



Manual for Participants

COGNITIVE BEHAVIOUR THERAPY for CFS/ME

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PROLOGUE

This manual aims to provide you with useful information and strategies to help you to overcome your chronic fatigue syndrome (CFS)/ myalgic encephalitis/encephalopathy (ME). Many of the strategies described in the manual are based on cognitive behaviour therapy, which has been shown to be effective in treating a wide range of problems, including CFS/ME. As CFS/ME affects people in different ways we have included information to address a variety of problems associated with the illness, but not all of them may seem relevant to you.

The information has been set out in an order that is commonly used by people to overcome their CFS/ME. However, you will be using this manual as part of your therapy sessions, so you may be advised to read it in a different order or to miss out sections if they do not appear to be relevant to you.

Blank copies of diaries that you will be using during your CBT sessions have been included in this manual. You may make copies of them for your own use.

There is a section at the end of the manual for your family or friends to read. This suggests ways in which they may be able to help you. Your therapist will be able to give you spare copies of this information, if necessary.

You will note that in the section titled “planning activity and rest”, there are two subsections: “for those whose activities have greatly reduced”, and “for those who generally do too much”. We have organized the information in this way as the difficulties associated with CFS/ME are so varied. If you have stopped or reduced most of your activities you will probably find the information “for those whose activities have greatly reduced” applicable. Alternatively, if you generally lead a very busy life with little time for relaxation, the information “for those who generally do too much” may be more helpful. In practice, many people have to consider both sections.

**CHRONIC FATIGUE SYNDROME (CFS)/ MYALGIC
ENCEPHALITIS/ENCEPHALOPATHY (ME)**

Chronic Fatigue Syndrome (CFS), Post Viral Fatigue Syndrome, and Myalgic Encephalomyelitis/Encephalopathy (ME) have all been used to describe similar illnesses. There is controversy about whether these are the same or different conditions. For brevity we will consider them together here as CFS/ME.

What are the symptoms?

Common to these illnesses are symptoms of physical and mental fatigue, usually made worse by exertion. Other symptoms may include difficulty with memory and concentration, muscular and joint pain, unrefreshing sleep, headache, tender lymph glands, and sore throats. Some people with CFS/ME also suffer from other health problems, such as irritable bowel syndrome, depression, and anxiety. There are often day-to-day fluctuations in the symptoms, some people have to give up work or studying, greatly reduce their social and leisure activities and/ or restrict what they can do at home or with the family.

How is the diagnosis made?

At present there is no clinical or blood test for CFS/ME and the diagnosis is made from the symptoms and associated disability. Fatigue may be a symptom of many illnesses (such as diabetes and anaemia) and a medical assessment is needed to exclude these other conditions. The term CFS/ME has been reserved for people whom characteristic fatigue and other symptoms cannot be explained by other diagnoses.

What is the cause?

No specific cause has been identified. There is some evidence for stress and viral infection as triggers. There is also evidence of changes in the immune, nervous and hormonal systems in people with CFS/ME. It is possible that different factors apply to different people.

COGNITIVE BEHAVIOURAL MODEL OF UNDERSTANDING CFS/ME

The cognitive behavioural model of CFS/ME draws a distinction between factors that precipitate and those that maintain it

FACTORS THAT MAY CONTRIBUTE TO THE DEVELOPMENT OF CFS/ME

There is a growing body of evidence that suggests that a number of factors may be involved in triggering the illness. It is likely that you will be able to identify with some, but probably not all of the triggers listed below.

1. Infections

An initial illness is often reported as the starting point of CFS/ME. This may be in the form of a viral infection, for example glandular fever. Sometimes people report having had a series of infections. However, there is no clear evidence of the virus or bacteria persisting once CFS/ME has become established, even though you may still feel that you have an infection from which you have not totally recovered. Recent research after glandular fever suggests that excessive rest during the acute phase may lead to worse symptoms several weeks and months later.

2. Lifestyle

Fatigue can develop in association with a busy lifestyle. Leading a busy lifestyle where there is little time for relaxation is stressful. Following an illness/infection, a person may feel under pressure to meet their previous levels of commitment whether this is at work or home etc and this may lead to exhaustion. Being too busy is as likely to lead to fatigue as being too inactive.

3. Life Events

Changing jobs, getting married, pregnancy, moving house, a bereavement, ending a long-term relationship are all stressful events which may lead to increased vulnerability to CFS/ME.

4. Personality

People with CFS/ME often report being hardworking, conscientious and having high expectations of themselves. This type of personality may lead to individuals striving very hard to achieve in all they do, leaving little time for pleasure.

5. No apparent cause

Some people will report that their condition developed for no apparent reason, e.g., it came out of the blue.

FACTORS THAT MAY MAINTAIN CFS/ME

Just as there are many factors associated with the development of CFS/ME, there are also many factors that maintain it.

These may include the following:-

- 1. Resuming normal activities too soon after an initial infection**
It can be helpful to rest in the initial stages of an acute illness, such as when you have a fever.
- 2. Resting too much**
Although resting for a short time is the correct thing to do when you have an acute illness or infection, prolonged rest can impede recovery and cause its own set of problems. Evidence suggests that the longer you rest when you have a viral illness, the more disabling fatigue you will have six months later. Prolonged rest reduces activity tolerance and also impairs the way that the body works. It will affect the cardiovascular system, nervous system and muscles.
- 3. Over-vigorous exercise alternating with resting for long periods**
This inadvertently makes the problem worse in the longer term, as it is difficult to establish any type of routine.
- 4. Receiving confusing messages about the illness, and how to deal with it.**
You may have sought help from a variety of people all of whom may have offered different treatment or advice. Receiving different messages may have resulted in you feeling baffled about what to do for the best and trying a variety of different treatments that have not been helpful.
- 5. Disturbed sleep pattern**
An irregular bed-time or getting up time or resting too much in the day, may contribute to disturbed and unrefreshing sleep at night. Not sleeping well at night is likely to increase feelings of fatigue and other symptoms.
- 6. Symptom focussing**
It is understandable that you would worry about symptoms that don't go away. Unfortunately a disadvantage of this is that the more you focus on the symptoms, the worse they can get.
- 7. Worries about activity making the illness worse**
You may experience increased pain or fatigue after any activity and naturally read this as a sign that you are harming your body. You may therefore have reduced your activities, and rested for long periods thinking that "resting" will help you to feel better.
- 8. Life stress and low mood**

Many people with CFS/ME experience major ongoing life stresses and problems related to the effects of their illness. These may include one or more of the following:

- Financial difficulties
- Worries about keeping a job, maintaining studies, etc
- Changing role within the family, e.g., loss of responsibility
- Reduced social contacts leading to feelings of isolation
- Feeling guilty about not being a “good” parent

These difficulties can understandably trigger feelings such as frustration, helplessness and loss of control over life. These feelings which are a natural response to stress, can lead to low mood for some people and depression in others. Low mood or depression can lead to a variety of problems including tiredness, which can further reduce the desire to be active.

PHYSIOLOGICAL ASPECTS OF CFS/ME

Many people with CFS/ME are concerned that their distressing symptoms may be related to a disease that hasn't been detected. Others are concerned that a virus (if one occurred at onset) is still present or has caused physical damage to the body. Intensive research has tried to establish whether disease, deficiencies or any other abnormal changes in the body may explain the very distressing and debilitating symptoms experienced by people with CFS/ME. To date, it appears that there is no one cause of CFS/ME. A variety of different triggers are reported, e.g. different types of infection or stressful life events. Some people can pinpoint the exact date that it started. For others the onset is more gradual.

Difficulty maintaining previous activity levels is common to all sufferers. Some sufferers feel so ill that they rest for long periods and give up many of their previous activities including work, social activities and managing the home. Others may be able to function at a reasonable level, e.g. go to work or look after their family, but due to pushing themselves so hard in the day, may do very little in the evenings or at weekends. Others tend to do too much on "good days" and push themselves too hard for their level of fitness, they then rest for long periods on other days.

Over time, reduced or irregular activity and increased periods of rest causes physical changes in the body. These changes cause unpleasant sensations and symptoms that can be very distressing. It is important to point out that these changes are reversible with physical rehabilitation and/or exercise.

Research has looked at the effects of rest in healthy people when they reduce their activities and many similarities between people with CFS/ME and healthy inactive people have been noted.

The following information describes the effects of prolonged periods of inactivity on the body:-

1. Changes in muscle function

- A decrease in the number of active cell mitochondria (tiny parts of the cell that act as a powerhouse) and their enzymes have been found in the muscles of people with CFS/ME when compared with healthy *active* people. The reduction of cell mitochondria has also been found in healthy *inactive* people. Fewer cell mitochondria may lead to production of lactic acid at low exercise levels, which in turn limits muscle performance.

These changes may account for the feeling of a lack of power or energy in the muscles.

- As reduced activity leads to less efficient muscles (reduced strength, tone and size), it is more difficult for the muscles to squeeze the blood back to the heart causing blood to pool in the lower part of the legs.

Pooling of blood can cause pain and a feeling of heaviness both during activity and rest.

- When muscles are not used regularly, they become unfit or de-conditioned. When these muscles contract during activity, uneven stresses are produced.

This may result in a feeling of weakness and unsteadiness followed by delayed pain and discomfort.

- In all individuals, muscle pain and stiffness are a natural consequence of beginning a new exercise programme or when unaccustomed exercise is taken.

2. Changes in the cardiovascular system

- The cardiovascular system (which incorporates the heart and blood vessels) becomes out of condition very quickly with rest. The longer you rest, the more changes occur.
- Physical changes that occur with cardiovascular deconditioning include:-
 - reduced blood volume after 1 or 2 days bed-rest
 - reduced volume of red blood cells after 8 days bed-rest which reduces the oxygen carrying capacity of the blood
 - volume of the heart reduces by about 15% after 20 days of bed-rest therefore less blood is pumped to other organs

These physical changes may result in making you feel breathless or dizzy when exercising, and contribute to your fatigue.

- Following a “lying down” rest there is a drop in blood pressure on standing up (postural hypotension) due to blood pooling in the limbs with gravity when we stand up. Consequently, less blood returns to the heart and therefore less blood goes to the brain.

The reduced blood flow to the brain causes dizziness and sometimes fainting on standing up. Restricting salt or liquids reduces blood volume and can exacerbate dizziness on standing.

3. Regulation of body temperature

- Due to changes in the blood volume and circulation following prolonged rest changes in superficial body temperature occur.

This may result in feeling hot and or cold, with excessive and inappropriate sweating at times

4. Visual and hearing changes

- Prolonged bed-rest results in a “headward” shift of bodily fluids.

This may result in visual problems and sensitivity to noise

5. Reduced tolerance to activity or exercise

- General de-conditioning of the body occurs as a result of prolonged rest or reduced activity.

This results in being less able to tolerate activity as fitness reduces. Muscle fatigue and feelings of heaviness as well as a general increase in overall fatigue occurs when active.

6. Changes in the nervous system

- One of the functions of the nervous system is to co-ordinate our muscles. Regular performance of an activity is required to maintain good co-ordination.
- Prolonged periods of inactivity therefore reduce our co-ordination.

This may result in unsteadiness, clumsiness and reduced accuracy on carrying out precise movements

7. Changes in mental functioning

- Prolonged rest deprives people of intellectual stimulation and has a dulling effect on intellectual activity.

This may impair concentration, memory, and the ability to find the correct word

8. Alteration of the biological clock

- This “clock”, which is located in a part of the brain called the hypothalamus regulates many body rhythms that run on an approximate 24 hour cycle. These rhythms are called circadian rhythms and they control vital functions such as:
 - sleeping and waking
 - feelings of tiredness and alertness
 - intellectual performance
 - memory
 - appetite
 - body temperature
 - the production of hormones, for example, cortisol
 - the activity of the immune system
- Circadian rhythms are responsible for your body “feeling” things at certain times of the day, for example, hunger, alertness, tiredness, needing to go to the toilet. The biological clock is affected by the events of the day and is reset each day by cues such as getting up or going to bed times, meal times and performing daily routines. The biological clock’s time keeping can be disturbed if not reset by these cues, this can happen in situations such as:
 - flying across different time zones (jet lag)
 - working shifts
 - experiencing illness

- If regular cues are lost, disruption of the clock results in a slipping of body rhythms that can lead to:
 - The “normal” intense feelings of tiredness at night shifting into the day making it difficult to cope with your usual routine.
 - The “normal” daytime rhythm shifting to the night, making you more alert and causing difficulty in getting to sleep.
 This can lead to:
 - *poor quality sleep at night*
 - *increasing fatigue during the day*
 - *poor concentration and forgetfulness*
 - *low mood*
 - *feeling unwell*
 - *headaches*
 - *muscle aches*
 - *loss of appetite*
 - *irregularities of bowel movement*
- As the symptoms of CFS/ME are so similar to those of jet lag, circadian rhythms of people with CFS/ME have been investigated. Evidence from some studies indicates that CFS/ME is associated with the biological clock losing control of the body rhythms.
- It is thought that an infection, a very stressful life event or an accumulation of persistent stress may contribute to us breaking our usual daily routine and normal sleep-waking cycle needed to reset the biological clock. This is because a stressful life event or an accumulation of stress can cause worry and disturb our sleep at night, leading to irregular getting up and going to bed times and increased rests during the day.
- The biological clock then loses control over body rhythms resulting in the above mentioned severe physical and mental symptoms of CFS/ME.

9. Disturbance of cortisol production

- Cortisol is a hormone whose production is controlled by a circadian rhythm. Cortisol switches on our metabolism in the morning to prepare us for the physical and mental challenges of the day. Exercise and other stress causes an increase in the level of cortisol in the bloodstream.
- Research shows that some people with CFS/ME have a lower level of cortisol, but no disease has been found that would account for this finding. The low cortisol levels found in people with CFS/ME are probably caused by disrupted sleep and irregular activity.
- Low cortisol levels have also been found in other people who have disrupted sleep such as a) healthy individuals who have rested in bed for more than 3 weeks b) healthy workers after working 5 nights of shift work c) people suffering from jet lag

Low cortisol may add to the feeling of tiredness, decreased alertness and poor performance seen in CFS/ME and night shift work.

10. Disturbance of the sleep-wake rhythm in CFS/ME

- Most people with CFS/ME complain of poor quality sleep. Common problems include difficulty in getting to sleep, restlessness, waking in the night and waking feeling unrefreshed and sleepy.
- In a study where the sleep patterns of healthy volunteers was deliberately disrupted to be similar to those with CFS/ME, they developed symptoms similar to those of CFS/ME including feeling unrefreshed and physically weak, sleepiness, poor concentration and muscle aches. However, when they were allowed to sleep undisturbed, their symptoms subsided. This study indicates that a disturbed sleep pattern can cause some symptoms of CFS/ME but that these symptoms are reversible.
- Disruption of sleep can affect the activity of the immune system, possibly increasing vulnerability to colds and infection.

Inactivity and being deprived of sleep cause an increase in the feelings of effort and fatigue when performing activity or exercise.

AUTONOMIC AROUSAL IN CFS/ME

Autonomic arousal is an automatic physical response of the body to a threatening or stressful situation. We can all remember having butterflies before an exam, an interview or going to the dentist! When we are in a situation that makes us feel anxious, there is increased activity of the central nervous system and an increased amount of the hormone adrenaline is released into the bloodstream. These natural changes have a protective function in preparing us for action when we feel threatened or encounter a stressful situation. However, the physical feelings that we experience when anxious can be very unpleasant.

Having CFS/ME can at times be very stressful. Not only may you be dealing with your illness, but you may also have other concerns related to your illness such as concerns about finances, if you are unable to work. You may also have worries about the cause and effects of CFS/ME on your own and others' lives. These worries may at times trigger feelings of anxiety. Entering a situation that you perceive as being stressful, whether doing something for the first time in months, or, increasing exercise etc, may lead to a further increase in anxiety. Sometimes anxiety occurs for no obvious reason.

The physical effects of anxiety include the following:

1. Increased heart rate

This can be felt as a racing pulse, palpitations, pounding or tightness in the chest.

Some people feel very frightened by these sensations and can become more anxious resulting in a further release of adrenaline that maintains the physical sensations

2. Increase in blood pressure

A high blood pressure is noted in some people with anxiety. This is likely to be associated with an exaggerated response by the autonomic nervous system, to stress.

There are usually no particular signs and symptoms of high blood pressure. High blood pressure is usually only detected in routine investigations by doctors or if another illness is present, e.g. heart or kidney problems.

3. Breathlessness which can lead to hyperventilation

This natural response to being anxious enables our lungs to be filled with oxygen to prepare us for action.

However, if over-breathing (hyperventilation) continues for a while, an array of unpleasant symptoms may occur because it reduces the amount of carbon dioxide in the blood. This changes the balance of chemicals in the blood causing tightening of the blood vessels and reduced blood supply, especially in the brain.

This reduced blood supply to the brain causes sensations such as light-headedness, dizziness, faintness, feeling unsteady, clumsiness, blurred vision, pins and needles, tingling or numbness (sometimes one-sided) in the limbs or face.. Cramp-like muscle spasms may be experienced, particularly in the hands

and feet. Increased sensitivity to light and noise may also occur. Other abnormal sensations such as feelings of being detached from oneself, feelings of unreality or being out of control may also occur.

Feeling faint is misleading because blood pressure is usually high in anxiety and fainting only occurs when blood pressure is very low. An exception to this is if someone has a blood and injury phobia. In this situation blood pressure drops and fainting can occur.

The muscles of the chest wall can be over-used during hyperventilation which may lead to *chest pain or discomfort*. If these sensations are interpreted as a major problem, i.e. as a problem with the heart, it can lead to a further increase in anxiety and adrenaline production leading to an increase of unpleasant sensations.

Over-breathing also results in increased use of the muscles of the head, neck and shoulders resulting in headaches, and localised stiffness and pain.

Over-use of the neck muscles in hyperventilation can be accompanied by sensations of tightness or a sore throat.

Excessive mouth breathing and reduced saliva production may also occur as a result of the increased nerve activity and release of adrenaline. This causes a dry mouth, swallowing difficulties and the feeling of a lump in the throat.

4. Blood flow is altered

When anxious, blood is redirected to muscles to prepare for action. Reduced blood flow to the skin may cause *pallor, pain, coldness of hands and feet and sometimes numbness or tingling*.

Reduced blood flow to the bowel affects the passage of food and can result in *symptoms of irritable bowel, for example, constipation and or diarrhoea and abdominal discomfort*.

5. Muscle tension

There is an increase in the tension of the muscles to prepare them for action. *This can cause aches, pain (particularly in the shoulders, neck, jaws and head) and fatigue. Twitching or trembling muscles may also occur.*

6. Visual disturbance

Increased nerve activity affects the muscles of the iris (coloured part of eye) causing dilation of the pupils, which lets in more light. This may help to explain the sensitivity to bright light in CFS/ME. The shape of the eye lens is altered to help improve side and distance vision. Together, these changes increase visual sensations that can be experienced as *blurring of vision*.

