that you find yourself working late into the night when you are feeling good, and then finding it difficult to get to sleep.

It is common to worry about difficulties or problems related to an illness like MS. People can also worry about the fact that they are not getting enough sleep, and how this will affect them and their fatigue the next day. All this can keep you from falling back asleep and might make you feel anxious or upset.

If you find yourself waking through stress and worrying:

- Set a bedtime, then 'turn off' an hour before that in order to start relaxing. For example, turn off the email and mobile phone, switch your thoughts away from the children once they are in bed, turn off work-related thoughts and try to do something you find relaxing, such as reading a book or watching television.
- Try setting a time during the day to be your 'worry' time. Make this at least two hours before you go to bed. Write down the problems or worries that go through your head when you lie awake at night. Write down the next step you need to take towards resolving the problem. Be specific, and if necessary break the problem down into small parts.
- If you wake, or fail to go to sleep by worrying, tell yourself you have the matter in hand and that worrying about it now is not going to help.
- If unhelpful thoughts pop into your mind, try some breathing exercises. Finish by imagining your most relaxing scene, such as lying in the warm sand on a beach, or imagining a beautiful sunset.

D) Sleeping too much

Some people find that due to their symptoms they are sleeping too much. You may hear people say that if you sleep for 12 hours it means that your body needs this amount of sleep. However, sleeping this amount every night is actually going to make you feel more tired. You will often wake up feeling un-refreshed. If you are very sleep deprived, having an extra long sleep can be restorative but it should not become a habit.

If you find you are sleeping too much (more than eight to nine hours a day):

- If you go to bed early, try going to bed a little later each night and continue to set your alarm for the same time each morning. Start off gradually. For instance, start by staying up for an extra 15 minutes, then 20 minutes the next night and so on.
- If you go to bed at a reasonable hour, but tend to sleep late, try to wake up each day a little earlier than the day before – with the aim of reducing your sleep to around 8 hours. Once again, do it gradually. Start off by waking up about 15 minutes earlier and increase this by around five minutes a day.
- Avoid daytime napping and resist the temptation to sleep during the day by sticking to your activity plan.
- These changes in your sleeping pattern will initially result in feeling more tired, which can be tough. If you stick with it, you will find that the reduced sleep, together with increasing your exercise, will help energise you.

Setting goals for improving sleep

Your sleep problem may get worse before it gets better. This can make it difficult to stick to your goals. Try not to get discouraged, because the long-term benefits of sticking to a good sleep plan can make a substantial difference to how you feel and how you cope in your daily life. Remember, you are retraining your body about sleep and it may take at least a month or two before you start to feel the difference.

Now that we have reviewed the different factors contributing to sleep problems, what factors might be affecting your sleep?

....

....

....

....

It will be important to set some clear weekly goals for improving your sleep, and to monitor your progress.

Some examples of what other people have set as goals are:

- Go to bed at 11pm and wake at 7am each day of the working week.
- Get out of bed and go and read in the lounge if I have not fallen asleep within 20 minutes.
- Even if I feel tired after a bad night's sleep, I will only rest by sitting down and I will avoid napping during the day.

Getting a good night’s sleep is one of a number of important factors that contribute to fatigue levels. If fatigue is a key problem for you, you may wish to read (or re-read) chapter four at this point. This chapter includes some material on managing fatigue through balancing rest/ relaxation and activity.

Diaphragmatic breathing

It might be impossible to control the amount of stress in our lives, particularly when living with a long-term condition. But learning to relax can be important, to break the cycle of tension and anxiety and help you with sleep. One strategy to help you to relax is to learn ‘diaphragmatic breathing’.

When people feel stressed or tense, they tend to over-breathe, by using shallow rapid breaths. This is a natural response to exertion or stress. However, people who are experiencing ongoing stress can get into a habit of continuously over-breathing. This does not provide enough oxygen for everyday activities and can result in physical sensations such as cramping (similar to muscle spasms), aches and pains, and uneasiness.

Without realising it, you might sometimes be breathing inefficiently and making your tension and symptoms worse. The most efficient form of breathing is called **diaphragmatic breathing**. This type of breathing uses the band of muscles which separate your chest from your abdomen (belly). This is called the diaphragm. It is located right under your rib cage. Diaphragmatic breathing uses all of the lung volume and gives you optimum oxygenation to your muscles. It is an easy, quick method of relieving tension.

Diaphragmatic breathing:

Firstly, observe your normal breathing pattern for a few breaths.
Then:

- Place your hand below your rib cage on your abdomen.
- Your diaphragm is the muscle that sits below your ribs and helps to move the chest wall in and out when you breathe.
- Breathe out gently.
- Now breathe in through your nose, taking the air down as far as you can into your lungs.
- When you breathe in, your hand should move outwards and you should see your abdomen rise up.
- Some people make the mistake of pulling their diaphragm inwards as they breathe in. This only allows the oxygen to get to the top half of the lungs, so make sure you move your diaphragm outwards.
- Now breathe out gently through your mouth allowing your diaphragm to fall.
- Focus more on the outward breath and think RELAX as you let it go.
- Let all the air escape from your lungs through your mouth, but don’t use any force to do this.
- After each breath pause for 1-2 seconds before breathing again.

Once you have practised diaphragmatic breathing a few times and feel that you have the hang of it, it can be done in almost any situation: sitting at a desk at work, driving your car, or lying in bed at night. It is a useful, simple technique to use before you go into any stressful situation, or to quickly de-stress if you feel you need to.