7. Sweating

Increased sweating occurs to allow for heat loss causing *clammy hands and feet*

8. Sleep disturbance

As adrenaline increases at times of stress, sleep disturbance such as *difficulty getting to sleep or frequent wakening* is very common and can be accompanied by *nightmares and sweating*.

9. Mental functioning

Anxiety may affect mental functioning in a number of ways and contribute to the following:

- Mood disturbance; e.g. irritability, being easily upset,*
- Inability to concentrate, forgetfulness, indecisiveness*
- Restlessness; e.g. fidgety, inability to sit still*
- Tendency to go over things again and again*

Everyone experiences physical symptoms of anxiety in a different way and rarely experience all of the symptoms listed above. When these symptoms are extreme, they can easily be misinterpreted as signs of a serious disease that can trigger further unpleasant symptoms that can occasionally trigger a panic attack.

An increase in nerve activity and adrenaline production can *precipitate feelings of weakness and exhaustion and these can add to the fatigue and muscle aches* of CFS/ME.

During periods of prolonged physical or mental exertion, there is increased activity of the nervous systems and increased adrenaline production. This leads to symptoms similar to those experienced in a flu-like illness, such as *aches and pains, headache, sweating, feeling hot and cold, chest tightness and sore throat*. If a person experiences these symptoms after activity, they may reduce or avoid activities, as they may believe that they are coming down with flu or a cold. Limiting activity can perpetuate the physical effects of anxiety and lead to a further reduction of fitness and muscle strength.

COGNITIVE BEHAVIOUR THERAPY (CBT) **FOR CFS/ME**

CBT is designed to help you to discover the most useful ways of managing and overcoming your illness. The aim of treatment is to help you to change certain patterns of thinking and behaviour that may be partially responsible for maintaining your CFS/ME. It also aims to help you to develop strategies for dealing with other factors-physical, emotional, social or financial- that may also be impacting on your illness.

WHAT WILL IT INVOLVE?

1. Monitoring your activity levels

Completing your activity diaries daily will enable you to build up an accurate picture of what you are doing each day. You will see at a glance whether there are times when you are doing too much or doing too little.

2. Setting targets

This will help you to focus on what you would like to work towards during the next few months. Targets should be varied in order to make your lifestyle as balanced as possible.

3. Stabilizing your activity and rests

This will involve planning a programme of scheduled activity and rest, which you will review and change every couple of weeks or so. The aim is to carry out the same amount of activity and rest each day, to avoid 'bursts of activity' when feeling well, and 'long periods of rest' when fatigued. Introducing short periods of relaxation will be important if you generally do too much.

4. Increasing or changing your activities

When you have established a routine including planned activity and rest, you will take steps to work towards your targets for treatment, (end of treatment targets). This will involve you gradually increasing some activities e.g. exercise, introducing new activities eg doing a course, and in some cases reducing activities e.g. long working hours.

5. Establishing a sleep routine

How you do this will depend on the sleep problem you may have. It may include:- cutting out sleep during the day, reducing sleep at night, and having a regular getting up and going to bed time.

6. Learning to overcome unhelpful thoughts and beliefs

This will initially involve identifying thoughts that may be hampering your progress and result in you feeling frustrated such as "I'll never get better" or "I haven't achieved anything today". You will then learn to challenge these thoughts by coming up with more helpful alternatives.

7. Learning how to consolidate your gains and make further progress

This will involve gaining a better understanding of your illness e.g. the factors that maintain or exacerbate it, learning how to address these problem areas and how to continue to work towards your long term goals. In addition, you will learn how to deal with potential problems.

WHAT CAN YOU EXPECT FROM THE CBT PROGRAMME?

- To understand more about your illness and the way that it affects you.
- To become more in control of your illness by recognising your limitations and developing a better balance between activity e.g, work, chores, socializing and rest/relaxation.
- To become competent in reviewing and updating your activity programme so that you will be able to continue to work towards your long term goals when you have finished the CBT programme.
- To learn how to identify and challenge any unhelpful thoughts that may be hampering your progress
- To recognize and deal with any blocks that may be making it difficult for you to progress.
- To learn how to recognise and to manage a set-back (an increase in your symptoms)

A few words of warning!

For people whose activities have greatly reduced:

Initially, you may experience a slight increase in your symptoms when you start your activity programme. However, this is usually only temporary, and occurs as a result of changing your “usual” routine and increasing or introducing new activities. Once you become “used” to your new routine your symptoms should gradually decrease.

For people who generally do too much:

Your symptoms should gradually decrease as you have more relaxation time. However, if you embark on new activities such as sport, or change your routine significantly you may notice a temporary increase in your symptoms until you get more used to the activity/new routine.

Everyone:

At times you may find the programme difficult. This is understandable, because you may have been used to doing things when you felt like doing them, be it resting, sleeping, working, doing chores, etc. As you will be aiming to do things at regular times, irrespective of how you are feeling, there may be times when you feel frustrated that you cannot do what you feel like doing. For example, sometimes you may feel like resting for longer than your programme says and at other times feel that you want to continue with a particular activity, but your programme says that you are meant to be resting. These feelings are normal, but it is important that you do not succumb to them too often, as it may result in resuming old patterns of behaviour that were unhelpful in the past.

Persevere with your programme however difficult it may seem, and in time you will appreciate the benefits of gradually changing the way you do things.

Most people experience one or two minor set-backs (increased symptoms) during treatment for one reason or another. It is important to maintain the programme as far as possible at these times. Although set-backs can be irritating, they can be a good opportunity to learn more about your CFS/ME. They also give you the opportunity of becoming an expert in managing “difficult” times.

Remember- the benefits of continuing with cognitive behaviour therapy makes overcoming the difficulties worthwhile

SAMPLE TIMETABLE

The following timetable gives you an idea of what you may be doing during your sessions while you are attending the course of cognitive behaviour therapy with your therapist.

Early weeks (4 weeks)

- Learn about possible triggers and factors that may be maintaining your CFS/ME
- Start to record what you do during the day in an “activity diary” to see how much activity and rest you have in a typical week
- Record your sleep in a “sleep diary” to find out more about your sleep pattern
- Set “targets”, so that you have some clear goals to work towards.
- Write an activity programme that you will carry out every day. This programme will include chunks of planned periods of rest and activity that will be devised using information from your activity diary and sleep diary.

Middle weeks (8–16 weeks)

- Review and change your activity programme every couple of weeks. Changes to your programme will depend on a number of factors e.g. how successful you were in achieving your previous goals.
- Start work on cognitive therapy section
- Address any other problems that you have identified

Last few weeks (4 weeks)

- Continue relevant work from earlier sessions
- Think about how to manage setbacks and write a plan for this
- Complete the section on “evaluation of my progress”; this will help you to overcome any remaining problem areas.
- Write a plan for the next 3 months in order to continue to work towards targets that you may not have achieved, and to add new ones.

Consolidation

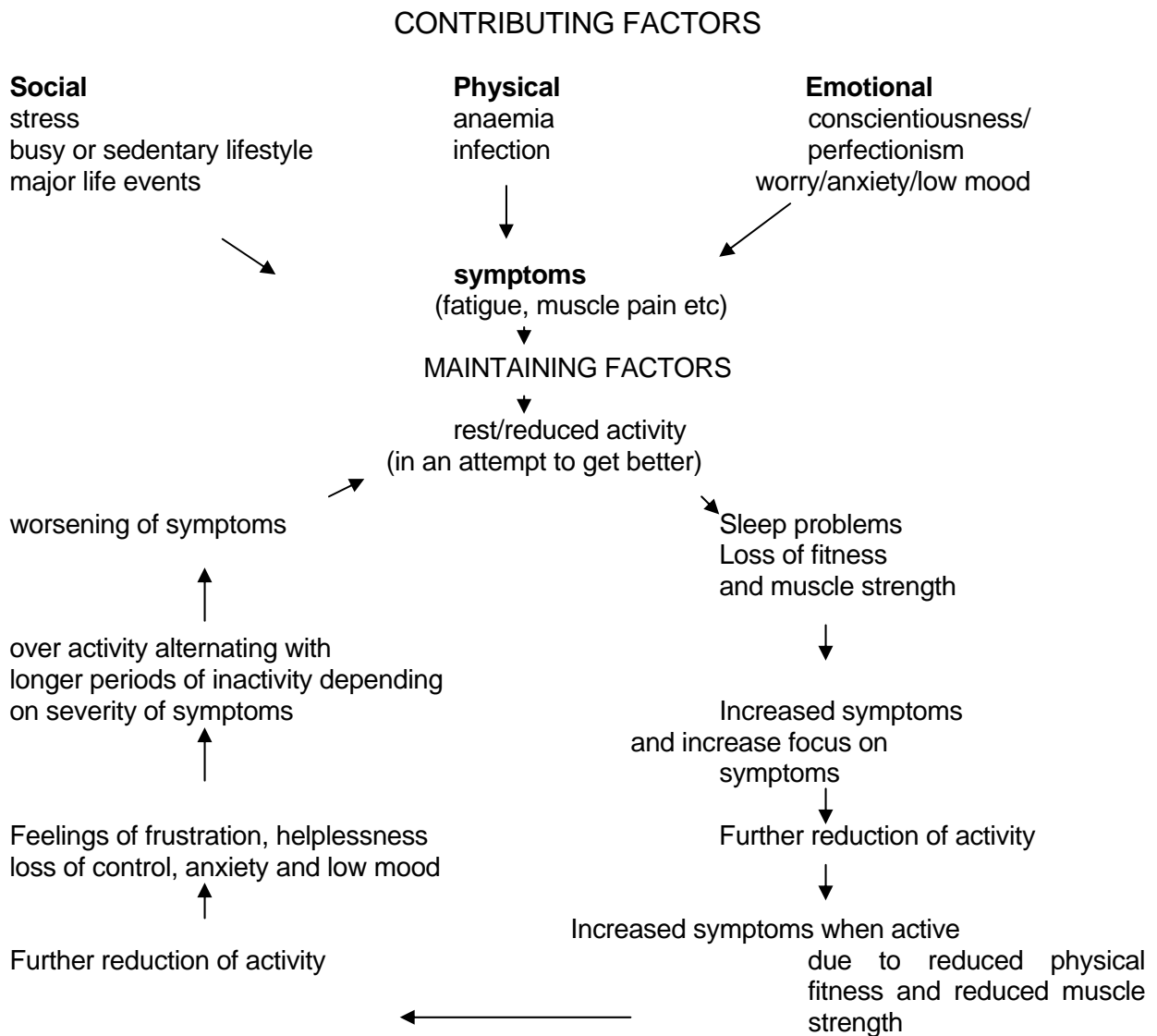
In order for you to make further progress after your CBT sessions have ended, it will be important that you evaluate your progress at regular intervals. You will spend time discussing this issue with your therapist towards the end of your sessions.

A VICIOUS CIRCLE OF FATIGUE

We have already discussed factors that may contribute to the development of CFS/ME and factors that may be involved in keeping the illness going. Because CFS/ME is a complex illness, it can be helpful to illustrate the above factors with a diagram. The diagram of the vicious circle below has factors that are common to many sufferers. Although it is unlikely that you will completely agree with it, you may be able to identify with some parts.

The diagram:

- Summarizes factors that contribute to the development of CFS/ME.
- Illustrates factors that may contribute to maintaining CFS/ME.



In order to help you to understand your CFS/ME better, you may like to use the next page to draw your own vicious circle

A VICIOUS CIRCLE OF FATIGUE

ACTIVITY DIARIES

In order for you to gain an accurate picture of how you spend each day, it is important that you record what you do in your activity diary every day.

For the first two weeks, the diaries are used to form a baseline of your activity to see exactly what you do each day. After a week or so, you may see a pattern emerging, for example, you may notice that you tend to be fairly active in the morning and rest all afternoon, or you may be busy during the week and do very little at the weekend. You may notice that you have short bursts of activity throughout the day, or you may not see any pattern at all.

After completing your activity diary for a couple of weeks, it is time to construct an activity programme. The information from your activity diaries will help you to decide on how much rest and activity you should have each day.

WHAT DO I HAVE TO DO?

1. Write down what you are doing at the times allocated in your activity diary.
2. Include as much detail as possible, for example length of activities etc.
3. Complete your diaries for every hour of the day, however trivial the activity may seem at the time.
4. Record your activities at regular intervals throughout the day. The task may seem too overwhelming at the end of the day and you may forget some of the details.

Please see examples of completed activity diaries on the next three pages.

A blank activity diary may be found on page 27.

Include example of a completed activity diary

Include example of a completed activity diary

Include example of a completed activity diary

Blank diary to photocopy

IMPROVING YOUR SLEEP

In the section “physiological aspects of CFS/ME”, we mentioned that sleep problems occur frequently in people suffering from CFS/ME. Common difficulties include:- taking a long time to go to sleep at night; frequent or prolonged awakenings during the night; waking early; or sleeping too much. The quality of sleep is often poor and sufferers will often report waking up feeling exhausted.

If you are having sleep problems like those described above:

1. Read the information in this section
2. Complete a Sleep Diary for two weeks, to build up an accurate picture of your sleep pattern.
3. Use the information from your sleep diary and information from this section to improve your sleep. You can discuss your suggestions with your therapist and then include them in your activity programme.

An example of a completed sleep diary and a blank sleep diary may be found at the end of this section on sleep

LIFESTYLE AND ENVIRONMENTAL FACTORS THAT CONTRIBUTE TO POOR SLEEP

- *An irregular sleep pattern* can disrupt the body clock and lead to the loss of certain cues such as feeling tired in the evening and alert in the morning.
- *Daytime Inactivity* can increase your feelings of fatigue, and desire for catnaps.
- *Sleeping in the day* will lead you to needing less sleep at night.
- *Drinks and other substances* such as caffeine containing drinks (coffee, tea, cola), alcohol, cigarettes and certain medications can affect sleep by making it difficult to go to sleep or waking you up in the night.
- *An uncomfortable sleeping environment* such as an uncomfortable mattress, being too hot/cold, a restless partner or excessive noise may keep you awake at night. Studying or other paperwork in your bedroom may make it more difficult for you to “switch off” at night. Long periods of wakefulness in your bed may lead you to associate your room or bed with being awake, therefore making it more difficult for you to go to sleep.
- *An overly active mind or worries at bed time* can lead to tension, restlessness and an inability to relax making it more difficult to fall asleep.
- *Sleeping too much* can make you feel constantly tired, as the sleep is often “light” and non-refreshing.

STRATEGIES TO IMPROVE YOUR SLEEP

You may find that your sleep will improve once you get into more of a routine during the day or when you slightly increase your level of activity. On the other hand you may need to follow some of the methods described below for a few weeks to notice any significant changes.

1. **Establish a routine**

The aim of establishing a routine is to help your body clock to get used to a set routine. Establishing a routine will help to regulate your body (circadian) rhythms so that you begin to “feel” things at certain times each day and establish a regular sleep-wake cycle. We do not recommend that you should go to bed at the same time every evening, as you may not feel sleepy at that time. However, you may find that when you start getting up at the same time each day you get “more” tired at a particular time of the evening and therefore naturally start going to bed at a similar time each day.

The guidelines below will help you to establish a routine. If your sleep pattern is very erratic, you may find it difficult to put them into practice all at once. Short sharp shock treatment works for some people, i.e. implementing all the guidelines at once, whereas a more gradual approach works for others.

In order to establish a routine:

- *Get up at the same time each day* even if you have not had much sleep the previous night. It may be helpful to set your alarm clock.
- *Do not nap during the day* even if you feel very tired.
- *Do not go to bed early* even if you feel very tired, or to make up for lost sleep.

2. **How to associate your bed and bedroom with sleep rather than being awake**

If you have had poor sleep for a long time, you may find that when you get into bed, instead of feeling sleepy, you feel wide awake or restless which will make it harder for you to fall asleep. Subconsciously, you may therefore associate your bed/bedroom with being “awake” rather than being “asleep” which may make it harder to fall asleep.

The following guidelines aim to help you to associate your bed and bedroom with sleep rather than being awake.

- Avoid using your bedroom during the day if at all possible. If you live in a bed-sit or in one room in a house or student accommodation, try to have a separate work area in your room, so that you just use your bed for sleep.
- Do not read, study, watch television, or sort out the day’s problems etc in bed, as these are waking activities.
- Go to bed when sleepy rather than at a time you think you should go. For example, if you think that you should go to bed at about 11.00, but do not feel sleepy, wait until you feel sleepy.
- Do not be tempted to go to bed very early (e.g., before 9.30pm), even if you feel very sleepy, as you may wake in the middle of the night or early in the morning.
- Turn the light off straight away when you get into bed.
- If you are not asleep within 20 minutes, go to another room and sit and relax or read until you feel sleepy again.
- Repeat the previous step as often as is required, and also if you wake up for periods of more than about 20 minutes in the night.

Try to follow this programme rigidly. It can take several weeks to establish an efficient and regular pattern.

3. Establish an optimal sleep pattern

An optimal sleep pattern is one that provides you with good quality sleep, few wakeful periods and a short time to fall asleep.

Your sleep pattern is *optimal* when it is both *efficient* and *regular*. By *efficient*, we mean that the more time you are asleep when in bed, the more *efficient* your sleep is. To establish your optimal sleep pattern, you will reduce the amount of time you are in bed, in order to increase the amount of time you are asleep. This can be done in conjunction with the guidelines in the above two sections, or alone.

- Calculate your total time asleep on an “average” night.
- Stay in bed for the time that you are usually asleep only.
For example: If you are usually in bed for 10 hours a night, but are only asleep for 6 hours in total, you should only stay in bed for 6 hours.
You may feel more tired for a while, but the slight sleep deprivation you may experience will in turn produce faster sleep onset, reduced broken sleep and a deeper sleep.
- The time in bed can be gradually increased as your sleep efficiency improves (if applicable).

4. Reduce your sleep at night, if you sleep too much.

Sleeping for longer than you used to before having CFS/ME may contribute to feelings of exhaustion in the morning. If you sleep for more than about an hour longer than prior to having CFS/ME, you may feel better if you reduce the amount of time you sleep at night.

- Cut down your sleep time gradually- either by going to bed 1/2 hour later, or getting up 1/2 hour earlier.
- Establish a set waking up time and going to bed-time.
- Be consistent in either getting up earlier, or going to bed later.
- Do not compensate by getting up later or going to bed earlier, even if you feel more tired.
- Review your sleep-pattern weekly, and continue to reduce your sleep time gradually until you are more “refreshed” on waking.

You may feel more tired for the first few weeks after changing your sleep routine, but in the long run you can expect the quality of your sleep to increase as the quantity of your sleep decreases.

5. Sleep Hygiene

Sleep hygiene refers to lifestyle and environmental factors that may be beneficial or detrimental to sleep.

The following guidelines may help to promote an improved sleep pattern

- *Exercise:* Avoid exercise within 3 hours of bed-time, as this may waken you up. Exercise in the late afternoon may deepen sleep.
- *Diet:* A light snack before bed-time may be sleep inducing, but a heavy meal too close to bed-time will interfere with sleep. Fluid intake should be limited.
- *Caffeine* is a central nervous system stimulant and is associated with delaying sleep onset and it can cause wakefulness. Substances containing caffeine, e.g. coffee, tea, chocolate and coke should be avoided 4-6 hours before bed time, or during the night if you wake up. Coffee has approximately twice as much caffeine as the other drinks although this depends on its preparation.
- *Nicotine:* is also a central nervous system stimulant and although many people say that cigarettes help them to relax, the overall effect is one of stimulation rather than relaxation. Smoking cigarettes should therefore be avoided near bed-time and during night time wakings.
- *Alcohol:* is a central nervous system depressant, although it may speed up sleep onset, it often causes disrupted sleep later in the night as it is metabolised. A milky drink before bed can help you to feel sleepy and will not cause you to waken in the night. (We know that it is unusual for people with CFS/ME to drink much alcohol)
- *Environment:* Your bed and mattress should be comfortable. Minimise light, noise and excessive temperature during your sleep period. Your room temperature should be around 18° C. Use blinds if necessary, ear plugs if you live in a particularly noisy place and are unable to get used to it and use a fan/ heating to control temperature.

6. **Preparing for sleep**

Establishing a set routine will help you to prepare both mentally and physically for going to sleep.

- Try to wind down in the hour or so before you go to bed.
- Include relaxing activities such as watching television, having a warm bath, listening to music in your schedule.
- Avoid stimulating activities which will keep you alert, for example work, studying, decision making.
- Develop a regular order of doing things, e.g. locking up the house, turning out the lights, brushing your teeth etc. This will act as a signal to your body that it is preparing for sleep.

7. **Problem solving strategy for reducing worries at night**

Lying in bed at night worrying about problems can make you feel tense and prevent you from going to sleep. The strategy described below may help you to reduce worries at night, therefore helping you to feel more relaxed and allowing you to get to sleep more quickly:

- Set aside 20 minutes in the early evening.
- Write down problems or loose ends that you have not dealt with during the day. Write down possible steps to resolve the problems, or to tie up the loose ends. Allocate time to do the actual work.

- Consider other longer term problems which may intrude on your sleep, for example, emotional, financial or other worries.
- Write down the first or next positive step of action to take and when you will take it.
- If you cannot go to sleep or wake up worrying about a problem, remind yourself that you have the matter in hand, and that worrying about it now will not help.
- If new worries occur to you at night, write them down on a notepad or a piece of paper, and 'deal' with them the next day.
- You may also find it helpful to refer to the section on worry and anxiety and the section on cognitive therapy.

8. How to deal with frustration about not being able to sleep

If you become frustrated about not being able to fall asleep, and worry about the possible 'negative' consequences the next day, it is likely that you will inhibit sleep further by trying harder to fall asleep which may result in you feeling more tense.

- Do not try too hard to fall asleep.
- Tell yourself that 'sleep will come when it is ready', and that 'relaxing in bed is almost as good.'
- Try to keep your eyes open in the darkened room and as they (naturally) try to close tell yourself to 'resist closing them for another few seconds'. This procedure "tempts" sleep to take over.
- Visualise a pleasing scene or try repeating a neutral word (such as "the") every few seconds.
- Relaxation, e.g., by focussing on breathing slowly may be helpful. This may be carried out in bed at night. It can also be practised at other times of the day.
 - Concentrate on your breathing
 - Try to breathe slowly
 - Repeat silently the words 'in' and 'out'- in time to your breathing.

Example of a completed sleep diary

sleep diary

TARGETS FOR TREATMENT

Setting targets is a very important step in helping you to overcoming your CFS/ME. It will give you the opportunity to think about what you would like to work towards in the coming months.

IMPORTANT FACTS ABOUT TARGETS

- Targets are things that you would like to be doing in the longer term, rather than something you want to achieve immediately.
- It is important that you have *different* types of targets to work towards to make your life as balanced as possible. Rather than working on one particular area of your life, e.g. work, ensure that your targets contain a *mixture* of activities.
- It is important to remember that pleasurable activities are as important as work, chores etc.
- It is important that you set yourself *realistic* and *achievable* targets.
- Be wary of being too “driven” or “ambition orientated” when setting your targets
For example, if you have not worked for several years, it would be better to set yourself a target of voluntary or part-time work, rather than full-time work. Or if you have not walked for a long time, it would be better to set a target of walking for 15 minutes a day rather than walking for an hour or so!
- You will be able to change your targets once your initial ones have been achieved.
- It is important to make your targets *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 targets is very restricted due to your level of symptoms, setting targets will provide you with a clear direction and focus.

HOW TO SET TARGETS

1. Look at the list of target areas below to give you some ideas for your targets.
2. Write a list of things that you would like to work towards over the coming months. Take your list to discuss with your therapist at your next appointment.
3. Prioritize your list into 4 target areas, (e.g. work, social, exercise, leisure)
4. Look at the examples of targets on the next page, to ensure that your targets are clearly defined and specific.

Example 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, e.g.- reading, playing a musical instrument, painting, writing letters, “quality time with children” etc. You may have neglected hobbies or you may have always had a burning desire to try something new!

b) Work/Education

If you are not working, you may consider going back to your old job, (if applicable), doing part-time work, or doing some voluntary work.

If you are working, you may feel that you are working excessively, and would benefit from reducing your hours.

You may 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. The section on work, courses and resources in this manual may provide you with some relevant information.

c) Social Activities

You may find that you have reduced or lost contact with some friends and family. Consider a regular time for talking to/meeting up with those people. Alternatively you may like to explore options of meeting new people.

d) Exercise

In the past you may have exercised regularly. On the other hand you may never have been particularly fit and have had exercise on a “to do” list for many years. You may like to consider time for a particular type of exercise.

e) Chores/DIY/Gardening

If you are overwhelmed by a “to do” list, e.g., chores/DIY/gardening etc, plan a regular time to do them.

f) Sleep

If sleep is a major problem, you may target a specific getting up time/going to bed time.

g) Miscellaneous**Examples of clearly defined targets**

To go shopping twice a week for half an hour

To have a friend for coffee once a week for 1/2 an hour

To walk for 15 minutes daily

To do voluntary work x 3 per week for at least 2 hours on each occasion.

To go out with friends weekly for up to 3 hours

To swim twice weekly for half an hour on each occasion

To do a course at college for 3 hours weekly.

To do gardening x 3 per week for half an hour.

To spend 1 hour daily on my hobby (Specify the hobby)

To do 1 hour of chores daily, e.g.- ironing, washing, cleaning.

To work part-time in my trained profession

To have 2 breaks at work of at least 15 minutes on each occasion.

To sit and read the paper/ magazine for half an hour daily

To get up by 9 am each day

Examples of not clearly defined targets

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 TARGETS INTO MANAGEABLE STEPS

Targets are goals for the longer term, and therefore in order for you to be able to achieve them, you will need to break down each one into manageable steps. You can then gradually introduce the steps into your activity programme.

1. Look at the examples of targets that have been broken down into manageable steps.
2. Think of ways to break each of your targets down into manageable steps.
3. Make each step small and grade it from easy to difficult.

Examples of breaking down targets into manageable steps

Target

To go for 2 x 10 minute walk daily

Steps to achieving Target

- To get out of bed/from my chair each hour and walk round the room
- To walk round my house for 1 minute every hour
- To walk round the garden/house for 2 minutes each hour
- To go for 3 x 3 minute walks daily
- To go for 3 x 5 minute walks daily
- To go for 2 x 7 minute walks daily
- To go for 2 x 10 minute walks daily

Target.

To go out with friends for up to 3 hours weekly

Steps to achieving Target

- To talk to a friend on the phone for 15 minutes x 3 weekly
- To go to a friend who lives close-by for 1/2 hour weekly
- To go to a friend who lives close-by for an hour weekly
- To go out with a friend to a local venue for an hour weekly
- To go out with friend(s) for 1 ½ hours weekly
- To go out with friend(s) for 2 hours weekly
- To go out with friend(s) for 2 ½ hours weekly
- To go out with friend(s) for 3 hours weekly

Target

To read for ½ hour x 2 daily

Steps to achieving Target

- To read for 15 minutes x 2 daily
- To read for 20 minutes x 2 daily
- To read for 30 minutes x 2 daily

Target

To do voluntary work 3 x per week for at least 2 hours on each occasion

Steps to achieving Target

- To write a list of voluntary work in which you might be interested.
- To contact the appropriate association(s) for information
- Plan steps which will help you to sustain the activity in which you will be involved, e.g. standing for longer periods (if working in a charity shop), reading/computer work (if doing administrative work) etc.
- Arrange informal visit(s) to the work place
- Arrange a graded work schedule if possible, for example:
 - 1 hour x 2 weekly for a couple of weeks.
 - 1 hour x 3 weekly.
 - 2 hours x 3 weekly

Target

To do something relaxing for myself for 1 hour, every day

Steps to achieving target

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

You may only need 2 or 3 steps to achieve your targets, or you may need a lot more. Use extra paper if necessary.

TARGET BREAKDOWN SHEET

TARGET	STEPS TO ACHIEVING TARGET
	1.
	2.
	3.
	4.
	5.
	6.
	7.
	8.

TARGET	STEPS TO ACHIEVING TARGET
	1.
	2.
	3.
	4.
	5.
	6.
	7.
	8.

TARGET	STEPS TO ACHIEVING TARGET
	1.
	2.
	3.
	4.
	5.
	6.
	7.
	8.

TARGET	STEPS TO ACHIEVING TARGET
	1.
	2.
	3.
	4.
	5.
	6.
	7.
	8.

PLANNING ACTIVITY AND REST

We have separated the section on planning activity and rest into two parts, due to the diversity of problems suffered by people with CFS/ME.

1. For people whose activities have greatly reduced:

This section aims to help people who have significantly reduced most of, or all of their activities and want to increase some of them and introduce new ones. (Please turn to page 41)

2. for people who generally do too much:

This section aims to help people who are able to manage aspects of their lives such as work, but feel so exhausted that they are unable to do much else. (Please turn to page 47)

It may be helpful to look at both sections, although you are likely to find one more applicable than the other.

PLANNING ACTIVITY AND REST

FOR PEOPLE WHOSE ACTIVITIES HAVE GREATLY REDUCED

In the “Vicious Circle” section we discussed factors that may contribute to CFS/ME being maintained. By now, you may have had the chance to draw your own vicious circle and have a better understanding of what factors are responsible for keeping your CFS/ME going.

A very common factor that contributes to the maintenance of CFS/ME is reduced activity and increased rest. As we explained in the section “Physiological aspects of CFS/ME”, reduced or irregular activity and prolonged periods of rest cause physical changes in the body. These changes cause unpleasant sensations and symptoms that can be very distressing and often lead people to an erratic pattern of rest and activity dependent on how they feel.

Your symptoms may be so severe that you spend much of your time confined to bed or a chair and your days and nights run into each other. You may find that any activity is exhausting, e.g. brushing your hair, talking, walking around the room, getting dressed or washed. On the other hand, you may find that you can be reasonably active on some days, but as a result of “doing too much”, you become more fatigued and symptomatic resulting in being unable to do very much on other days.

It is likely that you will have tried a variety of things to help improve your situation, but you may feel that you are taking two steps forward and one step back.

We all need adequate rest to be healthy. Sufferers of CFS/ME often find that they rest more than before, but rarely find it refreshing. This may be due to the following:-

1. Your body does not get a chance to get used to a regular routine, as you may be resting in response to your symptoms of fatigue and pain, rather than in a planned way.
2. Although you probably feel that you need more rest, too much rest can be counter-productive as it may lead to disturbed sleep, reduced physical fitness and in fact can make you feel more tired and lethargic.
3. It may be difficult for you to relax properly, as you may find it hard to “switch off” when you try to rest, e.g. you may be thinking about all of the jobs that you need to do.

IMPORTANT FACTS TO CONSIDER WHEN PLANNING AN ACTIVITY PROGRAMME

- The key to becoming more active is to make activity and rest **consistent**, regardless of how you feel. It is important that you plan small chunks of activity at regular intervals, rather than long periods of occasional activity. As you increase your level of everyday activities you will gradually become stronger, and will be able to cut down on rest.
- It is important to plan in advance what you are going to do each day, by creating an “activity programme”. Try to plan to do about the same amount of activity, and have the same number of rests each day. This may be difficult due to practical restraints, but aim for as much consistency as possible.
- When writing your first Activity Programme, aim for about as much “overall” activity as you are having at present. So, for example, if you do all your cleaning on one day and it takes you 2 hours, break it down into 4 half hourly chunks spread throughout the week.
- It is important to think about what you will do during your rest time. Rests are a time for you to try to “relax”. What you do in your rest time will depend on your level of fatigue and individual problems. Some people may find that reading is relaxing, others may find it a major activity. Listening to the radio/music, watching television are other “relaxing” things to consider. The important thing is that the rest time is used as a “break” from activity.
- Try to avoid using your bed for rests or sleeping during the day however tired you feel. Sleeping in the day or resting in your room is likely to affect your sleep at night.

STEPS TO CREATING AN ACTIVITY PROGRAMME.

Planning activities

1. Write a list of activities that you would like to do during the next week or on your activity programme. A blank activity programme for you to photocopy can be found on page 51.
2. Write down the amount of time that you wish to spend on each activity.
3. Use your activity diaries for guidance on the time to be spent on an activity during the week.
4. Remember to make your activities manageable chunks, rather than one long activity. For example, if you have been doing 1 solid hour of housework each day, divide it into 3 chunks of 20 minutes.

Planning rests

1. Look at the activity diaries that you completed during the previous fortnight and estimate the average amount of rest taken each day.
2. Write down on your activity programme the number of rests to be taken each day, and the length of each rest.
For example:
 - 3 x 1 hour rest each day.
 - Or 2 x 1/2 hour rest each day.
 - Or 8 x 3/4 hour rest each day.

Use the formula below to calculate your initial amount of rests if necessary

1. Look at your activity diaries and add up the total number of hours of rest that you have taken during the day for the past 14 days.
2. Divide the number of hours by 14, to give you an estimate of the amount of rest, that you should have each day.

Example

	TOTAL REST IN 14 DAYS	AMOUNT OF REST EACH DAY
REST	42 HOURS	3 HOURS

Example of an initial activity programme

For someone who is currently resting for about 3 hours a day..

- To get up and dressed by 8 a.m. daily.
- To have 3 x 1 hour rests in a chair (e.g. at 10am, 2pm and 6pm), daily
- To go for 3 x 10 minute daily walks
- To read for 20 minutes daily
- To do chores for 1/2 hour x 2 daily
- To talk to friends for 15 minutes daily on the phone
- To go to bed by 11.00 p.m.

For someone who is resting for about 6 hours a day.

- To get up and dressed by 9.00am daily.
- To go for 2 x 10 minute walks daily
- To do chores for 15 minutes x 4 daily
- To talk to friends for 10 minutes x 3 weekly, by phone
- To read for 10 minutes x 2 daily
- To rest in a chair for 1/2 hour every hour
- To go to bed by 11.00pm daily

For someone who is resting for most of the day

- To get out of bed by 9.00 am daily
- To walk around the house for 1 minute each hour.
- To rest for 50 minutes each hour.
- Activity for 10 minutes each hour (To be specified)
 - E.g. To eat 3 meals a day.
 - Get washed and brush teeth by 9.30 daily
 - Get dressed by 10.30 daily
 - Read for 10 minutes twice daily.
 - Wash and dry dishes x 2 daily.

Recording your activities

You will already be used to recording your activities in your activity diary. Please continue to write down details of what you are doing for each hour of the day.

Please refer to the section on “activity diaries” for more information, if necessary.

Remember that completing your activity diaries is a very important part of your programme as it will help you to monitor your progress.

What to expect when you start your activity programme

As we mentioned earlier in the manual, your symptoms may slightly increase when you start your programme. However, this is usually only temporary and occurs as a result of changing your “usual” routine. Even though you may feel like resting more, it is important that you keep going with your activity programme. You will hopefully find that your symptoms will gradually decrease although this may take a few weeks.

INCREASING YOUR ACTIVITY LEVELS

Once you have established a more consistent pattern of activity and rest, you will then be in a position to start to *gradually* increase the amount of activity you do each day. This will probably be about two weeks after you start your programme, when you are more used to doing things at regular times.

How to increase your activity levels

1. Look at your activity programme and ask yourself for each different activity- How successful was I at completing it?
2. Look at the chart below, to decide how to change your levels of activity

% OF SUCCESS IN ACHIEVING ACTIVITY 0 = no success 100 = complete success	POSSIBLE REASONS FOR ACHIEVEMENT/ NON ACHIEVEMENT	HOW TO CHANGE YOUR ACTIVITY LEVEL
0-25%	activity level set too high an acute illness relapse of symptoms	Reduce your activity level
25-50%	activity level set slightly too high.	Reduce your activity level slightly, if nearer 25% achievement level, otherwise keep activity level the same
50-75%	activity level set about right	Keep your activity level the same if nearer the 50% achievement level, otherwise *slightly increase the activity level.
75-100%	activity level set about right	*increase your activity level, unless you have reached your ultimate goal, in which case keep the activity level the same.

*The amount of time by which you increase your activity, will depend on what the activity is, and the time that you are already spending on it.

How often should you make changes to your activity programme?

How often you *change* your activity programme, will depend on how successful you are in achieving your plans. However, we would recommend that you include 15-30 minutes each week in which to review your activity programme. This will give you the opportunity to assess your progress and help you to decide whether you can make any changes to your activity programme for the next week.

When should you introduce new activities?

You may consider introducing new activities:-

- When the overall success of the previous week's/fortnight activity programme, reaches 75%;
- When you have achieved a target;
- If for circumstances beyond your control, you are unable to continue a particular target;
- When your rests have decreased, (if applicable), and you have the time for more activities.

How to decrease your rests

Once your programme has been established for a few weeks you will hopefully have recovered from any temporary increase in fatigue and feel that you are able to reduce your rests. Gradually cut down the *amount* of time you spend resting at first, then in a few weeks, you may find that you can gradually reduce the *number* of rests.

It is not necessary for your fatigue to have decreased for you to increase or start a new activity .

PLANNING ACTIVITY AND REST

FOR PEOPLE WHO GENERALLY DO TOO MUCH

We have already discussed how chronic fatigue can lead to a repetitive pattern of rest and activity dependent on how you feel. This pattern is generally very hard to break out of, and can be very frustrating. People who generally do too much are often able to 'keep going' at work, maintain their home or study for long periods, but in the evenings and at weekends spend most of their time resting or sleeping in an attempt to feel better. This pattern can be very frustrating as you may miss out on pleasurable activities such as seeing friends, going out for the day, doing some exercise or pursuing your hobbies.