Homework task – Sleep goals

You might want to use this 'Sleep goals' sheet to set and monitor some goals on getting a better night's sleep.

Record how you got on with meeting these goals.

Sleep goals sheet

Goals	Mon > Tue	Tue > Wed	Wed > Thu	Thu > Fri	Fri > Sat	Sat > Sun	Sun > Mon

Turn over for your 'Sleep diary' sheets

Sleep diary – example

	Mon	Tue	Wed	Thu	Fri	Sat	Sun
1. I went to bed at... o' clock and turned the lights out at... o' clock	10.30 11.15	9.20 11.00	10.00 10.15	10.15 10.15	10.15 10.40	11.30 11.30	9.45 10.00
2. After turning the lights out, I fell asleep in… minutes	35 mins	20 mins	10 mins	15 mins	10 mins	5 mins	25 mins
3. My sleep was interrupted... times	3	2	2	1	2	1	n/a
4. My sleep was interrupted for... minutes	20mins 10mins 15 mins	30 mins 5 mins	5 mins 15 mins	15 mins	5 mins 20 mins	2 hours	n/a
5. I woke up at... o'clock	7.30	6.30	8.00	8.00	8.10	9.00	7.40
6. I got out of bed for the day at... o'clock	9.00	7.50	8.40	8.10	8.20	10.00	8.00
7. I catnapped for... minutes/hours in total	20 mins	1hr 30 mins	15 mins	n/a	n/a	1hr	20 mins
8. When I got up this morning I felt: (1=exhausted, 5=very refreshed)	3	2	2	3	3	1	4
9. Overall my sleep last night was: (1=very restless, 5=very sound)	2	2	3	3	3	2	4

Sleep diary

	Mon	Tue	Wed	Thu	Fri	Sat	Sun
1. I went to bed at... o’ clock and turned the lights out at... o’ clock							
2. After turning the lights out, I fell asleep in… minutes							
3. My sleep was interrupted... times							
4. My sleep was interrupted for... minutes							
5. I woke up at... o’clock							
6. I got out of bed for the day at... o’clock							
7. I catnapped for... minutes/hours in total							
8. When I got up this morning I felt: (1=exhausted, 5=very refreshed)							
9. Overall my sleep last night was: (1=very restless, 5=very sound)							

CHAPTER SEVEN: Managing stress

Stress is a common part of daily life. A condition like MS often increases the burden of stress. Although we can't take stress away, managing stress better can have a number of beneficial effects, such as better sleep quality and enjoyment of life. In a previous treatment trial, the authors of this manual showed that reducing stress helped reduce fatigue.

There is also good evidence that when we are stressed we are more prone to infections such as colds and flu. Infections such as these are related to higher rates of relapse in MS, so managing stress may also have direct benefits for your health in general.

What happens when I am stressed?

Stress causes a physiological response in your body known as the 'fight or flight' response. It causes your autonomic nervous system to become more active, to prepare your body for action. Stress hormones such as adrenaline are released, your heart starts pumping faster to supply blood to the muscles, your muscles tense up, and breathing increases to get a larger supply of oxygen. In the short term, this response can be helpful. It helps you get out of dangerous situations – much as if you need to run away from a wild animal.

But in modern life, most of the things that stress us are not physical dangers which require a 'fight or flight' response. Rather, they are daily hassles like dealing with the medical profession, having too many things to do, and sitting in traffic. Unfortunately, our bodies react in the same way to these stressors. Over time, this over-activation of the nervous system can have negative effects on our immune system, our experience of symptoms and our health.

What does this chapter include?

This chapter covers three main areas related to stress management.

1 The first is relaxation, which helps reduce the physiological impact of stress or 'fight or flight' response.

2 The second provides some general tips to reduce the impact stress has on your life, including prioritising, planning and having a good exercise regime.

3 The final section deals with managing unhelpful thoughts in the context of stress.

Homework tasks

There are three different homework tasks attached to each of these sections, to be found at the end of the chapter. We suggest you focus on the one aspect of homework that you feel will benefit you most, rather than tackling all three.

1. Relaxation

The importance of relaxation

As already explained, the response to a stressful situation is an automatic ‘fight or flight’ response. This includes the activation of muscle tension. Muscle tension is a natural response which increases alertness and strength in challenging situations. Ideally, people should experience only certain periods of tension during their day, along with other times when their muscles are relaxed.

Therefore, it seems that relaxing should come naturally. But when people have been under stress for a long period of time without realising it, they rarely allow the muscle tension to become de-activated. This prolonged tension might begin to get in the way of normal activities, rather than improving performance.

In this way, people might end up in a continual state of tension. Instead of helping them to cope, this adds to their symptoms and the anxiety that they feel about their symptoms. Even as you read this manual, take a moment to reflect on your level of muscle tension. Are you in a position to breathe deeply or are you hunched over the manual? Are your shoulders loose or are they tight? Are you frowning or squinting? Are you sitting back in your chair or are you balanced on the edge?

It is important to break this cycle of tension, anxiety and symptoms by learning how to consciously relax. If you are experiencing a lot of tension and continued stress, this might take some effort on your part.

In general, learning to relax is important for most people who have a busy or stressful lifestyle. The health benefits of relaxation include pain relief, a decrease in heart rate and blood pressure, reduction of anxiety and a general sense of calm and well-being. It will take time to learn how to relax and also to experience the benefits. Following are some specific exercises which will require your active participation over the next few weeks. They will equip you with the experience of relaxation along with the skills to achieve it.

Breathe easy

When people feel stressed or tense, they tend to over-breathe, by using shallow rapid breaths. This is a natural response to exertion or stress. However, people who are experiencing ongoing stress can get into a habit of continuously over-breathing. This does not provide enough oxygen for everyday activities and can result in physical sensations such as dizziness, aches and pains, tiredness and uneasiness.

Without realising it, you might be breathing inefficiently and making your tension and symptoms worse. The most efficient form of breathing is called ‘diaphragmatic breathing’. We explain this in detail in the chapter on sleep (chapter six). Before you try relaxation, go through this section on breathing.

Once you feel you have mastered diaphragmatic breathing, you can proceed to the relaxation training exercises.

Relaxation training

Relaxation training is best done with the help of relaxation CDs. Your therapist can suggest suitable ones you might try or there are commercially available products that you can purchase on the internet. Below are some suggestions of how to prepare yourself for relaxation and brief descriptions of two different types of relaxation techniques used as part of the original research.

Preparation: To prepare for the relaxation exercises, you will need a CD player and a comfortable chair. Use pillows if needed to ensure that your head and legs are supported in a comfortable position. If you don’t have an appropriate chair, you can use pillows or cushions against a wall. If you prefer, you can also try the exercises lying down on a comfortable surface, such as a bed.

Relaxation routines should help you to:

- recognise tension
- relax your body
- let go of tension in specific muscles

You need a time and a space where you won’t be interrupted. In order to do this, it might be worthwhile explaining the exercises and your need to concentrate on them to those around you.

Each relaxation routine is usually about ten minutes long. Try out both types of routines so that you can master two different techniques. You might find you prefer one over the other. It is fine to use either one, or you can alternate between them over time. Both routines employ progressive relaxation techniques which will guide you to relax all parts of your body in a progressive manner. Your goal is to acquire the skill of deep relaxation.

Routine One: Progressive muscle relaxation

The progressive muscle relaxation routine requires you to tense and then relax various muscles of your body in an orderly sequence. This process will help you to experience the physical sensation of tension and then contrast this with the physical sensation of relaxation. By participating in that process, you will improve your ability to identify tension and to release tension in various parts of your body. At first, you might need the contrast of tensing your muscles in order to relax them, but eventually you should be able to induce relaxation in your muscles without tensing them first.

Note: if you experience muscle spasms, that might not be a suitable technique. Check with an appropriate health care professional before trying it out.

Routine Two: Guided imagery relaxation

The second routine combines relaxation imagery with breathing and isometric techniques to induce the sensation of deep relaxation – both physical and mental. This routine needs you to work mentally to create images which help you to recognise your state of tension and relaxation. Like routine one, you will be asked to work progressively through different muscle groups. In addition, routine two should finish with a guided journey involving the whole body that might induce a very deep state of relaxation.

Important tips when learning relaxation

- Learning relaxation for the first time is rather like trying to get fit for the first time. Initially, it feels very hard with few benefits. Most people do not feel different overnight. However, if you persevere, the positive effects of relaxation can be hugely beneficial.
- Try to incorporate relaxation activities into your daily schedule for at least 14 days. If you do one exercise each day it should take no longer than 15 minutes.
- Once you feel you have become proficient at relaxing, you might choose to do a relaxation technique two or three times a week, or when you have had a particularly bad or stressful day.
- You shouldn’t try or allow yourself to go to sleep during the relaxation routines. You need to be awake to learn relaxation skills. It may in time improve your sleep.

- As you try these routines, you might become more aware of your tension. This could make you feel even more tense. But remember that this is okay, and with perseverance you will learn how to relax.
- You also may feel some anxiety about relaxing the ‘right’ way, which can increase your tension. Some people feel very uncomfortable when they try to let go of their tension. They don’t feel comfortable with the feeling of being relaxed. Try to relax gradually more each time you do the exercises.

Setting goals for relaxation

As with any of the other behavioural changes you have worked on, we suggest that you set some goals to help you develop the habit of relaxation. On the ‘Relaxation diary’ at the end of this chapter (page 101) we have left a place for you to set these goals and to monitor your daily progress for a period of 15 days. In order to see if you are improving, we have left a place for you to rate your degree of relaxation after you have finished the exercises.

As with any of your other goals we suggest that you try and be specific about what you are going to do and when you are going to do it. Also, try to upgrade from diaphragmatic breathing to the more complex forms of relaxation.

A good way to start might be by setting daily goals for the first five days. Once you have a good feel for what works best, you can then set your programme for the further 10 days. Here is an example list of goals for a five-day period and the ratings of success:

Rate your relaxation following your chosen exercise on the following scale:

0 1 2 3 4 5 6 7 8 9 10

as tense as I can be moderately relaxed completely relaxed

	Goal	Achieved	Rating
Day 1	Diaphragmatic breathing three times after each meal	2/3	3
Day 2	Diaphragmatic breathing after breakfast and lunch and before bed	2/3	5
Day 3	Diaphragmatic breathing after breakfast and lunch and before bed	2/3	6
Day 4	Progressive muscle relaxation before bedtime	1/1	2
Day 5	Guided imagery before bedtime	1/1	5

2. General tips to reduce the impact stress has on your life

Learning how to say "no"

In an earlier chapter we discussed the importance of developing a consistent pattern of activity, rest and sleep. This change in routine may at times make it difficult to respond to all demands and requests from others.