The key to improving your health is to make your life as balanced as possible. It is therefore important that you identify areas that you could change. For example, do you find that you will keep going at work without taking breaks? Do you find that you do not sit down at home until you have taken your children to school, tidied the house and done the shopping? Do you find that you do not leave work until you have completed all of your work, even if it is late? Do you study for hours without taking a break and then have to sleep for a couple of days because you feel so fatigued? If the answer to some of the above questions is yes, then maybe you could consider some of the following ideas?

- Could you leave work a little earlier?
- Could you have a proper lunch break, instead of eating a sandwich at your desk.
- Could you leave the cleaning, washing, preparing meals, etc, and sit down for half an hour?
- Could you plan one or two pleasurable activities each week?
- Could you put aside one hour for yourself each day?
- Could you break up your studies with a brisk walk?

IMPORTANT FACTS TO CONSIDER WHEN PLANNING AN ACTIVITY PROGRAMME

- It is important to plan in advance what you are going to do each day by creating an activity programme once a week. This will help you to balance your time between things that you have to do, e.g. work/studies/managing your home with pleasurable activities e.g. seeing friends and having time to relax e.g. reading a book.
- Try to include a few short breaks each day into your busy schedule. Even if you are working in a demanding job or looking after young children, it should be possible to ensure that you have at least a 15 minute break in the morning and afternoon, as well as at least a half hour lunch break.
- Do **not** be tempted to carry out long periods of activities without breaks even if you feel that you have a lot of energy. You are likely to pay for it later and *feel* that you need to rest for a long time to feel better.
- Do not be tempted to catch up with rest at the weekend. Once you start taking regular breaks in the day, you should hopefully feel less tired at the weekend and have a bit more energy. Try to plan a few "pleasurable" activities for the weekend as well as a bit of time to catch up with chores, etc, if necessary.

Refer to your target breakdown sheet on page 39, for guidance on some of the activities that you may like to include in your activity programme.

STEPS TO CREATING AN ACTIVITY PROGRAMME

Planning activities

1. Write a list of activities that you would like to perform during the next week on your activity programme. Refer to your targets for treatment. A blank activity programme for you to photocopy can be found on page 51.
2. Write down the amount of time that you wish to spend on each activity.
3. Use your activity diaries for guidance on the total amount of time to be spent on an activity during the week.
4. When writing your first activity programme, aim for about as much “overall” activity as you are having at present. So, for example, if you do all of your chores at the weekend, break the amount of time that you usually spend on them into small chunks to do on 2 or 3 days.
5. Remember to make your activities manageable chunks rather than one long activity. For example, if you plan to do some gardening at a weekend, plan 2 x ½ hour periods rather than a 1 hour period.

Planning relaxation time

Whether you are working, studying or managing a home and/or looking after children, regular time for relaxation is important. Taking breaks can help you to feel a lot better and will hopefully contribute to you having a bit more energy to do the things that you want to do at the weekends. What you find relaxing is a very personal thing. It may be reading a book, listening to music, pottering in the garden, having a long bath.

In order for you to plan relaxation time:

1. Look at the activity diaries that you completed during the previous fortnight and estimate the amount of rest or relaxation time you had. (You may find that on some days you rested very little, but at weekends, you rested for much of the time).
2. Divide the total amount of rest you have taken during the day in the past 2 weeks by 14 to calculate the amount of relaxation time to be taken each day. (This will mean increasing rests on some days and reducing them on others)
3. Write down on your activity programme the number of breaks to be taken each day, and the length of each one. If you are working or studying, you will need to consider what is achievable in relation to your commitments.

For example:

2 x 15 minute breaks and 1 x 1 hour break each day.

Or 3 x ½ hour breaks each day

Examples of an initial activity programme

For someone who works full time

- To have at least 2 x 15 minute breaks and a ½ hour lunch break at work.
- To leave work on time, at least 2 x per week.
- To have ½ hour exercise, at least twice weekly.
- To spend 1hour daily doing something relaxing, e.g, listening to music, watching television.
- To go out socially x 1 weekly for 2 hours.
- To go to bed by 11.00 during the week.

For someone who cares for family/home full -time

- To have 1 x 15 minute break at home in the morning and afternoon daily
- To have 1/2 hour break at lunch time daily.
- To spend 2 x 1 hours daily cleaning/cooking/other chores.
- To go for 2 x 15 minute walks daily.
- To go out with friends/partner weekly for 2 hours.
- To stop chores by 9.00pm daily.
- To spend at least 1 hour daily on hobby/reading daily.

Recording your activities.

You will already be used to recording your activities in your activity diary. Please continue to write down details of what you are doing for each hour of the day.

Please refer to the section on “activity diaries” for more information if necessary.

Remember that completing your activity diaries is a very important part of your programme, as it will help you to monitor your progress.

What to expect when you start your activity programme

It may take a few weeks for you to start feeling better. Initially, when you begin your activity programme you may find that your fatigue and other symptoms remain the same or slightly increase. This is particularly likely to happen if you significantly change your usual routine or start a new activity. On the other hand, if you are introducing more regular breaks into your day, you may notice a slight decrease in your fatigue.

Even if you notice a slight increase in your symptoms, It is important that you maintain your activity programme. Your symptoms should gradually decrease after a few weeks.

CHANGING YOUR ACTIVITY LEVELS

Once you have established a more consistent pattern of activity and rest, you will be in a position to start to GRADUALLY introduce new activities e.g. hobbies or social events. This will probably be about two weeks after you start your programme, when you are more used to doing things at regular times.

1. Look at the activity programme that you made yourself for the past week, and ask yourself for **each** different activity-

How successful was I at completing it?

You may consider introducing new activities when:-

- the overall success of the previous weeks activity programme reaches 75%.
- you have completed a particular target,
- If for circumstances beyond your control, you are unable to continue a particular target.

Reviewing your programme each week will help you to assess your progress, although you may only make changes to it every fortnight. From now on, include 15 minutes – ½ an hour a week to review your homework and plan your next activity programme.

Remember to make time for relaxation - with no specific activity.

ACTIVITY PROGRAMME

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____
7. _____
8. _____
9. _____
10. _____
11. _____
12. _____
13. _____
14. _____
15. _____
16. _____

TARGET ACHIEVEMENT RECORD

When you feel that you have established a good routine and are **consistently** maintaining your activity programme, you may like to record your activities on target achievement records. These records will help you track your progress, but only require a ✓ in a box, rather than writing details of what you have done.

Target achievement records are less time consuming than activity diaries, but do not be tempted to use them until you feel confident about your routine.

Please see overleaf for an example of a completed target achievement record, followed by a blank one for your use.

Insert example of target achievement records

target achievement record

OVERCOMING UNHELPFUL THINKING PATTERNS

For the past few weeks, you will have been working on establishing a regular pattern of activity, rest and sleep. You will hopefully feel that you are making some progress and are starting to feel less fatigued and have fewer symptoms. Sometimes progress can seem very slow and there may be times when you feel despondent and feel that you are having difficulty with your programme. This section aims to help you to understand and tackle some of these difficulties in order for you to get back on track with your treatment programme and make further progress.

Unhelpful thinking patterns can inadvertently make it difficult to make progress. For example, thoughts about activity increasing your pain and fatigue are unhelpful, as they may lead you to reduce or stop certain activities.

This section discusses ways to help you to identify and change unhelpful thinking patterns. This is based on cognitive therapy.

Cognitive derives from cognition, which refers to the human faculty of thinking, reasoning and understanding.

SECTION ONE: Addresses the topic of tackling unhelpful thoughts.

SECTION TWO: Addresses the topic of tackling unhelpful assumptions and core beliefs.

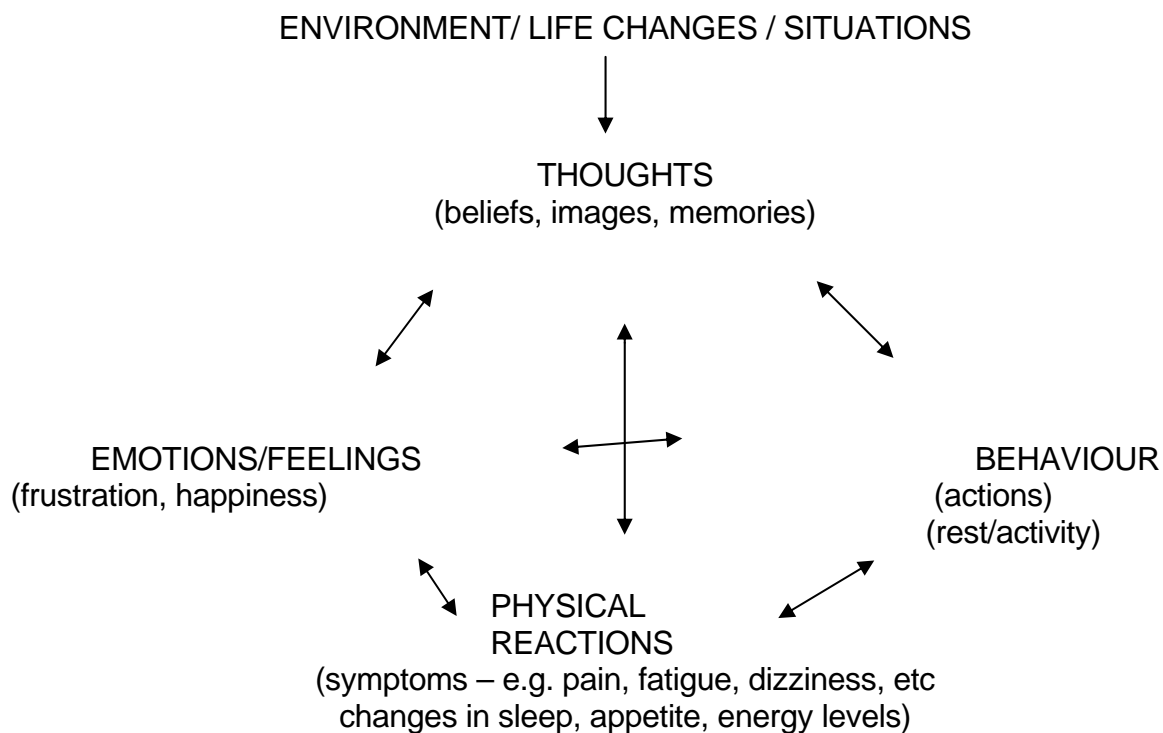
SECTION ONE:

TACKLING UNHELPFUL THOUGHTS

Our lives are influenced by an inter-connection between 5 areas:-

- Thoughts (beliefs, images, memories)
- Feelings (moods or emotions),
- Behaviours (what we do, ie activity, sleep, rest)
- Physical reactions (fatigue, pain, dizziness, changes in energy levels, sleep appetite etc)
- Environment (what is happening in our life- past and present)

Each area directly influences each of the other 4 areas as shown in the diagram below. Understanding this interaction may help us to understand and manage certain problems more effectively.



For example

- If someone gives you a present (behaviour) it is likely that you would feel happy (emotion).
- If you cut your finger (behaviour), it is likely that you would feel pain (physical reaction) and depending on how bad it is you may feel dizzy or sick (physical reactions) and feel cross with yourself for being careless (emotions)
- If you pass an exam/ receive promotion (environment) you are likely to have positive thoughts about yourself (thoughts) and be happy (emotion) and may go out and celebrate (behaviour)

You can *think* about a situation in a variety of ways, but the way that you *think* about the situation will determine how you *feel*.

Example

It is 8.00pm, and your guests should have been at your house for dinner ½ hour ago:

Possible thoughts

Possible feelings

- | | |
|---|---------------|
| • They're stuck in a traffic jam and will be here soon | content |
| • Thank goodness they're late, it has given me some extra time to get myself and the food ready | relieved |
| • Maybe they're not coming and just couldn't be bothered to phone | irritated |
| • They've probably just forgotten, I'll give them a couple of minutes and then phone them | understanding |
| • They obviously don't like me any more otherwise they would have been here on time | sad |

You can see that each different thought is likely to lead to different feelings or emotions, e.g. relief, sadness, irritation etc. It is likely that as a result of these thoughts and feelings, people would behave in different ways. For example:

- The "content" person may have been "relaxed" if/when the guests arrived and had an "enjoyable" evening.
- The "irritated" person may have been "curt" to their guests and had a "difficult" evening.

However if we change the way we think about something, it can affect our behaviour, our emotions, physical reactions, and can lead to changes in our lifestyle. Changing our behaviour can influence the way we feel both physically and emotionally.

- So, using the above example, if the "irritated" person changed their thoughts to "they're probably just stuck in a traffic jam and will be here soon", they are likely to feel more "relaxed" when their guests arrive, and have a pleasant evening.

Changes in our life will influence our emotions, physical feelings, thoughts and behaviour. It is likely that promotion, passing exams, winning the lottery etc, will make us feel happy, feel good about ourselves and be a cause for celebration. Failing exams, illness, relationship break-ups and financial difficulties are changes in our lives that may make us feel upset, worried, stressed, tired and may lead us to feel down, withdraw from others etc.

UNHELPFUL THOUGHTS ASSOCIATED WITH CFS

When suffering from a debilitating illness, such as CFS/ME, it may be difficult at times to retain a positive attitude when you feel so unwell, your life has become restricted and your future appears uncertain. At times you may feel frustrated, demoralised or worried about your health and associated problems. These feelings can make it harder for you to make progress.

When you begin your programme, you may have thoughts such as:-

- “I am feeling more fatigued than when I started the programme, what’s the point in continuing!”
- “I haven’t managed to get up at the agreed time for the last few days, it’s just too hard!”

These are examples of “unhelpful thoughts” which may make it difficult at times for you to continue with your programme.

We have noticed that many people with CFS/ME have unhelpful thoughts that can be divided into two main areas:

1. **Fears about their illness**

This is understandable as the symptoms are both debilitating and distressing and there are differing attitudes from “experts”, relatives and friends about not only the illness itself, but also what you should and shouldn’t do.

Example of how an unhelpful thought related to fears about illness may affect other areas of a person’s life

Situation: Woke up feeling exhausted and very achy after walking too far the previous day

Thought: I must be getting worse.

Behaviour: Rest for most of the day.

Emotions: ‘Worried’ about making CFS/ME worse
‘Annoyed’ for giving in to tiredness

Physical Worsening /more aware of physical symptoms e.g. fatigue and aching

Can you think of any personal examples of how thoughts about CFS/ME have influenced other aspects of your life? If so, please write them in the spaces provided below.

Situation:

Thought:

Behaviour:

Emotions:

Physical:

2. Having extremely high personal standards and self-expectations

Prior to developing CFS/ME, many sufferers report being very busy, energetic people who are very driven, often successful and have high expectations of themselves (perfectionists). Due to the nature of CFS/ME, it can be very difficult to maintain previous personal standards or activity levels, which can lead to the following:

- Being overly self-critical
- Worry about starting new things, fearing not being able to do them well enough
- Doubting your own judgement, making it hard to complete tasks
- Focusing on things that you haven't 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

Example of how unhelpful thoughts related to perfectionism may affect a person with CFS/ME

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

Thought: I'm useless! I should have handed in the essay/ finished painting the bathroom/ tidied my bedroom by now.

Emotions: 'Frustrated' about not completing the tasks that I set myself
'Worried' about missing another deadline

Behaviour: Unable to relax or concentrate on any one thing

Physical: Feel more fatigued

Can you think of any personal examples of how “perfectionist” thoughts have influenced other aspects of your life since you developed CFS/ME? If so, please write them in the spaces provided below.

Situation:

Thought:

Behaviour:

Emotion:

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 CFS/ME; for example; relationship issues, finances, moving house etc. These thoughts may also make you feel a bit down and may in turn negatively affect your thoughts about your CFS/ME.

Characteristics of unhelpful thoughts

- *Automatic:* As with all thoughts, unhelpful ones tend to pop into our head 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 as they can be hard to change

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 on your ***Unhelpful Thoughts Diary*** as soon as possible so that you remember the details.

- **In the *situation* column**

Write down what you were doing or thinking about prior to having a strong feeling or change in your emotion/mood.

- **In the *emotion* column**

Write down the emotion or feeling that you had when you had an unhelpful thought(s)

Write down the intensity of your emotion on a 0-100% scale

- **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 - 100% scale.
0% means that you do not believe it at all.
100% means that you believe the thought completely, without any doubts.

Initially 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.

An example of a completed unhelpful thoughts diary may be found on the next

A blank unhelpful thoughts diary may be found on page 63.

EXAMPLE OF A COMPLETED UNHELPFUL THOUGHTS DIARY

Date	Situation What was I doing at the time of the thoughts	Emotion How did I feel? Rate intensity 0 -100%	Unhelpful thoughts What thoughts went through my mind just before I started to feel this way? Rate belief in each thought (0-100%)
	Sitting down after a 10 minute walk feeling exhausted. Meeting up with old friends from work.	Frustrated 70% Worried 80% Sad 80%	I feel so tired, <u>*I must be making myself worse</u> . I am now too tired to do anything. 80% **I feel so out of touch with everyone. **I haven't worked for over a year and have nothing to contribute to the conversation. **They must think that I am very boring.

* underlined part that particularly provoked emotion

** Broke down thoughts into separate ones

For practice, use the following chart to write any unhelpful thoughts you have had recently, using the chart above for guidance. You may then transfer them on to an Unhelpful Thoughts Diary to discuss with your therapist.

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

UNHELPFUL THOUGHTS DIARY

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

STANDING BACK FROM YOUR UNHELPFUL THOUGHTS

Once you have identified some unhelpful thoughts, the very act of taking a step back from them can in itself be very powerful, as they can be seen for what they really are, just thoughts. Prefixing an unhelpful thought with “I am having the thought that”.....can be enough to help you to achieve this aim. Your therapist may be able to suggest other ways to help you to distance yourself from your unhelpful thoughts, thereby helping to reduce the sometimes powerful effect they can have.

Although some people find that standing back from their thoughts can lead to a positive change in the way they feel, this is not always the case. The next section discusses how to identify thinking errors which helps you to dissect each unhelpful thought. The section following that discusses ways of challenging your unhelpful thoughts, i.e. helping you to look at things in a more balanced way.

EVALUATE YOUR UNHELPFUL THOUGHTS

Once you have become aware of unhelpful thoughts, the next step is to examine them more closely to look for thinking errors.

What are thinking errors?

These can be described as unhelpful thinking patterns that seem plausible but often involve distortions of reality.

Why do I need to identify unhelpful thinking patterns?

Identifying unhelpful thinking patterns will help you to stand back and dissect the thought, bringing you one step closer to coming up with helpful alternatives. You may notice that you have a tendency towards one or more of the unhelpful thinking patterns listed on the next two pages.