Learning how to say no to commitments or to other people can be difficult. It is important to realise that saying no is not a failure or 'cop-out'. Not when it helps you to become healthier and more capable of doing the things that you want or need to do. We are all entitled to say no. It doesn't mean that we are rejecting the person who is asking things of us. Clare gave us a good example of how she has learnt to say no:

> "If it's a bad day for mobility then I'll say, 'I'm having a bad day everybody, I'm not going to cook dinner tonight. I'm sure there's some stuff in the fridge. You can get on with it.' And they're all right with that now, while before I used to be quite frightened to say things like that."

In chapter eight we will talk more about assertiveness. In the meantime, think if saying no is a problem for you. Try to identify situations where you would have liked to say no but did not.

Prioritising

Part of saying no to some things or people is becoming aware of your needs and priorities. By saying yes to those people and things in your life which are the most important to you, you will soon see which things are not necessary.

While priorities are often dictated by responsibilities to family and work, it is also important to realise the importance of self-care. Prioritise spending time to do the things that you enjoy, that help you to relax or that get you exercising.

Here's a good example:

> "...And I have things like gardeners and cleaners, so that I'm not tied up with the chores any more. I'm able to do with my life the nice things, rather than struggling, which I was before – struggling to do the everyday stuff, while really it doesn't need me to do that. The MS nurse said a very sensible thing to me: she said, 'Delegate. If you can't do it, or don't want to do it, or it's too hard, delegate.' And once I realised that I could delegate and I could get other people to do things for me, without it making me feel bad, then that was okay.
>
> Well that, that's liberation, really. It means that I can do the nice things, without feeling that, 'Oh God, I'm a bad person 'cos I've not cleaned the oven'... I'm not valued anymore on the cleanliness of my oven and my kitchen floor, because it's someone else's job to do it. So it's a bit of a head change for me, not to do things myself. It is quite hard for me to have to wait for things, and that has been difficult, but now I know that the key to it all is to get other people to do the things that I can't do, so that I can do the things I enjoy. And I like gardening still, but I don't have to go round and double dig anything. The gardener does all the big stuff. But I can go round and pull out bits of weed and that satisfies me perfectly well."

Planning

Prioritising and planning often go hand in hand. Research has shown that for many people it is the small or minor hassles facing them everyday that really get them down. Quite often with some thought or planning, these can be handled differently.

The key to getting on top of these situations is to break the problem down into smaller manageable parts. You will have covered some of this in chapter three – goal setting and problem solving.

For example, you may feel stressed about your situation at work. It may at first seem impossible to change your work environment. However, you might be able to change the way you think about your work, the way you respond to your work environment, or your interaction with the people at work. You might be able to make simple changes like making sure that you take half an hour for lunch, or perhaps letting people know that you have MS, so they can understand if it affects your performance sometimes.

Planning may involve putting certain things on hold so that you make sure you have enough energy to do the things you most want to do. Pete seems to be very good at doing this:

> “If it’s something I really, really want to do, like if I’m going to a party or going out or something, I am very careful about not overdoing it that day, or even two days before, because I’m not going to be stopped from doing anything.”

Sometimes it means planning ahead for what may happen in the longer term future:

> Rather than being reactive and managing the symptoms as they are now, it’s looking forward to if it gets worse. What do you need in order to manage it, to cope day-to-day around the house? What other things do you need? What help do you need from other people? So it is getting these things in place, almost like having an insurance policy, so that if it does get worse, and quickly, then I have things in place to manage it.

Allowing yourself to use assistance when you need it

Many people with MS hold off using assistive devices (such as sticks) or making adaptations to their home which may make mobility and/or independence easier. Suzanne describes why she does this:

> "You don't want people to be sitting round saying, 'Oh, poor thing'. Absolutely not. You want to be independent and seen as a proper person, rather than an invalid."

Although this is an understandable reaction, the thought that you are not seen as 'a proper person' may not be entirely accurate. If you are struggling with mobility and don't use assistance, this often means you have less energy to do other, more enjoyable things. Studies have shown that people who use assistive devices when they need them are less fatigued and experience better quality of life than those who don't.

Looking after yourself

By looking after yourself and making your health a priority, you will, in the long run, have more energy and time for others. It might seem that you don't have time for activities that will help you to cope and relax. But by making some time available each day for yourself and your health, you will have more quality time overall.

Reward yourself with something you enjoy

Stress happens. We all have some episodes in our lives that are difficult, heartrending, painful or frustrating. It is important to surround those times with something that is pleasurable or nourishing to your sense of being.

People who feel stressed usually say that they have no time to do enjoyable things. Make it a priority to take time to do the small things that you enjoy – particularly when you are stressed. These might just be simple things such as walking through a park, curling up with a good book, reading the newspaper, catching up with close friends, taking a hot bath, or just simply putting your feet up. You might want to experiment with one or more of these general strategies to decrease the negative effects of stress.

Exercise and keeping healthy

Exercise can decrease stress and improve your sense of well-being. This is because when you exercise your breathing and heart rate increase to deliver oxygen to the muscles to allow them to work efficiently. This can flush the adrenaline and other stress hormones that may have accumulated over the day out of your body. It also stimulates many of the 'feel-good' hormones, including hormones which provide a sense of well-being and natural pain relief.

Jill and Graham both found that exercise and maintaining a healthy lifestyle were things they could do which helped them feel like they were actively doing something to manage their MS:

> "I keep exercising. I do all things that I can possibly do to keep myself in good shape. And my illness will just carry on, whatever it wants to do, and all I can do is just keep exercising and just keep doing the things that I can like eating a healthy diet. Just stay positive, knowing that you are doing all you can do yourself."

> "MS hasn't really had much of an effect on my life. I did change my job, my career, I stopped drinking, I stopped smoking…changed my lifestyle and that helped…110 per cent...doing things that help me help myself makes me quite strong."

Most people are aware of the importance of regular exercise to maintain health. Unfortunately, although we know it is good for us, it can be hard to fit it into our busy lifestyles. Setting specific goals in this area can help. If you are someone who already exercises on a regular basis, you should strive to keep that schedule consistent – but remember the goal of moderation and don't over do it.

However, if you have stopped exercising because of your illness or time constraints – or if you are someone who has never had a regular schedule of exercise – then this section is really important for you. MS is not a reason to stop exercising. You might have to modify your exercise because of the constraints of your MS, but it is important to note that regular exercise is beneficial, not harmful, to MS.

Some people, when they hear the word 'exercise', immediately think gym membership, weight training, marathons, and so on. In fact, exercise can be easier and more available. Research has shown that as little as 30 minutes of continuous aerobic exercise three times a week (such as walking) can be beneficial to health. Even this small amount of exercise can improve your fitness and the quality of your sleep.

So a brisk walk three times a week for half an hour or more is better than no exercise at all. If walking is difficult, you might want to try exercises like swimming, using a bike at the gym or Pilates.

The MS Trust has produced a useful exercise DVD that you may want to refer to: www.mstrust.org.uk/movement/moveit.jsp

As with the other aspects of daily life, the goal in self-management is consistent exercise. By planning your exercise activities, you can be sure to exercise the suggested amount.

The homework sheet entitled 'Goals for stress management' is designed for you to set goals or targets in any of the areas in this section that you feel you would like to work on. Here are some possible exercise goals.

1. Start going to the gym for 20 minutes twice a week on a Monday and Wednesday after work. Increase to three times a week in three weeks' time.
2. Walk three times a week – on a Tuesday, Thursday and Saturday when I get up. Start with a 10 minute walk. Then upgrade my walks by one minute a day, so that by the end of the programme I am walking for 30 minutes each time.

3. Changing your thinking

Our daily activities are often ‘framed’ by our thoughts and feelings about them. As you have already learnt in chapter five, sometimes these are unhelpful and can add to the stressful impact of the event. Changing your thinking from unhelpful negative thoughts to a more balanced perspective can help manage your stress.

Sue provides a good example of this:

> Sue finds that by taking an hour walk on the beach she feels much better. She is able to relax and feel more positive about her problems. This is often offset by her feelings of guilt for taking this time out of her busy schedule. She feels she is letting her family down by not getting practical errands done during this time. Sue learns how to think differently about this time out. She tells herself that she will have more energy for the people and things in her life if she takes this time out to relax and exercise. She replaces the idea of letting her family down with a new thought of ‘self-care’.

In chapter five we focused quite a bit on negative thoughts in relation to your condition or symptoms. Here are some examples of thoughts that are commonly related to feeling stressed. You might like to use the blank ‘Stress-related thought diary’ we have provided on page 103 to identify unhelpful thoughts you might have in stressful situations.

Date	Situation	Feeling	Unhelpful thought	Alternative thought
20 May	A friend of yours tells you about how she is helping out at your son’s school.	Guilty	I should be a better mother like her and more involved in my son’s schooling.	We are all different. She really enjoys helping out at the school. It is not really my sort of thing. I prefer to do things with my son on his own like helping with homework or reading him books.
21 May	A deadline at work.	Stressed	I will never get this done in time. There is far too much else to do and I don’t even know where to start.	I always feel stressed when there is a deadline but I know I always get things in on time. I need to prioritise the deadline and other things will need to wait or be delegated to other people.
24 May	Going on holiday to Europe on a cheap budget airline.	Anxious	I don’t know if I can cope with getting on the flight. I am not good on stairs and I am worried I might fall and make a fool of myself.	It may be best to let the airline know that I may have trouble. They have people who can help out in these instances and will arrange for me to board first or last.

Homework tasks

In this chapter, a number of homework tasks have been suggested. You might want to choose the one (or ones) that is most relevant to you, rather than attempting them all at once.

Relaxation diary (below) **Goals for stress management** (p102)

Stress-related thought diary (p103)

Relaxation diary

Rate your relaxation following your chosen exercise on the following scale:

0	1	2	3	4	5	6	7	8	9	10
as tense as I can be					moderately relaxed					completely relaxed

	Goal	Achieved	Rating
Day 1			
Day 2			
Day 3			
Day 4			
Day 5			
Day 6			
Day 7			
Day 8			
Day 9			
Day 10			
Day 11			
Day 12			
Day 13			
Day 14			
Day 15			

Goals for stress management

This homework sheet is for you to set goals or targets in **any** of the strategies in this chapter that you feel you would like to work on. Keep track of how you get on.

Saying no/ prioritising/ planning

Goals	Mon	Tue	Wed	Thu	Fri	Sat	Sun
e.g. Don't be pressurised into taking Louise to school every day – let her get the bus unless raining	Yes	Yes	Yes	No	Yes	n/a	n/a

Looking after yourself, doing things you enjoy

Goals	Mon	Tue	Wed	Thu	Fri	Sat	Sun
e.g. 30 minutes a day to relax and read a good book or watch television	Yes	No	No	Yes	Yes	No	Yes

Exercise

Goals	Mon	Tue	Wed	Thu	Fri	Sat	Sun
e.g. Walk dog four times a week for 20 minutes	No	n/a	Yes	n/a	Yes	Yes	Yes

Stress-related thought diary

Use this sheet for identifying unhelpful thoughts around stressful situations

Date	Situation	Feeling	Unhelpful thought	Alternative thought

You may wish to refer back to chapter five, (especially pages 67 and 70) for a reminder on using thought diaries and developing alternative thoughts

CHAPTER EIGHT:
Managing social relationships

From previous chapters, it is clear how important it is to have people around you who you can talk to and can support you emotionally. It is also important, at times, to get practical help and assistance. The purpose of this chapter is to look at ways you can maximise the support you get from family, friends and health professionals.