UNHELPFUL PATTERNS OF THINKING

<p>Unhelpful thinking pattern (Thinking error / distortion)</p>	<p>Description</p>	<p>Example</p>
<p>All or nothing thinking, also called black and white thinking</p>	<p>Looking at a situation with only 2 categories, instead of on a continuum</p>	<p>“If I can’t stay out until late, then there is no point in going out at all”.</p>
<p>Over generalisation</p>	<p>Making a negative assumption that because something has happened once, it will naturally happen again.</p>	<p>“I felt much worse when I increased my exercise before, so I am bound to feel the same when I increase my exercise next time”.</p>
<p>Eliminating the positive</p>	<p>Dwelling on bad experiences, and discounting positive aspects.</p>	<p>“I have had a terrible week and I have achieved nothing”.</p>
<p>‘Should’ and ‘must’ statements</p>	<p>Fixed expectations of how you think yourself or others should behave. You may overestimate how bad it is if these expectations are not met</p>	<p>“I should be able to cope better by now, I’m not trying hard enough”. “I must make more of an effort in future”.</p>
<p>Catastrophizing</p>	<p>Getting things out of proportion, so that they appear worse than they really are.</p>	<p>“My muscles ache and I feel more tired today, I must be doing some permanent damage to myself”.</p>
<p>Emotional reasoning</p>	<p>Taking a feeling as being evidence of fact. You ‘feel’ (believe) it so strongly and discount evidence to the contrary</p>	<p>“I <i>feel</i> a real failure; I am no better now than I was a few months ago.</p>

UNHELPFUL PATTERNS OF THINKING

Unhelpful thinking pattern (Thinking error / distortion)	Description	Example
Labelling	Putting a 'fixed' or 'global' label on yourself or others without considering evidence that doesn't support it.	"I'm incompetent". "My colleagues are totally insensitive".
Mental filter	Paying undue attention to one negative detail instead of seeing the whole picture	"One or two of my exam marks were dreadful, (even though others were good); I don't deserve to pass my degree".
Mind reading	Believing that you know what others are thinking, without considering other more likely possibilities	" They think that just because I don't look ill, that I am not ill".
Personalisation	Believing that others are behaving in a certain (negative) way because of you	"My doctor was irritable because I went to see him for two weeks running"
Tunnel vision	Seeing only the negative aspects of a situation	I feel just as tired as I did 3 months ago, there has been no improvement in my illness

HOW TO CHALLENGE YOUR UNHELPFUL THOUGHTS

The following questions aim to help you to look for more helpful and realistic alternatives to your unhelpful thoughts by:-

- detecting possible thinking errors or distortions
- looking at the situation from another point of view
- finding evidence that does not support them

1. What thinking errors am I making?
2. Have I had experiences that indicate that this thought is not true all of the time?
3. Am I assuming that this view is the only one, or might another person look at it in a different way?
4. If my best friend or someone I loved had been in a similar situation, would I say the things that I have said to myself to him or to her? What might I say to them?
5. If my best friend or someone that is close to me knew that I was thinking these things, what would they say to me?
6. What is the actual evidence that this thought is true?
7. Is there any evidence that this thought may not be entirely accurate?
8. Are there any small things that contradict my thoughts that I might be discounting as not important?
9. Am I blaming myself for something that wasn't entirely my fault?
10. Am I being too self-critical and expecting too much of myself?
11. What are the advantages and disadvantages of thinking this way?

How to write an action plan

Challenging your unhelpful thoughts may not always be enough to help you to feel better or to convince you that they are incorrect. Writing an action plan will provide you with practical strategies to help you to break old habits of thinking and strengthen new ones. In some instances, having an action plan may help you to build up evidence that contradicts your unhelpful thoughts.

The type of action plan that you make will depend on the type of unhelpful thoughts you have. Please see examples below

Illness related thoughts

I will never get better

Action

Write down any improvements I have made, however small

Thoughts related to perfectionism

I haven't achieved anything today

Action

Write a list of what I have achieved today

Thoughts related to doing something new

I won't be able to remember the information, I haven't studied for years

Action

Read a page of a book and see how many facts I can remember

How to complete your new thoughts diary

1. Complete the first 4 columns as you did when you completed your unhelpful thought diaries.
2. Refer to the previous 3 pages to help you to complete the last 3 columns.

- **In the *situation* column**

Write down what you were doing or thinking about prior to having a strong feeling or change in your mood.

- **In the *emotion* column**

Write down the emotion or feeling that you had at the time that you had your unhelpful thought.

Write down how strong your emotion was on a 0-100% scale.

- **In the *unhelpful thought* column**

Write down the actual thought(s) that went through your mind.

Write down how much you believe each thought, on a 0 - 100% scale.

- **In the *evidence for and against your thoughts* column**

Write down any thinking errors that are apparent in your unhelpful thoughts.

Write down your answers to the questions listed on the previous page.

Not all of the questions will be relevant but try to come up with at least 3 or 4 answers.

- **In the *alternative thoughts* column**

Write down alternative thoughts after reflecting on the information that you have written in the previous column. The idea is for these thoughts to be more balanced and helpful.

Rate each new belief in terms of how much you believe it. 0% -100% scale.

0 % means that you do not believe it at all,

100% means that you believe it completely.

- **In the *outcome* column**

Re-rate your belief in your unhelpful thoughts on 0-100% scale

Re-rate the intensity of your emotions on a 0-100% scale

- **In the *Action Plan* column**

Write down any strategies that will help you to overcome your unhelpful thinking patterns / improve your situation / help you to feel better etc .

POINTS TO BEAR IN MIND WHEN TACKLING UNHELPFUL THOUGHTS

- Do not give up if you find the procedure difficult. Constantly evaluating and challenging our thoughts is not something that we normally do. Follow the guidelines carefully and hopefully in time you will find it easier and helpful.
- It can be difficult to think of ‘evidence against your unhelpful thoughts’ or ‘alternative thoughts’ when you feel upset/angry etc. However, it is important that you write down your unhelpful thoughts as soon as you can, so you do not forget any details. If you are unable to think of evidence against your unhelpful thoughts or alternative ones straight away, do not worry, do something else until you feel calmer; you will then be in a better position to tackle them.
- Alternative thoughts are ones that help you to change the way you feel about a situation or problem. They do not have to be relentlessly positive!
- It will take time and practice to build up belief in your alternative responses.
- Try not to feel discouraged if you have the same type of thoughts recurring; this is likely to happen if unhelpful thinking is well established. Keep challenging your thought however often it occurs; this will help to reduce your belief in the original thought.
- Eventually, you may be able to challenge your unhelpful thoughts in your head. Initially, however, writing them down is easier, and will help you to be more objective.
- Remember that there is no right or wrong way of thinking. The aim of challenging your unhelpful thoughts is to help you to feel better.

An example of a completed "New Thoughts Diary" may be found overleaf, followed by a blank New Thoughts Diary

INSERT AN EXAMPLE OF A COMPLETED NEW THOUGHTS DIARY

A BLANK NEW THOUGHTS DIARY

SECTION TWO

TACKLING UNHELPFUL ASSUMPTIONS AND CORE BELIEFS

Addressing your unhelpful thoughts may be all that is necessary to help you to overcome or deal with certain problems more effectively. However, if you feel that you have thoughts that are based on a particular theme, or thoughts that come up again and again however much you challenge them, then you may find this section helpful.

We have different levels of belief.

1. Automatic thoughts

In the previous section you worked on your “unhelpful” automatic thoughts.

They are the most accessible and after some practice are fairly easy to identify. Automatic thoughts are generally the things that we say to ourselves. They can be a direct reflection of our assumptions or core beliefs or they may be driven by them.

2. Assumptions

These operate as rules that guide our daily actions and expectations. They are less obvious than automatic thoughts. They are usually stated as ‘should’ statements, or ‘if....then...’ sentences.

Example: ‘I should be better by now’.
 ‘I should be back at work by now’
 ‘If I don’t get at least 75% in my exam, then I’m incompetent’.
 ‘If I’m not talkative when I go out, then people will think I’m boring’.
 ‘If I ask for help, then people will think that I am weak

The development of assumptions are influenced by our core beliefs

3. Core Beliefs

These are our deepest level of belief. Core beliefs are absolute statements that we may hold about our self, other people or the world.

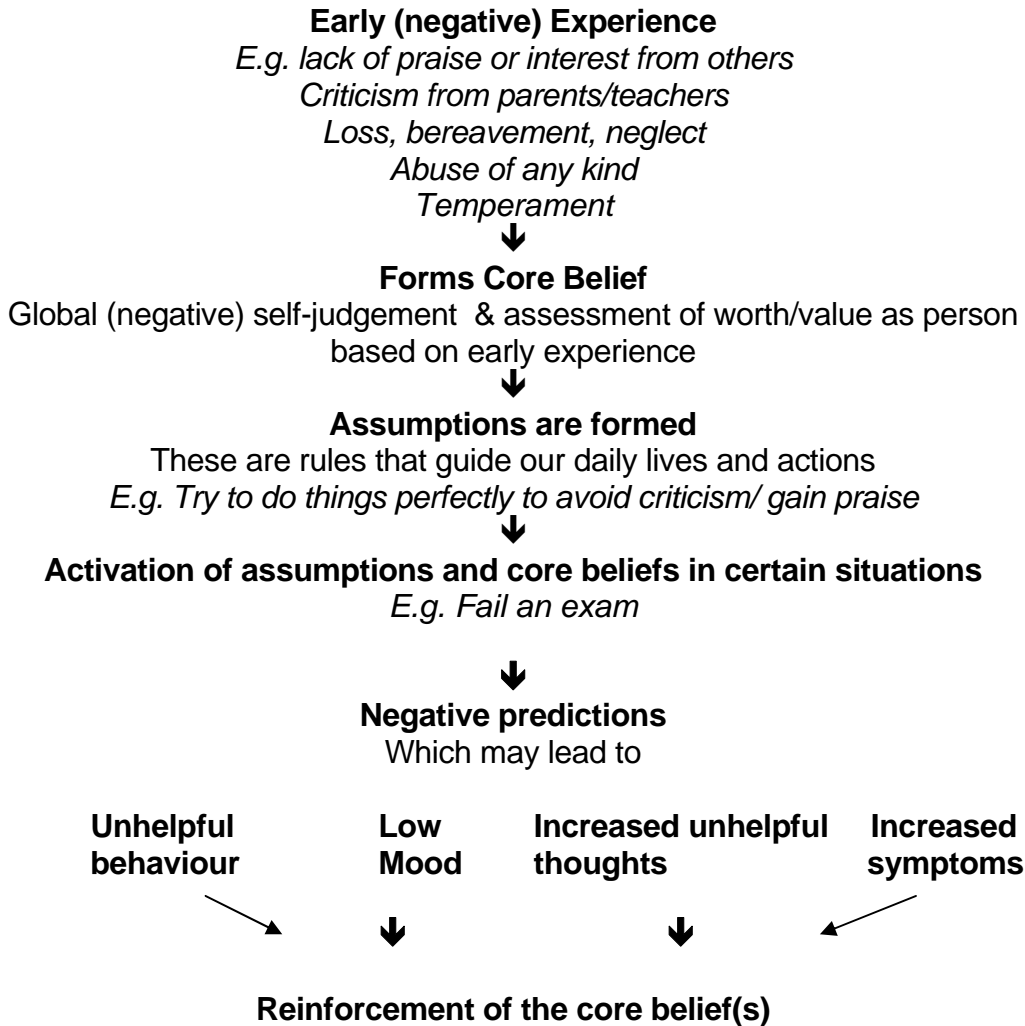
Example of Core Beliefs: ‘I am unlovable’ ‘I am loveable’
 ‘I am a failure’ ‘I am good enough’

Where do assumptions and core beliefs come from?

On the basis of experiences that we have while growing up, we form conclusions (beliefs or assumptions) in order to try to make sense of ourselves, other people and the world. If we encounter trauma, for example, bullying, abuse, excessive criticism etc, we are more likely to develop negative core beliefs or assumptions than if we do not experience these things. .

In certain situations these beliefs or assumptions may be activated resulting in us thinking, feeling and behaving in a way that may further exacerbate the unhelpful thoughts and feelings and reinforce our beliefs. (Please see the diagram on the next page).

The formation of (negative) core beliefs and possible consequences



The rules and beliefs that we acquire as young children are not necessarily true, but we are unable to be flexible with our thinking until we are older. For example, if a young child is scratched or bitten by a cat, they may think that all cats are malicious and be frightened of them. It is unlikely that they will change their attitude until they are older when they may see friends playing with cats. They may then learn that some cats are friendly, and some cats are not. When we get older, not only do we learn to be more flexible with our rules and beliefs, but also learn to change our behaviour according to the situation. For example, we usually learn that it is safe to approach a dog that is wagging its tail, but not to approach one that is growling.

Some of our beliefs from childhood however, may stay with us into adulthood. This may occur as a result of traumatic experiences, or facing situations that reinforce our beliefs. For example, a child who is constantly being criticized at home and/or at school might conclude that she is bad and develop a core belief of being a failure. If she then fails some exams, or is rejected in her attempts to get a job, then this may further reinforce her beliefs.

Because our core beliefs help us to make sense of the world at a young age, it rarely occurs to us to evaluate whether they are the most useful ways of understanding our

adult experiences. Instead, we may act, think, and feel as if these beliefs are still 100% true. Although many core beliefs stem from childhood, powerful negative experiences such as witnessing or experiencing trauma; living in chaotic, unpredictable circumstances; or experiencing persistent unhappiness for whatever reason can develop into negative core beliefs at any age. Persistent negative interactions with other people, for example observing a highly successful sibling who receives much praise can develop into 'unhelpful' core beliefs about others, e.g., 'others are more competent than me'.

What is the point of trying to change unhelpful assumptions and core beliefs?

Although in reality we all probably have a number of core beliefs that shift slightly depending on the situation we are in, when we have a particularly "entrenched" negative belief, or frequently face situations that activate it/them, then we will tend to act and feel in ways consistent with these beliefs.

Addressing unhelpful core beliefs by learning to challenge them can help us to look at things in a more positive way and reduce the number of unhelpful thoughts that we experience. Furthermore, developing new assumptions and core beliefs may help to change behaviour in ways consistent with new beliefs.

For example:

If you have a core belief such as, I am a failure;

An assumption may be along the lines of 'If I don't do well all of the time then I am not good enough'.

As a result of this assumption, it is likely that you would set harsh rules for your self and rarely be happy as you would be striving so hard to attain perfection. (Perfection is a concept that doesn't fit reality). You would also probably be very self-critical and be unwilling to try new activities fearing making mistakes.

However, if you were able to challenge your negative core belief, you may be able to believe you were good enough some of the time. This may help you to develop a new core belief such as, I am good enough. Your assumption may then change to something like 'If I try to do my best, then I will be successful some of the time' It is likely that your rules would then be less harsh and you would be more willing to accept mistakes, be pleased about things that you achieve and be more inclined to take risks to try new things etc.

HOW TO IDENTIFY ASSUMPTIONS AND CORE BELIEFS

Look at your unhelpful thoughts in your unhelpful thought diaries, to see if there are any themes that occur repeatedly. If there are, they might provide a clue to your assumptions and core beliefs.

OR

If you are unable to find any assumptions or core beliefs, you may find the second technique more helpful.

Downward arrow technique:

1. Find an unhelpful thought in one of your unhelpful thoughts diary or new thoughts diary, which was associated with an intense emotion.
2. Write down the situation where you had the unhelpful thought, the thought itself, and ask yourself the following question as many times as it takes to arrive at a core belief about yourself.

‘What does this say or mean about me?’

Example:

Situation: You are called into see your boss at work

Thought: He doesn't think my work is good enough, I'm bound to get the sack

‘What does this say or mean about me?’

I'm no good at my job

‘What does this say or mean about me?’

I'm no good at anything

‘What does this say or mean about me?’

Core Belief: I am incompetent

Sometimes, identifying core beliefs about yourself will be enough to understand a recurrent problem in your life. However, identifying and challenging unhelpful core beliefs about others may help you to get things better into perspective. For example, having a core belief that ‘everyone is more competent than me’; could compound the core belief about being incompetent. If, however, you can change your belief to ‘others are not competent all of the time,’ it may help you to get things better into perspective, and may help you to feel less ‘incompetent’.

Identifying core belief worksheets may be found on the next 3 pages. You may use them to identify core beliefs about yourself, others or the world.

IDENTIFYING CORE BELIEF WORKSHEET
ABOUT ME

Situation:

Unhelpful thought:

What does this say or mean about me?

What does this say or mean about me?

What does this say or mean about me?

What does this say or mean about me?

Core belief:

IDENTIFYING CORE BELIEF WORKSHEET
ABOUT OTHER PEOPLE

Situation:

Unhelpful thought:

What does this say or mean about others?

What does this say or mean about others?

What does this say or mean about others?

What does this say or mean about others?

Core belief:

IDENTIFYING CORE BELIEF WORKSHEET
ABOUT THE WORLD

Situation:

Unhelpful thought:

What does this say or mean about the world?

What does this say or mean about the world?

What does this say or mean about the world?

What does this say or mean about the world?

Core belief:

It can sometimes be helpful to try to understand where particular thoughts, beliefs and assumptions have come from and the effects they may have on you. On the next page, there is a diagram that illustrates an example of how core beliefs may be formed and maintained. You may use the page after that, to fill in your own example, if you wish.

**EXAMPLE:
DIAGRAM OF HOW CORE BELIEFS MAY BE FORMED AND MAINTAINED**

Background information

Which experiences contributed to the development and maintenance of the core belief

Criticism from parents & teachers; lack of praise, clever older sibling, being bullied

Core Belief(s)

What is my most central core belief?

I am inadequate

Conditional assumptions

Rules that guide our behaviour usually expressed as “if”, “then” statements

If I don't: get a good mark / come top of the class / receive praise for my work
Then: I've failed / I'm not good enough

Compensatory strategies

Behaviours that help cope with my core belief

Have very high standards	Avoid asking for help
Work very hard	Over-prepare

Typical situations

Where beliefs or assumptions may become activated

- a. Reflecting on a meeting
- b. Preparing for a lecture
- c. Reviewing a piece of own work
- d. Meeting new people

Unhelpful automatic thoughts and emotion (s)

That may occur in the above situations and reinforce core belief

- a. I must have looked stupid when I got tongue tied in the meeting (embarrassed)
- b. What if I can't answer all of the questions (anxious)
- c. I can see many mistakes in my work (upset)
- d. They'll think that I am really boring (sad)

Behaviour in response to thoughts

- a. Try to avoid further meetings
- b. Spend excessive time reading around the subject
- c. Throw my work in the bin and start again
- d. Make excuses and leave early/avoid going out

DIAGRAM OF HOW CORE BELIEFS MAY BE FORMED AND MAINTAINED

Background information
Which experiences contributed to the development and maintenance of the core belief

Core Belief(s)
What is my most central core belief?

Conditional assumptions
Rules that guide our behaviour usually expressed as “if”, “then” statements

Compensatory strategies
Behaviours that help cope with my core belief

Typical situations
Where beliefs or assumptions may become activated

Unhelpful automatic thoughts and emotion(s)
That may occur in the above situations and reinforce core belief

Behaviour in response to thoughts

CHALLENGING CORE BELIEFS

Core beliefs can take a lot longer to change than unhelpful thoughts because we require a lot more convincing that beliefs that we hold to be absolute, are not 100% true. It may take weeks or months to change core beliefs. You have already learned how to challenge your unhelpful thoughts, so you will have acquired techniques that will help you in challenging your core beliefs.