Our interviews with people with MS highlighted that many people found that those around them said and did unhelpful things. Here are a couple of examples:

> “Family were not very helpful. They were a load of drips really [laughs]. Close family was fine, but more distant family would say things like ‘Are you better now?’ and ‘I’ve been to this wonderful disability shop’ and I’d think, ‘No I don’t want to know about that’. I wasn’t ready for it, so they’re trying to be helpful, but some of the things that they were offering… I’m sure were very helpful in the long run, but at the time felt very clumsy.”

> “People perhaps try to be a bit too helpful at times. I mean I don’t mind anybody helping…but sometimes they sort of try to take over and they want to do the job.”

Other people made it clear how interactions with the medical profession can be difficult. Doctors and other health professionals do not always provide exactly what people hope for or expect. This can lead to frustration and disappointment.

Unfortunately, we can't determine how people will respond to us. However, we can learn to ask more clearly for the type of support we would like, or let people know what we find unhelpful. The first part of this chapter will deal with how to use assertiveness to deal with these issues.

The second half looks at how we can make best use of the support that is available. People who feel that they have good social support find adjusting to MS easier. It is not just a matter of what is support is available, but how good we are at making best use of it. If you feel you are not particularly good at making best use of your support or feel that there are certain types of support you are not getting, this section will be helpful for you.

Becoming more assertive

Assertive people are able to communicate clearly and confidently what they think or feel without being angry or aggressive.

Maggie gave us an example of how she has learned to be assertive in order to make sure things she wants and needs happen in her household of teenagers:

> "I don't say, 'Would somebody possibly, just this once, mind taking the bins out for me, please?' No. I don't do any of that anymore. I now say, 'Tom – put the bins out now, please'. And it's clearer to them and it's clearer to me what I'm after. So it's all about clarity and expectation. I do expect some things, but I now ask for them directly, rather than expect a mind reader..."

On the other hand, Barbara's anecdote is a good example of not feeling able to be assertive:

> "I'm not very good at saying 'no'. Like the other day I found myself saying 'Of course I'll pick your children up from school and give them tea' and at the same time thinking, 'I don't wanna do this'. I'm always saying 'It's alright. I can do that.' or 'Yes of course I can sell 20 tickets for the school barn dance!' [laughs]"

What is self-assertion?

The core of self-assertion is an awareness of, and respect for, one's own feelings. It is being able to express one's needs, wants, feelings and beliefs in a direct, honest and appropriate way. It is being able to stand up for one's own rights without violating another person's rights.

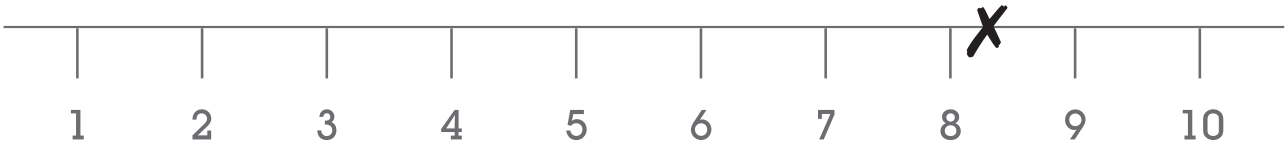
Assertiveness can be divided into four areas:

1. **Expression of positive feelings**
2. **Expression of negative feelings**
3. **Limit setting**
4. **Self-initiation**

The first step to become more assertive is to be more aware of situations where you find it hard or easy to express your feelings and opinions. Below you will find examples of the four areas of assertion as listed above. Please rate yourself by marking on the line where you feel best describes how good you are in this particular situation.

No. 1. (left-hand side of the scale)
= never able to achieve this.

No. 10. (right-hand side of the scale)
= always able to achieve this.



AREA 1 – Expression of positive feelings

This involves sharing with other people feelings of warmth, appreciation and affection.

1. Letting someone know that you care about him/ her

1 2 3 4 5 6 7 8 9 10

2. Letting someone know that you are grateful for something they have done for you

1 2 3 4 5 6 7 8 9 10

3. Telling someone that you like something about them or their actions

1 2 3 4 5 6 7 8 9 10

4. Letting a person know that you are pleased with his or her praise and that you appreciated it

1 2 3 4 5 6 7 8 9 10

The core of self-assertion is an awareness of, and respect for, one's own feelings

AREA 2 – Expression of negative feelings

This involves sharing with other people feelings of discomfort, annoyance, hurt and fury.

1. Letting someone know that they are responsible for creating a particular problem for you

1 2 3 4 5 6 7 8 9 10

2. Letting someone know that you are angry with them in a direct, honest manner

1 2 3 4 5 6 7 8 9 10

3. Letting someone know that you dislike what they are doing, and wish them to stop

1 2 3 4 5 6 7 8 9 10

4. Being able to say you are disappointed because of a change in plans

1 2 3 4 5 6 7 8 9 10

AREA 3 – Limit setting

This is setting your own boundaries, independent of the external demands of other people – such as how you spend your time, how much privacy, emotional and physical space you need.

1. Being able to say you do not wish to answer a particular question which you consider too personal

1 2 3 4 5 6 7 8 9 10

2. Being able to refuse a persistent friend's invitation out when you wish to spend an evening by yourself

1 2 3 4 5 6 7 8 9 10

3. Being able to refuse to accept something as your responsibility when it is not

1 2 3 4 5 6 7 8 9 10

4. Being able to ask someone to stop smoking as it offends you

1 2 3 4 5 6 7 8 9 10

Area 4 – Self-initiation

Through self-initiation we say 'yes', expressing what we wish to do, initiating those actions and expressions that fit us as a person.

1. Asking someone for help in handling a difficult situation that you do not feel able to manage yourself

1 2 3 4 5 6 7 8 9 10

2. Asking for what you need and want from another person

1 2 3 4 5 6 7 8 9 10

3. Being able to express your own opinions even when they do not agree with others

1 2 3 4 5 6 7 8 9 10

4. Inviting a friend out for an evening

1 2 3 4 5 6 7 8 9 10

Now list three situations related to your MS that you would like to be able to deal with more assertively in the future.

Situation 1:

Situation 2:

Situation 3:

How to be more assertive

This is easier said than done. Many people believe that being assertive is similar to being *aggressive*. This is not the case. Aggression is an act against others; assertion is appropriate standing up for yourself.

People who are assertive are generally able to communicate with a variety of people including strangers, friends or family. This communication is open, direct and honest. They are able to say how they feel, what their views are, and what they want. In contrast to the *passive* person who waits for things to happen, the assertive person attempts to make things happen.

Of course this is not always easy, but an assertive person tends to have a more compromising style and accepts that at times they will get more of what they want while at other times less.

There are many reasons why people have difficulty being assertive. It might be related to a fear of appearing selfish or pushy, or a fear of being disliked or rejected. It might come from a fear of negative consequences. Alternatively, it might be related to feeling particularly stressed, which could influence your level of confidence and therefore degree of assertiveness.

Sometimes we don't know what to say, or we don't know how to say it, or we might be unsure we're right. It could be that we are conforming to a role (for example, employee to boss) and do not realise we could be more assertive. Occasionally, we set rigid requirements for being assertive, such as feeling the need to have all the facts or a fear that the other person may not be able to take it.

Whatever the reason, any individual, including yourself, has the right to the following:

1. the right to be treated with respect
2. the right to have and express feelings and opinions
3. the right to be listened to and taken seriously
4. the right to set personal goals
5. the right to say no without feeling guilty
6. the right to ask for things
7. the right to ask for information from professionals
8. the right to make mistakes

Let's now look at a couple of examples where it may be difficult to assert yourself – for all sorts of reasons, not least because you might feel you are in a less powerful or a vulnerable situation. As a child, this can happen with parents and teachers. As an adult, communicating with doctors might lead you to feel unable to assert yourself.

Situation with the medical profession

You think you might be developing an MS relapse. Over the past few days, you have developed a strange tingling and numbness in your right arm. You are worried it may be a relapse. However, you are worried about going on steroids so are not sure whether you should talk about this with your doctor. As a result, you only mention it towards the end of the consultation.

Listed below are a number of potential responses you might get from your doctor. Alongside are assertive replies that you might be able to draw on and use, with practice.

Doctor	Potential assertive replies
1. I can't discuss something new now.	How long have we got left for this appointment? As this is really worrying me, I'd like to spend five minutes talking about it now. Can we make an appointment, convenient to us both, when we can discuss this in more detail?
2. Well, from what you are telling me, I had best put you on a course of steroids.	Before we do that, can I ask about the pros and cons of the medication? I am worried this will be my third lot in 18 months. Can I make another appointment next week, in case the symptoms die down and I don't need them? I would like more time to discuss the medication with you.

Situation with a friend

Before your MS, you used to go drinking with the lads at the pub most Friday nights. Your symptoms have recently got worse and you decided it was better not to drink. As a result, you have been avoiding your mates so that they don't ask you to come along to the pub. However, you bump into your friend Dave at the supermarket and he jokingly says, "Where have you been mate? Feels like you're trying to avoid us."

Non-assertive response:

No, no, not at all. Just been very busy at work. I will catch up with you this Friday. (When Friday comes you don't end up going, feel guilty and avoid your friend even more.)

Assertive response:

I miss our Friday nights but my MS has got worse and drinking seems to be bad for my symptoms. It would be good to catch up though. Why don't you come around and watch the football on the weekend?

Homework task – Assertiveness log

Try to identify situations where you were not assertive but wish you had been. For each of these, see if you can come up with an assertive response.

It may help to practise some of these responses with your nurse-therapist in your next session.

Getting the right type of support

In order to make the best use of your supports and relationships it is important to know who can offer what type of support.

Not every person can offer you the same support. For example, you might find that when it comes to finding practical solutions, a male friend or partner might be the most useful. If you wanted to talk about how you were feeling, a female friend might offer the best support. In fact, it is probably better to share the support among your friends, family and professionals – so you don't have to rely on just one person, and so nobody feels burdened.

Below is a table which you can use to write down who you have in your life that supports you, and what type of support they are good at giving. Types of support can include:

- emotional support – from people you can talk to about your feelings
- practical support – from people who can do tasks for you like shopping or gardening
- informational support – from people who can give you practical information about your symptoms or illness

My support network

Person's name	What support are they likely to be good at
1.	
2.	
3.	
4.	
5.	
6.	
7.	
8.	