There are two main ways of challenging core beliefs:-

- Finding evidence that does not support your belief
- Testing out the validity of your existing thoughts, assumptions and core beliefs by doing behavioural experiments.

How to record evidence that a core belief is not 100% true.

1. Please use sheet- 'challenging core beliefs'
2. Choose a core belief you would like to evaluate.
3. On the "challenging core belief sheet", record experiences that indicate that your belief is not true 100% of the time. Try to find at least one piece of evidence every day for the first week, however small.
4. When you are able to find a piece of evidence most days that refutes your belief is true 100% of the time, then try to find two or three pieces of evidence each day.
5. When you have a list of about 20 to 25 items, look at them and draw your own conclusions about whether your original core belief accurately describes your whole experience.

Conduct behavioural experiments to test your core beliefs

As we have already mentioned, behavioural experiments can be a helpful way of challenging unhelpful thoughts, beliefs and assumptions. They may also be used to help you to strengthen more helpful thoughts, assumptions and core beliefs. For example, if you have a belief of being "unlikeable" or "unpopular", you might have a range of unhelpful thoughts such as "people do not enjoy my company", "people think I am boring", etc. You may therefore conduct an experiment to test out this thought such as contacting friends and suggesting going out/ inviting them for a coffee etc; or say hello or smile at 10 people. You could make a prediction of what you think may happen and then draw your own conclusions from the results of your experiments.

A challenging core belief sheet may be found on the next page, followed by a behavioural experiment record.

CHALLENGING CORE BELIEF RECORD

Core belief: _____

Write down evidence or experiences that suggest that the core belief is not 100% true all of the time

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____
7. _____
8. _____
9. _____
10. _____
11. _____
12. _____
13. _____
14. _____
15. _____
16. _____
17. _____
18. _____
19. _____
20. _____
21. _____

INSERT BEHAVIOURAL EXPERIMENT FORM

IDENTIFYING A NEW BELIEF

It is time to move on to identifying a new belief when you do not feel that your core belief truly reflects how you feel. It may take you a few weeks or months to reach this stage. Based on the conclusions that you drew from challenging your core beliefs and conducting experiments to disprove your belief, you will hopefully have developed a more realistic and helpful belief about yourself.

A new core belief may be the **opposite** of the old negative core belief.

Example:

Old belief:	I am unlikeable	I am incompetent
New belief:	I am likeable	I am competent

This does not mean that you have to be likeable / competent to everyone.

A new core belief may change an **absolute** belief to a **qualified** belief

Example:

Old belief:	Everyone is better than me.
New belief:	Not everyone is better than me, I am better than some people at certain things.

How to record evidence that supports an alternative belief

Just as you recorded evidence to indicate that your old core belief was not true all of the time, it is important that you find evidence to support and strengthen your belief in your new core belief.

1. Write out your new core belief on the sheet named 'new core belief record'.
2. Over the coming weeks, record small events and experiences that support your new belief. You may also like to think about events and experiences from your past, that support your new belief. This is important, as you will hopefully notice a gradual increase in your confidence in your new belief.

NEW BELIEF RECORD

New Core Belief: _____

Write down evidence or experiences that support the new belief:

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____
7. _____
8. _____
9. _____
10. _____
11. _____
12. _____
13. _____
14. _____
15. _____
16. _____
17. _____
18. _____
19. _____
20. _____
21. _____

POINTS TO BEAR IN MIND ABOUT TACKLING CORE BELIEFS.

- It will take much time and patience to complete this section.
- Go at your own pace, do not rush this section.
- Reducing your belief in 'negative' core beliefs often takes a long time, this is because they have generally developed and been reinforced over a long period.
- Developing and strengthening your new core beliefs can take time as you may initially have difficulty in finding experiences that are consistent with them.
- Persevering with challenging core beliefs then strengthening and reinforcing new core beliefs will positively influence the way you think, feel and behave.
- There will be times in your life when you feel greater levels of distress and at these times you can expect to have more unhelpful thoughts, and your unhelpful core belief(s) may return. At these times, review all of the work that you have done from both sections and repeat any of the worksheets necessary to help you to challenge your unhelpful thinking patterns and strengthen your new beliefs.

BLOCKS TO RECOVERY

At times you may feel that although you are doing everything possible to help yourself to get better, you are having some problems in making progress. You may be following your programme conscientiously but find that you are taking two steps forward and one step backwards. This can be extremely frustrating and can sometimes make you feel like doing things as and when you are able to rather than following a consistent pattern of activity and rest as described in this manual.

These “blocks” may be something of which you are totally unaware, or maybe in the back of your mind. However, when they are “dealt” with, you may find that you can move forward in a more productive way.

Below is a list of things that may be influencing your progress:

1). Fear about increased activity making you worse

- Worry about doing more can prevent you from taking the risks that are necessary to help you to overcome CFS/ME.
- Increased pain or fatigue that may occur as a direct result of doing more, can be misinterpreted as doing yourself permanent harm. The increased pain or fatigue can then lead you to reduce the amount that you do.

2). Having extremely high personal standards and self-expectations that cause you distress if you are unable to meet them (perfectionism)

We have already mentioned that these personality traits may be one of a number of trigger factors in CFS/ME. The reasons that they may form a block to recovery include:

- Trying to complete an activity in one go, e.g. an essay or painting a room. This is likely to increase your feelings of exhaustion and lead to prolonged rest.
- Not being able to relax properly, as you feel you “should” be doing something “useful”.
- Avoiding new activities or resuming old activities for fear of not doing things well enough.
- Difficulty in finishing tasks due to excessive doubts. Your doubts may lead you to check things or do things repeatedly and make it difficult for you to move on to another task, e.g. writing letters or an essay, doing housework.
- Never feeling that you have done anything well enough, which may make you feel dissatisfied which in turn can have a negative effect on mood
- Having an overly active inner critic- i.e. focusing on the things that you have not done and ignoring all that you have done (focusing on 10% that you haven’t done)

3) In receipt of benefits or a permanent health insurance:

When you are severely restricted by your illness, there is no doubt that the financial support provided by these schemes is very important. However, in certain situations, they may inadvertently prolong your illness for the following reasons:-

- You may feel trapped by your benefits or policy, ie, they may stipulate that you can only work for a few hours a week, earn only £20.00 a week, or do no work at all. Although you may feel that you have improved and are able to do *some* work, you may remain on your benefits fearing that if you come off them you may not be able to manage your work and risk financial problems.

- You may be having to attend regular medical check ups or appeals that can be very stressful and time consuming and make it more difficult for you to concentrate on gradually increasing your activity levels.
- You may fear having to go back to a job that you know contributed to you getting ill in the first place.

4) Other illness

Having another illness on top of your CFS/ME can make it very difficult for you to make consistent progress.

- You may have increased pain on top of your CFS/ME making it more difficult to exercise or sleep
- If you are depressed or become depressed as a result of your CFS/ME this can lead to increased feelings of fatigue.

5) Conflicting advice or being in receipt of different kinds of therapy/diets

- Although there is a lot of information to support CBT for CFS/ME, there are health professionals who would suggest that you need other tests or should try different types of treatments, this can lead to confusion.
- Starting new treatments or diets for your CFS/ME while you are doing CBT can make it difficult for you to fully concentrate on your programme.

6) The “wrong” kind of social support

This may seem a contradiction in terms! The examples below illustrate how the wrong kind of support can make it more difficult for you to move forward for the following reasons:

- If you have a very supportive family member (partner, parent or child) who is used to doing everything for you, it may be difficult for you to increase your activity levels. Your relative may feel that they have your best interest at heart and discourage you from doing more. They may have difficulty accepting that in order to make progress, you need to do things at regular times even if you are feeling very fatigued. If family members have been your “carer” during your illness, they can sometimes feel that they no longer have a role when you are getting better which can sometimes lead them to be critical of your CBT programme or suggest that you are making yourself worse. This may then lead you to question the validity of the programme and deter you from persevering with it particularly when you have a lot of symptoms.
- If you have a family member who does not take your illness seriously or does not understand the CBT programme they may not recognise the importance of your regular pattern of activity and rest. Comments such as:- “Are you resting again?” or “Lets go out for the day” or “You look better today”, may make it harder for you to stick to your programme.
- If you live alone and have no family members or close friends that live nearby, you may have difficulty looking after yourself properly- e.g. cooking for yourself, shopping etc.

7) Cultural issues

Some cultures have difficulty in accepting different kinds of illnesses, particularly if an obvious physical cause cannot be found. This may lead the person to continue to have

many “unnecessary” tests rather than concentrating on their CBT programme. It does not mean that just because an organic cause cannot be found, the “distressing” symptoms are not real.

8) Ongoing “stressful” situations

Stress of any sort can make it more difficult for you to make consistent progress however hard you try. Increased stress can increase your levels of fatigue and also make it more difficult for you to “switch off” at bed-time or when you are supposed to be resting or relaxing.

Below is a list of potentially stressful situations:

- a. Life events such as moving house, getting married, bereavements etc
- b. Financial difficulties
- c. Work – you may feel that your employers are not very understanding about your CFS/ME.

You may find that you have too much work to do in too little time or have too many deadlines to meet.

- d. Environment – you may live in an uncomfortable, unpleasant or chaotic environment where it may be difficult to relax. You may feel that your home is in a mess as you have difficulty keeping it tidy, filing papers, doing DIY, etc. There may be a lot of noise in your home or near by, e.g. other occupants, neighbours or traffic. Your house may be too hot or too cold. You may not get on with the people with whom you live.
- e. Relationship difficulties.
- f. Loneliness.
- g. Illness or other problems with a family member.

9) Breaking through comfort zones

If you have had CFS for a number of years, you may have stopped doing a lot of things that you used to do. Some of the things may be quite big, e.g. working, socializing or studying. On the other hand some of the things may be quite small e.g. paying bills or phoning people. Whenever any of us stop doing things for some time, we lose confidence in our ability to do them. Our lack of confidence in our ability to do things or our worry about things not going to plan may stop us from resuming old activities.

The tables on the next few pages may give you a few ideas of how to tackle the “blocks”

TYPE OF BLOCK	ACTION TO TAKE
Fear of increased activity making you worse	Read the following sections: <ul style="list-style-type: none"> - Physiological Explanation - Planning Activity and Rest - Overcoming unhelpful thinking patterns
Perfectionism	Read the following section: <ul style="list-style-type: none"> - Overcoming unhelpful thinking patterns Write 3 things that you managed to do each day, however small they may seem-e.g. "Did the washing up" Praise yourself for the things that you have achieved each day instead of criticising yourself for the things that you have not done. Focus on pleasure and having fun Read: "Dare to be average" – a chapter from Feeling Good, by David Burns and/or Overcoming perfectionism, by Antony and Swinson
In receipt of benefits	Read the following section: <ul style="list-style-type: none"> - Work, courses and resources Find out about your rights, e.g. how much you can earn before the benefits stop: Contact citizens advice bureau (CAB) Contact DHSS Find out about back to work schemes in your area Do a course or voluntary work to gradually build up your stamina and confidence. Realistically assess your financial position Discuss any of the above with a therapist or friend
In receipt of Income protection (IP)	Discuss the advantages and disadvantages of being on IP with family/therapist etc Discuss different alternatives with your employer (e.g., the possibility of a graded return to work) Do a course or voluntary work to gradually build up your stamina and confidence. Discuss different settlement options with your employer, e.g. redundancy package.
Other illness	Ensure that your therapist is in communication with any professional you are seeing for another illness/ problem so that they can discuss the implications of CBT etc. Discuss the effects of your other illness with your therapist, so that you can discuss strategies to overcome difficulties.

TYPE OF BLOCK	ACTION TO TAKE
Breaking through comfort zones	<p>Read the section on worry and anxiety related to chronic fatigue syndrome</p> <p>Read the section on overcoming unhelpful thinking patterns</p> <p>Discuss your concerns with your therapist so that you can agree a plan of action</p> <p>Write a list of things that you have not done for a long time and put them in order from easy to difficult. Incorporate one or two items from your list in your Activity Programme each week.</p>
Ongoing stressful situations	<p>Read section on problem solving to think about any alternative ways that you can deal with your situation.</p> <p>Plan a short daily worry time to think about how to address your problems</p> <p>Prioritise time to relax</p> <p>Utilise any relevant resources depending on your particular stress, e.g. financial advisers to discuss financial issues, landlords/ environmental health department to discuss problematic living conditions etc.</p> <p>Discuss your particular worries with a close friend or relative.</p>

Full references for all books mentioned above can be found on page 120.

WORK, COURSES AND RESOURCES

If you are considering returning to work, doing a course or finding a new job, it can be difficult to know where to start. You may not know what opportunities are available to you or you may be worried about how your CFS/ME may affect your prospects.

The Disability Discrimination Act

Many people with CFS/ME, or in recovery from it, are worried about how it may affect either their employment prospects or their current employment. People thinking about future employment are often worried that their illness record or diagnosis will be held against them. People in employment are often concerned that they will be dismissed for sick time, or for being unable to work the amount of hours they previously did, or for being unable to perform their previous duties. In fact most of these concerns are addressed by the Disability Discrimination Act of 1996.

This act defines disability as:

"a physical or mental impairment which has a substantial and long-term adverse effect on [the persons] ability to carry out normal day-to-day activities."

The definition is broad, and covers most cases of CFS/ME. "Long term" is defined as either having existed for 12 months or being likely to exist for twelve months after onset. The act also covers those who are in recovery from disability, even if they do not currently fulfil the diagnostic criteria.

What does it do?

The act is a set of guidelines which attempts to protect the recruitment and employment rights of disabled individuals. It also has clauses concerning service providers' obligations to disabled users. We will not describe these latter clauses here. A useful summary of the act is available on <http://www.disability.gov.uk/dda/> . The employment laws apply only to places where 15 or more people are employed.

Recruitment rights are protected in that it is no longer legitimate to discriminate against a job applicant because of their disability history, without justification. Disclosure of a CFS/ME diagnosis and/or related sick time is not then, in general, a legitimate basis for refusing employment, unless the potential employer, after the appropriate advice, considers that the job description is not compatible with the current degree of disability.

If one is already employed and becomes disabled, employment rights make it the responsibility of employers to make all reasonable attempts to adjust conditions of employment to accommodate the altered ability of their employee. Again, they cannot refuse to do so without justification.

The terms of the Act are not precise and are open to interpretation. Alterations of employment conditions could include deployment within the organization, alterations of existing role or change in working conditions, such as hours worked. The employer is enjoined to make any such "reasonable" adjustments. They cannot do so "without justification". What counts as reasonable and justified

Information for people who are in receipt of benefits

If you have been ill for some time you may be in receipt of benefits. However, some people are not aware that they are able to claim benefits. The information below summarizes the most common benefits claimed by people with CFS/ME.

1. *Invalidity benefit (IB) can be claimed if:-*
 - statutory sick pay (SSP) has ended or you cannot claim SSP.
 - you have paid national insurance contributions
 - you have been incapable of work because of sickness or disability for at least 4 days in a row including weekends and public holidays

2. *Income Support (IS) can be claimed:-*
 - by people on a low income
 - by people who are between age 16-59
 - by people who are not working, or work less than 16 hours a week on average

3. *Severe Disablement Allowance (SDA) can be claimed:-*
 - by people who have been unable to work for at least 28 weeks in a row because of illness or disability
 - if you have never been able to work
 - By people aged 16-64
 - If you are unable to claim IB because you have not paid enough NI contributions

If you are in receipt of benefits you may be aware that there are rules that determine how much work you can do without your benefits being affected. You may feel trapped, because on one hand you feel ready for some part time work, but on the other hand may have concerns about how your income will be affected if you return to work. A useful way of bridging the 'benefit gap' of not being well enough to work, but being well enough to do some part-time work is to consider "permitted work". Below, is some information about work rules that have recently been introduced.

New Work rules for people on Incapacity Benefit (from 8th April 2002).

Any person receiving a benefit on the basis of incapacity, e.g. incapacity benefit, severe disablement allowance, national insurance credits, income support, housing benefit or council tax benefit, will be able to work for less than 16 hours a week and earn no more than £72 a week for 26 weeks.

In addition to this, a person may be able to do one of the following:-

- Extend the above for a further 26 weeks if they are working with a Job Broker, Disability Employment Adviser or Personal Adviser who agrees that an extension is likely to improve their capacity to move into full-time work (16 hours or more a week);
- Work and earn no more than £20 a week, at any time, without a time limit
- Do supported permitted work* and earn no more than £67.50 a week without time limit

*Under the new permitted work rules, the definition of "supported permitted work" is work that is supervised by someone who is employed by a public/local authority or a voluntary organization, and it is their job to arrange work for disabled people.

This work could be done in the community or in a sheltered workshop. It also includes work done as part of a hospital treatment programme.

Eligible people undertaking work under the permitted work rules will not need their doctor's approval to do so, but they should tell the office that pays their benefit before starting work. As long as the permitted work rules are observed, their earnings will not affect their incapacity benefit and/or severe disablement allowance. However, income support, housing benefit or council tax benefit could be reduced. It would therefore be advisable to seek advice from the office that pays your benefit so that you are fully informed of your position before starting work. When permitted work is available you must apply to the benefits agency to get a permitted work form (PW1).

Income Protection (IP)

IP is an insurance scheme where usually, part of your salary is paid whilst you are unable to work. Usually, the policy is held between the employer and the insurance company. Many insurance companies are willing to negotiate a gradual return to work with part-payment until full-time work is achieved. Some insurers' are willing to pay for rehabilitation and cognitive behaviour therapy as a way of helping people to return to work. Some employer's will offer redundancy packages on health grounds.

Employment and educational schemes

Below, is a list of organizations for you to contact with regard to returning to work, finding new work, (voluntary or paid) or doing a training or educational course:

Disability employment advisors-

Disability employment advisors may be able to give advice on the following:-

- Education and training opportunities
- The best way to find work
- How any sort of work will affect your benefit entitlement
- Other welfare and benefit questions

For enquires about services in your area phone the Disabilities Services Helpline on 0800 328 4933

Work Care

Work care is a new government research initiative that aims to help people who have been off sick to return to work.

It can provide:

- Free specialist treatment
- A boost to your existing NHS healthcare with no waiting time

These are available if you have been off work due to ill health for up to 6 months, have a job to go back to, or feel unable to return to your job in the near future.

For further information call 0800 052 1659 or visit their web site at: www.workcare.co.uk

Jobcentre Plus

Jobcentre plus is a new business within the department of work and pensions. In April 2002, it replaced the employment service (which previously ran jobcentres) and parts of the benefits agency which provided services to people of working age through social security offices. It offers help in both finding work and claiming benefits under one roof.

You can get details of the areas covered by Jobcentre Plus Offices from your local Jobcentre plus, Jobcentre or social security office.