My support network

You might also find it helpful to draw your support people into this diagram:

Is there anyone who would offer you support but who you have not asked? Who are they and what kind of support could they offer? What has stopped you from asking them and what would it take to ask them?

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When stress levels are high, most people need their supports the most. So it is in our own interest to also think about how to look after our support people. It may be important to let off steam in ways that don't run the risk of upsetting others and damaging relationships (for example by going for a walk rather than getting into an argument). Similarly, making sure that you still do things you enjoy with the people around you – and that you return the support when it is needed – will help keep your relationships more balanced and in good working order.

In what ways do you already give things back to your relationships, and in what other ways can you reciprocate your social supports?

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Are there any ways you could improve your support network?
If so, what action(s) would you like to take?

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Assertiveness log

Situation	My response (a recent or typical response)	More assertive response

CHAPTER NINE:
Preparing for the future

Preparing for the future

Eight sessions is a relatively short time to make major changes in your behaviour or the way you think and feel.

There are specific circumstances that might increase your anxiety and distress about the illness and how to manage it – an MS relapse, stressful life events (such as changing job, bereavement, moving house). Going through any of these stressful events does not mean that you will automatically feel distress – it simply means that these are times when you are more at risk.

During a stressful time, it is a good idea to be extra vigilant. Look after yourself by making sure you use the techniques you have learnt during therapy. Also, remember to be extra kind to yourself when things get rough, rather than expecting more of yourself, or punishing yourself for feeling bad. When things get tough, it is easy to slip into the habit of doing one of two things: avoiding/ giving up altogether or plunging headlong into a frantic burst of activity. You can avoid this if you stick by the principles of consistency and moderation.

For all the reasons mentioned above, it is important to summarise the range of strategies you have learned during the last eight sessions. It is also important to identify ways you can build upon the progress you have made in managing your MS. At this stage, it might be worth focusing on issues like dealing with possible relapses in the future.

Summary of strategies

One way to maintain the changes you have made is to summarise and record for yourself what has been useful. Let's spend a few minutes reviewing what you have learned in the last eight weeks:

Week 1	
Week 2	
Week 3	
Week 4	
Week 5	
Week 6	
Week 7	
Week 8	

Sustaining and building upon improvements

In order to maintain the gains you have made, it is important to make sure the steps you have taken are part of your daily life.

By now, some of the activities which you practised a number of times as part of this programme are probably happening automatically. It is important to try and ensure that these activities remain part of your daily life.

In what ways would you like to continue to sustain and build upon the progress you have made?

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Other ways you can sustain and build on your progress are:

- making sure that you keep a sensible equilibrium, and that your days are balanced between different kinds of activity and relaxation
- choosing to continue to work on any remaining areas of difficulty (for example with unhelpful thoughts), by systematically and gradually using goal sheets or thought records
- continuing to set weekly targets, broken down into manageable chunks which are practised regularly
- keeping a diary of any remaining goals or tasks until you can achieve them consistently and regularly.

What are the strategies you will use to deal with a relapse or possible progression of your MS?

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Which health professionals can help you in the future?

Your programme of CBT and your regular contact with the therapist is coming to an end.

You will have learned some skills and focused on some material that should provide you with some strategies for coping with MS-related problems in the future. But don't forget that your local MS team are still available to consult when needed.

You might want to use the table on the next page to write down details of people such as your neurologist, MS nurse, GP and any other professionals you see regularly.

Having this information handy might be useful in case of any problems or concerns in the future.

Useful health professionals

Name	Job	Contact method	Useful for...
EXAMPLE: Sue Davies	MS Nurse	Phone the MS Service (01234 123456) for an appointment	Relapses, finding out about drugs information and advice, checking about worrying symptoms

Contact us

MS National Centre
372 Edgware Road
London NW2 6ND
T: 020 8438 0700

MS Society Cymru
Temple Court
Cathedral Road
Cardiff CF11 9HA
T: 029 2078 6676

MS Society Scotland
National Office
Ratho Park
88 Glasgow Road
Ratho Station
Newbridge
EH28 8PP
T: 0131 335 4050

MS Society
Northern Ireland
The Resource Centre
34 Annadale Avenue
Belfast BT7 3JJ
T: 028 9080 2802

National MS Helpline
Freephone 0808 800 8000
(weekdays 9am-9pm)

www.mssociety.org.uk

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MS Society

Multiple sclerosis (MS) is the most common disabling neurological disorder affecting young adults and we estimate that around 100,000 people in the UK have MS.

MS is the result of damage to myelin – the protective sheath surrounding nerve fibres of the central nervous system. This damage interferes with messages between the brain and other parts of the body.

For some people, MS is characterised by periods of relapse and remission while, for others, it has a progressive pattern. For everyone, it makes life unpredictable.

The MS Society is the UK's largest charity dedicated to supporting everyone whose life is touched by MS. We provide a freephone MS Helpline, grants for home adaptations, respite care and mobility aids, education and training, support for specialist MS nurses and a wide range of information. Local branches cater for people of all ages and interests and are run by people with direct experience of MS.

The MS Society also funds around 80 vital MS research projects in the UK.

Membership is open to people with MS, their families, carers, friends and supporters.

You can help the work of the MS Society by:

- becoming a member
- making a donation
- offering your time as a volunteer.

Disclaimer: We have made every effort to ensure that the information in this publication is correct. We do not accept liability for any errors or omissions. The law and government regulations may change. Be sure to seek local advice from the sources listed.

Written by Professor Rona Moss-Morris, Laura Dennison and Professor Trudie Chalder

Edited by James Bailey

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First edition, December 2010