For further information visit their web site at www.jobcentreplus.gov.uk

New Deal for disabled people

New deal for disabled people is a scheme that aims to give everyone on health-related disability benefits the chance to find rewarding work. If you are interested, Job brokers will be able to give you genuine support, tailored to your individual needs. The work will not affect your benefits.

For further information call the NDDP Helpline on 0800 137 177 or visit their website at www.newdeal.gov.uk/nddp

New Deal 50 plus

New deal 50 plus is a valuable package for people aged 50 or over to help them find work. It is for people who fulfil the following criteria:

- Are aged 50 or over
- For the last six months or more:
 - have received Income support (IS), Jobseeker's allowance (JSA), Incapacity Benefit (IB) or Severe Disablement Allowance (SDA), or
 - have signed at the job centre for National Insurance Credits only, or have been in receipt of IB credits only; or
 - you have been the partner of someone who claims benefit for them.

New Deal 50 plus offers the following:

- £60 per week employment credit, tax free, paid direct to you on top of your wage for the first year you are in full time work (30 hours or more per week), or £40 per week if you are in part time work (16 to 29 hours).
- Up to £750 for training that is relevant to your job and improves your skills in the long term.
- Personal advice and a wide range of support to improve your chances of finding the right sort of job
- Advice if you want to start your own business or become self-employed

For further information call 0845 606 2626 or visit their website at: www.newdeal.gov.uk

NB: Contact your Benefits Agency or local Job centre to find out how it may affect any existing benefits that you are receiving.

Linkline

Linkline is a free telephone helpline service for adults. It provides information and advice on training, learning and work.

Linkline can help with the following:

- Information on local education courses
- Where and how to get the money you need
- How to get the right training for a new job
- Where to go to get your CV up to scratch
- Help with interview skills
- Information on training locally
- Help with job searching

For further information call 0800 0641 481

Learndirect courses and centres

Learndirect offer a variety of courses to do, either at home, if you have internet access, or at one of the many centres in the UK. They can take from 15 minutes to a few hours to complete, but because they are broken down into small chunks, you can work at your own pace.

There are over 750 courses to do in four key areas:-

- Using information technology (IT)
- Information technology (IT) professional
- Skills for life
- Business Management

For further information phone 0800 100 900 or visit the website at: www.learndirect.co.uk

Voluntary work

There are a variety of organizations that may be contacted with a view to finding out about doing voluntary work.

Timebank (020 7401 5420)

- is a national volunteering campaign.
- It offers a number of ways to get involved in your local community
- Runs a number of targeted volunteer initiatives, e.g. in sport, the environment and the arts.

Volunteering.org.uk

- is an on-line resource for potential volunteers, volunteer managers and anyone seeking up to date information on volunteering.

NCVO (National Council for Voluntary Organizations) (020 7713 6161/ www.ncvo-vol.org.uk)

- Is the umbrella body for the voluntary sector in England

Citizens Advice Bureau (CAB)

The CAB is an organization that gives free, confidential, impartial and independent advice on a wide range of subjects including employment, benefits and housing matters.

For further information contact your nearest CAB by telephoning or dropping-in during working hours Monday to Friday. They also have websites, e.g.: www.citizensadvice.co.uk

Please note that this section was correct and up to date in March 2004.

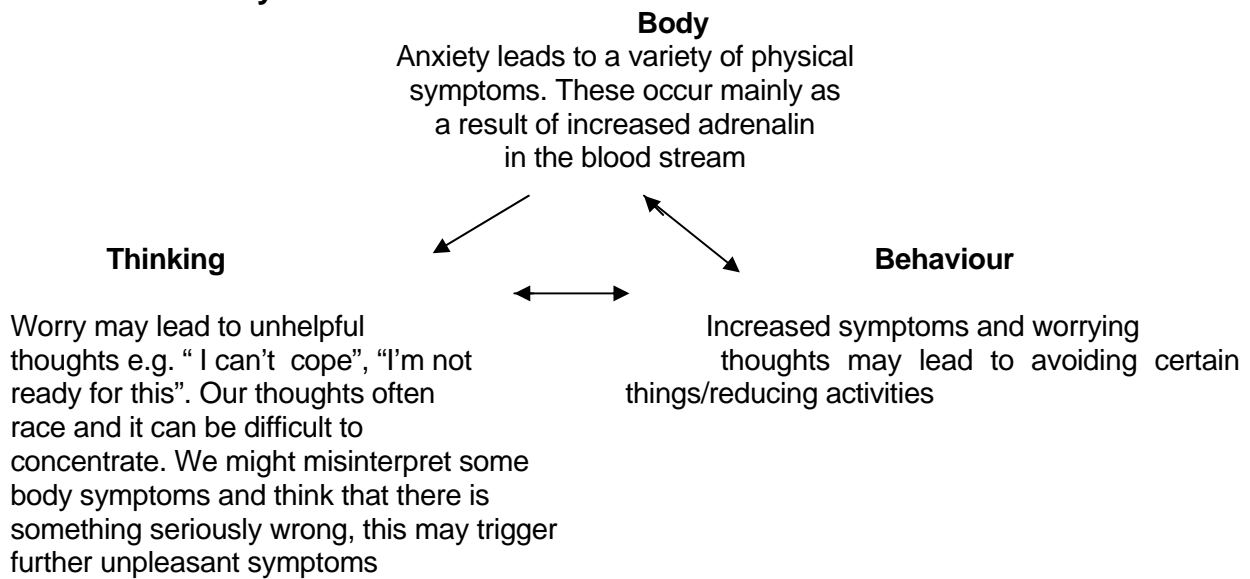
WORRY, STRESS AND ANXIETY RELATED TO CFS/ME

In the section physiological aspects of CFS/ME, we discussed how having CFS/ME (like any long-term illness) can at times be very stressful. Not only may you be trying to cope with your illness, but you may also have other concerns such as financial difficulties, or be trying to get back to work.

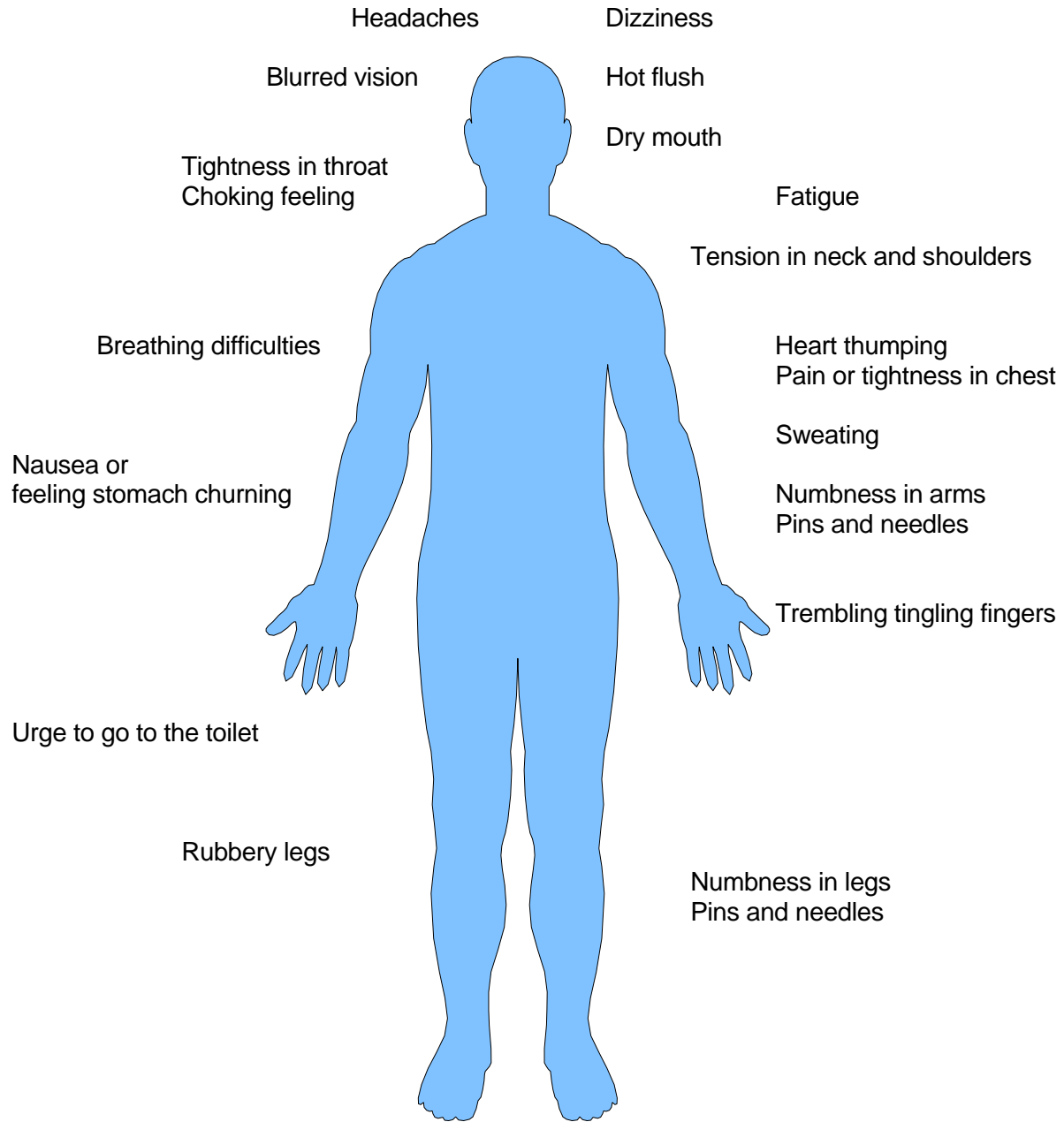
Over the past few weeks you may have started working towards a variety of targets in order to improve your lifestyle. This may have involved resuming some previous activities, such as going back to work, doing your own shopping, home management such as paying bills, travelling on public transport or meeting up with old friends again. As well as resuming some of your previous activities, you may be considering some new activities such as a course at college, a different type of job, or a new hobby.

Although you may be pleased to be in a position to start new activities or resume old ones, you may naturally feel a bit worried. Common worries include the following:- “Will I be able to do the work?”; “How will I cope with meeting new people at college for the first time when I haven’t met new people for such a long time?”; “How will I cope on the train, I haven’t travelled alone for ages?”; “How will I get on with my old friends, I haven’t seen them for such a long time?”. These worries are perfectly normal, because when we don’t practice something regularly we naturally lose confidence in our own ability to do things, and often when we try new things we are naturally apprehensive. These worries may trigger feelings of anxiety. We have already discussed some of the effects of anxiety in the physiological aspects section.

How does anxiety affect us?



COMMON PHYSICAL SIGNS OF EXTREME WORRY AND ANXIETY



Some of the feelings shown above may come on when you are extremely worried or anxious. Some may last a short time, e.g. heart thumping or breathlessness., others may persist when you no longer feel anxious, e.g. headaches, tension in neck and shoulders.

GENERAL WORRIES ASSOCIATED WITH CFS/ME

Listed below are some of the worries that people suffering from CFS/ME most commonly report:

1. Resuming previous activities/responsibilities
 - going back to work
 - managing the home
 - driving
 - making contact with old friends
2. Starting a new activity
 - a new job
 - a course at college/university
 - making new friends
3. The meaning of symptoms
 - How to interpret symptoms
 - What to do about them
 - How to get the activity level “right”
4. Giving up Benefits/Disability allowances
 - Financial concerns
 - Loss of “orange badge” for car
5. Difficulty in making decisions
6. Not knowing what to tell prospective employers
7. Feeling responsible/ blaming oneself for their illness/
effect on others.

HOW TO DEAL WITH YOUR WORRIES

STEP 1

Write any situations or activities that worry you in the space provided below.

- 1.
- 2.
- 3.
- 4.
- 5.
- 6.
- 7.

STEP 2

Look at your list and decide what you would like to tackle first. It may be helpful if you tackle the things that cause you the least worry and then you can tackle the more difficult situations as you gain confidence.

STEP 3

Decide whether **A**, **B** or **C** (below), is the best way of helping you to tackle each of your difficulties.

A Problem Solving

This is a process that can help you decide what you want and how to go about it effectively

B Exposure to situations which cause anxiety

This is a process that can help you to face situations that make you feel anxious, This may be because they are new, or because you haven't been in the situations for some time, due to your illness.

C Pie chart

This is a process that can help you to look at a problem / situation, in a more realistic way.

STEP 4

Include time to tackle your difficulties when you write your next activity programme.

(A) PROBLEM SOLVING

Problem Definition

What is your problem? Try to define it as clearly and objectively as possible

Alternative Solutions

Think of at least 3 alternative ways of solving the problem. This is important as the first solution you think of may not be the best one.

If you have difficulty thinking of any alternative solutions:

- Try to see the problem from someone else's point of view by asking the question, "If ----- was in my shoes, what would he or she do?"
- Use the point of view of someone that you feel has dealt well with a similar problem, or someone you feel is good at solving problems.
- Try to think how you solved a similar problem in the past

Evaluate Alternative Solutions

Once you have thought of as many alternative solutions as possible, the next step is to evaluate the possible outcome(s) of each one. Do this by writing down what you think the *positive* and *negative* consequence(s) of each of your alternative solutions might be.

Making a Decision

Now that you have considered the possible outcome of each solution, it is time to make a decision on which solution to the problem seems to be the best. It may be helpful to consider the following:

Is it achievable?

Make a Plan and Implement the Solution

This stage will vary according to the type of problem you are trying to solve. It may be that no planning is needed as it just involves saying something to someone, on the other hand, you may need to make a detailed plan.

Evaluate your Plan and Alternative Solution

Once you have tackled your problem by putting into action your chosen "Alternative Solution", ask yourself the following questions:

Did you follow your proposed plan in tackling the problem? (if you made one)

Did the outcome that you expected to occur, happen?

Are you satisfied with the outcome?

Would you use the same strategy(s) again?

Please see an example on the next page, followed by a blank copy for your own use

PROBLEM DEFINITION

Worried about how I will cope at college, whether I will be able to keep up with the work.

ALTERNATIVE SOLUTIONS

(Think of at least 3)

1. Speak to Tutor about my problems

EVALUATE SOLUTIONS

(What is a possible outcome of each alternative solution?)

May help my Tutor to understand my difficulties and be sympathetic if I am unable to meet deadlines. But it may make me feel different to others. Do I want that?

2. Put off course for a few months

Although I may feel a little better I may not be that much better, and I would still have to face the problem at some time.

3. Ensure a well- balanced programme with planned study time and a mixture of activities and relaxation

This will ensure that I work steadily at my course work as well as have time for other activities and relaxation. Be prepared to be more tired initially

CHOOSE THE BEST SOLUTION

Ensure a well balanced programme with planned study time and a mixture of other activities and relaxation.

MAKE A DETAILED PLAN

Find out at college how much course work I will be expected to do each week/term.

Review my current Activity Programme and include regular time for studying. Try to study for short, but frequent times rather than long occasional times.

Ensure that my programme includes a mixture of activities with relaxation time.

EVALUATE YOUR PLAN

It will not be immediately clear whether your solution was the best one as it is likely that you will be more tired initially when you start your course (as with any new activity). Review the situation after a couple of weeks and amend your activity programme, if necessary.

If after a month, you feel you are struggling, then it may be helpful to discuss your difficulties with your Tutor.

PROBLEM SOLVING

PROBLEM DEFINITION

ALTERNATIVE SOLUTIONS

(Think of at least 3)

1.

2.

3.

4.

EVALUATE SOLUTIONS

(What is a possible outcome of each alternative solution?)

1.

2.

3.

4.

CHOOSE THE BEST SOLUTION

MAKE A DETAILED PLAN

EVALUATE YOUR PLAN

(B) EXPOSURE TO SITUATIONS WHICH CAUSE ANXIETY

If you have CFS/ME, it is possible that you may have got out of the practice of doing certain things. If you don't practice things regularly you may lose confidence in your self.

We have all been in situations where we have felt initially anxious. For example:- Our first day at school, getting married, attending interviews etc. However, after a few minutes of

being in an anxiety provoking situation, we usually start to feel better and are able to concentrate on the matter in hand. That is because anxiety comes down naturally over time.

Exposure Therapy

This can be a very effective way of overcoming anxiety. It involves confronting situations that make you feel anxious repeatedly, until the anxiety subsides.

The following guidelines will hopefully help you to overcome anxiety in particular situations.

1. Write a list of all the situations that cause you anxiety.

Write them in order from the least difficult to the most difficult and start with the easiest thing on your list.

2. Plan specific tasks to do at regular times and as frequently as possible.

This obviously depends on “the situation” that makes you feel anxious, some situations are more accessible than others.

Phone a friend for 15 minutes x 3 per week

Go into a crowded shop for at least ½ hour x2 weekly.

3. Stay in the situation until your anxiety subsides.

Although feeling anxious is uncomfortable, it is not harmful. Do not leave the situation until your anxiety goes down and you feel a little better.

4. Expect to feel anxious

When confronting situations that you have not entered for some time, it is likely that you will feel anxious for a while. Wait and give these feelings time to pass. Remember that these feelings are nothing more than an exaggeration of quite normal bodily reactions to stress.

5. Keep a record of your “Exposure Tasks”

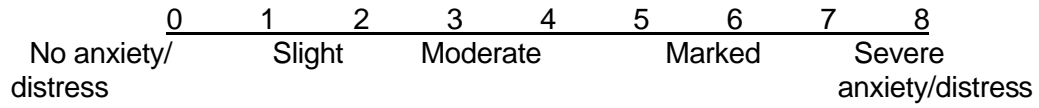
This will enable you to keep track of your progress with facing “difficult “ situations. Over time you will hopefully notice a decrease in the level of your anxiety and be in a position to move on to the more difficult things on your list.

A blank exposure task record may be found on the next page

EXPOSURE TASK RECORD

Name:

Please record your activities and rate how "anxious" you feel before, during and after each "exposure" task, using the scale below.

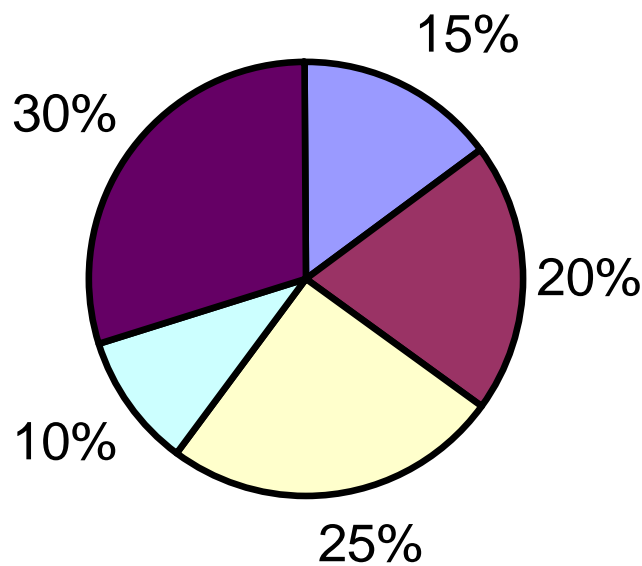


Date	Time Start/Finish	Task	B Before	D During	A After	COMMENTS

(C) PIE CHART

If you are focusing on a negative aspect of either yourself or a situation, it can be helpful to think about all the factors that may be involved. For example, if you feel responsible or blamed for something, it can be worth thinking about other factors or people that may have affected the outcome. You can then make a list and allocate them percentages.

Example: A project at work is delayed and I feel that it is all my fault.



Listed below are all the people and their respective involvement in the project

- 15%** Engineers - didn't repair the photocopier when asked
- 20%** Colleagues - didn't complete the work for the project on time
- 25%** Boss - was unrealistic about the time to complete the project.
- 10%** Secretary - didn't check for typographical errors, therefore amendments needed to be made.
- 30%** Me - I could have checked on the progress of the respective individuals sooner.

Conclusion: **Although the project went wrong, I can see that I didn't hold total responsibility**
MANAGEMENT OF SET-BACKS

There may be times when you have a set-back, i.e. you have an increase in symptoms for more than a day or two and are unable to maintain your levels of activity. A set-back may occur when you are working through this manual with your therapist, or when you have completed your course of cognitive behaviour therapy. At these times, you may feel that you are sliding backwards and are returning to 'old patterns', e.g. resting in response to symptoms, sleeping in the day, or overdoing it when you have a bit of energy. You may feel despondent and be uncertain about what to do for the best.

It is important to recognise that a set-back cannot always be avoided, but it can be dealt with quite easily. The important thing is to be able to recognise a set-back if it occurs, and to tackle it by taking some positive action.

Triggers

Set-backs can occur for no particular reason, but there are times when they are more likely to occur; for example:

- If you get an infection or another illness.
- If you have any fairly major life events. e.g, moving house, a bereavement, changing jobs, getting married or divorced.
- If you have a number of important deadlines to meet, e.g at work, college.
- If your mood is depressed.
- If you stop using the techniques described in this manual and resume old patterns of behaviour.

The situations listed above can increase fatigue and limit the opportunities to continue regular planned activities and relaxation.

HOW TO TACKLE SET-BACKS

Although having a set-back may seem a disaster at the time, it can help you to understand your CFS/ME better and enhance the way that you deal with it in the future. Most people overcome their setbacks quite easily and go on to make further progress. The important thing is not to panic!

1. If you have a temperature or another illness on top of your CFS/ME, it is important that you increase your rest for a day or so, ie until your temperature returns to normal. Do not be tempted to rest for longer, or until all of your symptoms subside, as this may prolong your recovery.
2. Try to nip your problems in the bud as soon as you realise that you are not managing so well with your programme as it will then take you less time to get back "on track" again.
3. Prioritise your activities: If you do not have time to carry out your programme or do not feel able to do so, do not give up, but modify it, until you can get back on track again.
4. Remember to balance your days as much as possible in terms of work and relaxation.
5. Are you asking too much of yourself at the present time? Lower your expectations and praise yourself for any achievements.

6. Discuss your concerns with your therapist at your next session.

A few extra points to consider if your cognitive behaviour therapy sessions have ended:-

1. Go back to basics. Review all of the information in the manual, particularly 'Planning Activity and Rests'.
2. It may be worth keeping an activity diary and a sleep diary (if this is a problem) for a week, to identify your patterns of activity, rest and sleep.
3. Based on the information in your activity diary and sleep diary, construct a basic programme to tackle the problem areas. Ensure that you plan manageable chunks of a variety of activities, with regular relaxation/rest periods.
4. In order to monitor your progress, you may like to record your activities on a target achievement record or activity diary for a few weeks.
5. If you continue to have problems overcoming a setback after trying these methods, contact your therapist.

PREVENTING SET-BACKS

During your sessions of CBT, you will have hopefully learned ways to reduce and manage your CFS/ME problems better. However, there are times when managing your fatigue will be more difficult than others. In order to try to prevent set-backs from occurring it may be helpful for you to complete the following section.

Can I identify any warning signs that make my CFS/ME worse?

What steps do I need to take if I find myself getting into difficulties?
(Please refer to the section on Set-Backs)

PREPARING FOR THE FUTURE

Hopefully this manual and your sessions of cognitive behaviour therapy will have helped you to find some useful ways of managing your CFS/ME and you will be well on your way to recovery. We hope that you will feel equipped with the necessary skills to conquer any remaining problems once your sessions have ended. After all, progress made up until now, is through your own efforts.

Sustaining and building upon improvements

- Many activities that were initially part of your programme are now likely to be part of your daily routine. It is important that they remain so, otherwise there is a risk of sliding backwards.
- If you have targets that you are still working towards, it may be helpful to continue to set yourself an activity programme every week or fortnight, until they have been achieved. This will help you to remain focused on building upon the improvements that you have already made.
- In order to track your progress, you may find it helpful to continue to keep some sort of record. It is not necessary for you to continue to complete activity diaries or target achievement records unless you find them particularly helpful.
- **On page 116, you will find an example of a record that tracks your progress and requires less writing (record of progress), followed by a blank one for you to photocopy.**

Making changes to your lifestyle

Making changes is an important part of sustaining a lasting improvement. If you don't capitalise on your gains you will find that they evaporate. It is therefore important to set yourself realistic and achievable targets in order to help you to continue to improve your health and lifestyle.

If you have been ill for a long time, not only may you have stopped many activities e.g. working and socializing, but other people may have taken over some of your previous responsibilities, for example, shopping, cooking, paying bills, DIY etc. If this is the case, then re-adjusting to your previous life can be an alarming prospect. The important thing is to remember to take things gradually, and if necessary, to break them down into manageable steps.

The following guidelines will help to reduce your fatigue, and increase your overall energy levels.

1. Make sure that your lifestyle is balanced between a mixture of different kinds of activity and relaxation.
2. Include an hour for yourself each day to do exactly what you *want* to do.
3. Ensure that you have regular short breaks when you are working/studying/looking after children etc.

4. Try to ensure that you maintain a regular sleep pattern, by going to bed and getting up at a similar time each day. An optimal amount of sleep is different for everyone; 8 hours is about average.
5. Aim for at least 30 minutes exercise twice a week.
6. Prioritise your activities if you find yourself doing too much.

Insert completed record of progress

Insert blank record of progress

EVALUATION OF PROGRESS

By the time that you come to this section of your manual, you will hopefully be feeling a little better and more able to manage your CFS/ME problems. As part of your course of CBT, you will be asked by your therapist, to complete this page before your last session.

Please complete the following sections in as much detail as possible.

1 a. What have I learned about CFS/ME?

b. What factors may have preceded my CFS/ME?

(e.g. constantly being busy, recurrent infections; aiming for perfection etc)

c. What factors may have contributed to my CFS/ME problem continuing?

(e.g. an erratic sleep pattern, long periods of activity followed by long rests \ etc)

2. What strategies have I found helpful from my CBT sessions?

(e.g, having regular breaks, going to bed at a set time, challenging unhelpful thoughts, etc)

3. What areas do I still need to work on?

(e.g, Targets for treatment I have not yet achieved; resting at regular times; cognitive work etc)

Please turn to the next page to plan targets that you would like to work towards over the next 3 months

TARGETS FOR MY BOOSTER SESSION

Please write the targets you plan to work towards during the next 3 months.

Write a detailed plan of how you aim to work towards your targets

FURTHER READING

Coping with chronic fatigue: Trudie Chalder (1998), Sheldon Press

Feeling Good: David D. Burns (1999), Avon Books.

When perfect isn't good enough; Strategies for coping with perfectionism: Martin M. Antony & Richard P. Swinson (1998), New Harbinger Publications.

Asserting yourself; A practical guide for positive change: Sharon A. Bower & Gordon H. Bower (1991, second edition), Perseus books.

A woman in your own right: Anne Dickinson (1982), Quartet Books.

Overcoming low self-esteem: Melanie Fennell (1999), Constable & Robinson.

Mind over mood: Dennis Greenberger & Christine Padesky (1998), Guilford Press

Overcoming anxiety; A self-help guide using cognitive behavioural techniques: Helen Kennerley (1997), Constable & Robinson

INFORMATION FOR RELATIVES, PARTNERS AND FRIENDS

It can be extremely helpful to people suffering from chronic fatigue syndrome (CFS) / myalgic encephalitis/encephalopathy (ME) to have someone who understands a little about their problems and the way in which they are trying to tackle them.

The purpose of the following information is to give you:-

- Some basic facts about CFS/ME
- Information about what the person may be doing when they attend sessions of cognitive behaviour therapy with a therapist
- The ways in which you can help them to get the best out of this manual.

FACTS ABOUT CFS/ME

What is CFS/ME?

Fatigue is something we all experience from time to time. It often develops after an infection and tends to be present when life is very busy and stressful.

Chronic fatigue syndrome (CFS), also known as or myalgic encephalitis/encephalopathy (ME) or post viral fatigue syndrome is a condition which affects people in different ways. The main symptom that affects all sufferers is persistent fatigue, which can be severe and disabling leading to a restricted life-style. Other associated problems may include painful muscles and/or joints, sore throats, headaches, dizziness, poor concentration and memory loss. Problems with sleep are common, for example; sleeping more during the day; having difficulty in going to sleep at night; and waking frequently. Sleep is seldom refreshing.

Fatigue will differ greatly between individuals. As a result of fatigue, and the other symptoms listed above, people's lives are generally restricted. This varies from people feeling so exhausted that they remain in bed most of the time, to people who are able to carry out activities for most of the time, but who become so exhausted at other times that they are unable to do anything.

What causes CFS/ME?

There has been a lot of speculation of different causes of CFS/ME, but it is unlikely that a single one will ever be identified. However factors which may be associated with the onset are described below.

- An initial illness or a series of infections is often reported as the start of CFS/ME.
- Fatigue can develop in association with a "busy" or "stressful" lifestyle, whether at work or at home.
- Stressful life events such as bereavements, moving house, changing jobs, getting married, pregnancy, ending a long-term relationship may lead to increased vulnerability to infections and/or fatigue.

- Having high personal expectations and driving to do things “perfectly” can be frustrating, cause despondency and fatigue

What keeps CFS/ME going?

People often ask why the CFS/ME keeps on going, months or maybe years after the person first became ill. Some of the reasons are listed below.

- Resuming normal activities too soon after an initial infection may sometimes delay recovery.
- Resting too much once an initial infection has subsided can cause its own set of problems. The body becomes out of condition quite quickly; the muscles, immune system and nervous system being particularly adversely affected. The problems which may ensue include:- muscle weakness, being more prone to illness, feeling sluggish with poor memory and poor concentration.
- Alternating over-vigorous exercise with resting for long periods can inadvertently make the problem worse in the longer term, as the body does not get used to a consistent pattern of activity or rest.
- An irregular bed-time or getting up time or resting too much in the day, may contribute to disturbed and unrefreshing sleep at night. Not sleeping well at night is likely to increase feelings of fatigue and other symptoms.
- Worries about activity making the illness worse may lead people to stop or reduce certain activities. This may lead people to feel frustrated and demoralised due to a changed lifestyle.
- Receiving advice from a variety of sources can lead to confusion, particularly if the advice given differs.
- The debilitating effects of CFS/ME can lead to other problems e.g. financial difficulties, reduced social contacts or changing roles within the family. These difficulties can understandably trigger feelings such as frustration, and helplessness. These feelings which are a natural human response to stress, can lead to low mood for some people and depression in others. Low mood can lead to a variety of problems including tiredness, which can further reduce the desire to be active.

COGNITIVE BEHAVIOUR THERAPY FOR CFS/ME

What is cognitive behaviour therapy?

Cognitive behaviour therapy (CBT) is a powerful and safe treatment which has been shown to be effective in a variety of illnesses, including CFS/ME, headaches and back pain. The aim of treatment is to change certain behaviours and cognitive factors, which are assumed to be partially responsible for perpetuating the symptoms and disability associated with CFS/ME. It also aims to help people to develop strategies for dealing with other factors-physical, emotional, social or financial- that may also be impacting on their illness.

Many people have successfully overcome CFS/ME using cognitive behaviour therapy, and have maintained and consolidated their improvement once treatment has ended

What does CBT involve?

Treatment is fairly structured and involves people attending regular appointments. Initially, sessions will be weekly, for a few weeks, then fortnightly. Each session lasts for about 50 minutes other than the first appointment which will last for 1 ½ hours. All sessions involve a review of progress, discussion of any difficulties and homework plans are agreed. Specific techniques are introduced as and when necessary.

Early sessions

In the first couple of sessions, a detailed history of the person's problems is taken. They will then be asked to keep a record of their activities in an activity diary and record details of their sleep in a sleep diary. This information will help to establish their current levels of activity and sleep pattern.

Planning a programme of consistent graded activity and planned rest

Once their current level of activity and rest has been established, a planned programme of consistent graded activity and planned rest will be devised, which will be carried out each day. The activity programme is carefully planned to ensure that it is manageable on "good" and "bad" days. This is important in the process of helping people to change their behaviour by doing things *consistently* rather than doing things or not doing things in response to how they feel.

The programme may initially consist of everything that they are currently doing, but put in to a different order to allow for planned rests, rather than rests when they *feel* they need them.

Middle sessions

Once the person is managing a consistent pattern of activity and rest, they will start working towards a variety of personal targets that they will have chosen at the beginning of treatment. They will gradually increase their activity levels to work towards each of their targets. Rest periods will be gradually reduced as their tolerance to activity increases. They will be encouraged to come up with their own ideas for their activity programme.

Cognitive Therapy

When they are managing their programme of consistent graded activity and rest, the second part of CBT is usually introduced, this is called cognitive therapy. Chronic illness, such as CFS/ME often leads people to feel demoralised, helpless, hopeless and frustrated. These feelings can lead to unhelpful or negative thinking patterns which in turn affects how people behave. Cognitive therapy aims to help people to examine their “unhelpful” or “negative” thoughts and then to challenge them by thinking of a more helpful alternative one. This part of CBT is important as unhelpful thoughts may block recovery.

Tackling other problems

Any other problems that were identified at assessment would be tackled during the middle sessions, e.g., employment issues.

Last few sessions

They will continue relevant work from earlier sessions.

Preparing for the future

To ensure that they are in a position to make further progress when their CBT sessions have ended, the following will be discussed:-

- How to manage a setback (if one should occur)
- A plan for 3 months until their booster session
- Ways of monitoring their progress (e.g. keeping a record of progress, including a regular time each week for reviewing and planning).

Booster session

After treatment has ended, they will have a booster session after 3 months. This appointment is used to evaluate progress, discuss any difficulties and discuss their plans for the future.

Homework

The success of treatment depends upon “homework”, which involves carrying out specific tasks regularly. They will be asked to keep an activity diary in which to record details of what they are doing each day. As treatment progresses, they may start using a target achievement record instead. They will bring their diaries to each appointment. These diaries are important as they help therapists to evaluate progress and are useful in determining any areas of difficulty that they may be having with their homework.

HOW CAN YOU HELP?

If you are close to someone with CFS/ME who is participating in a CBT treatment programme, your understanding and support can be extremely helpful in aiding them to get better.

- 1 Discuss with the person their views on how they best feel that you can help them. It may be that they want you to be significantly involved, on the other hand they may want to get on with it by themselves.
- 2 Take time to read the information in this leaflet, so that you understand what CBT is all about.
- 3 Give praise for any achievements that the person makes, as this is likely to help them to recognize that they are improving. Achievements may be very small, for example getting up 15 minutes earlier each day, walking 5 minutes twice daily, not sleeping during the day, reading the paper for 10 minutes daily etc. All achievements however small they appear, are signs of improvement.
- 4 Encourage all efforts that the person is making in relation to their programme, whether it is doing a particular homework activity, filling in their activity diaries, or reading information given to them by their therapist. Although CBT is often helpful, it can be time consuming and require a lot of effort, therefore, the more support given the better.
5. When the person has started to do the “cognitive” part of treatment, they will be initially trying to identify unhelpful thoughts. Examples include thoughts like:- “I will never get better”; “I should be able to do more”. Once the person is able to identify these unhelpful thoughts, they will learn to challenge them and try to think of more “helpful” or “positive” alternative thoughts. You may be asked to point out when they say something “negative” or “unhelpful”. Challenging unhelpful thoughts can at times be difficult, particularly when someone is feeling a bit down. Point out what they have achieved so far and remind them that they can overcome the illness by persevering and the small step by step achievements are the key to success.

Please also consider the following points:

- When starting CBT, people often notice an increase in their symptoms. This is usually temporary and occurs as a result of changing their patterns of activity and rest. Encouragement and support at this time is particularly necessary as they may (understandably) feel like reducing their activities in response to an increase in symptoms. It is important to stress that any increase of symptoms is both a normal and temporary side effect that occurs because they are doing more. Persevering with the programme is to be encouraged as people usually find that their symptoms gradually decrease and they are able to do the activities with less discomfort and then increase what they are doing.

- Sometimes people with CFS/ME want to do too much, this usually occurs on “good” days when they are feeling better. It is important at these times to encourage them to stick to their programme, as doing too much and not taking planned rests can lead to an unacceptable level of increased symptoms, delay progress and lead to a relapse.
- If the person wants you to be actively involved in their programme, it may be helpful for you both to set aside a regular time each week in which to discuss how they are getting on. This will give you the opportunity to reinforce their achievements, give encouragement when they are having difficulties and discuss any worries that you have in relation to their programme. It is important that you approach any concerns about their programme, whether you think they are doing too much or too little in a “non judgemental “ manner.
- Setbacks can occur at any time. They are a “blip” in the recovery phase and certainly do not mean that CBT has failed. Setbacks are more likely to occur in certain situations, for example if the person has another illness, moves house, has a bereavement, or has a number of deadlines to meet. These “stressful” situations may give rise to increased symptoms and an inability to maintain their programme. At these times, it is important to remind the person that setbacks are only temporary. Encourage them to read the appropriate sections of the manual in order to get back on track again. Setbacks should be viewed as a challenge to be overcome and not a disaster. If a setback occurs after the person’s CBT sessions have ended, then encourage the person to devise a small programme for a few weeks. or until they feel they are managing better.
- By the time that people are discharged from cognitive behaviour therapy, they will hopefully be able to do more and need less rest. It is important to encourage them to continue with a balance between different kinds of activities and rest. Breaking this routine or stopping certain activities or resting at irregular times may lead to a risk of sliding back. As long as a good balance of activity and rest is maintained, then recovery will be sustained. They may gradually make quite substantial changes to their lives, e.g. returning to work, starting college, taking over household responsibilities. Making these changes although sign of progress can be quite frightening, particularly if the person has been ill for some time. Your support and understanding will probably be appreciated.
- If you have any major worries about the programme that cannot be resolved between you, ask if you can attend an appointment with your partner/relative/friend.

