



Manual for Therapists

COGNITIVE BEHAVIOUR THERAPY for CFS/ME

Mary Burgess, Trudie Chalder

NB This manual was used in the PACE trial by healthcare professionals to support Cognitive Behaviour Therapy (CBT) and is available free of charge for down-loading at www.pacetrials.org, so long as no changes are made. Any use of this manual should acknowledge the PACE trial (www.pacetrials.org). This treatment should only be delivered by appropriately qualified healthcare professionals, who have received appropriate training and continued supervision in the use of CBT. The treatment described was not designed to be a stand-alone self-help approach. No responsibility is accepted by the authors for the application of CBT described in this manual outside of the PACE trial. The PACE trial team are unable to respond to queries or comments regarding the use of this manual or the treatment described.

ACKNOWLEDGEMENTS

We thank the following for their comments and contributions to the CBT therapists' manual: Jessica Bavinton, Diane Cox, Vincent Deary, Michael Sharpe, Bella Stensnas, Sue Wilkins, Giselle Withers, and Peter White.

Contents

Page

4.	Glossary and abbreviations
5.	Introduction
6.	Understanding CFS/ME
7.	Background
8.	Treatments to be compared in the PACE trial
16.	Summary table of supplementary therapies
17.	Cognitive behavioural model of understanding CFS/ME
21.	A cognitive behavioural approach to CFS/ME
22.	Aim of cognitive behaviour therapy
24.	Therapist Preparation
25.	An overview of treatment sessions
27.	General points to ensure adherence to protocol
28.	Distinguishing between APT, CBT and GET
30.	Supervision issues
31.	Knowledge and skills required
35.	Engaging the participant in treatment: Do's and Don'ts
36.	How to structure treatment sessions
37.	Discussing what is required of the participant
38.	Assessment issues
52.	Explanation of the cognitive behavioural model
56.	Helping participants to become their own therapist
57.	Involving a relative or friend as cotherapist
59.	How to set long-term targets
60.	Behavioural experiments
63.	Managing potential difficulties
73.	Treatment session plans
74.	A summary of session contents
79.	Session action plans
106.	References
108.	List of appendices

GLOSSARY AND ABBREVIATIONS

CBT	Cognitive behaviour therapy
CFS	Chronic Fatigue Syndrome
DNA	Did not attend
EBV	Epstein-Barr virus
IP	Income protection
ME	Myalgic encephalomyelitis/encephalopathy
PACE	Pacing, Activity, Cognitive behaviour therapy: a randomised Evaluation

INTRODUCTION

The aim of this manual is to describe the process of cognitive behavioural therapy (CBT), as applied to participants with chronic fatigue syndrome (CFS) and myalgic encephalitis/encephalopathy (ME). It provides a description of what should be covered in each session. It also covers some of the more subtle issues related to the therapeutic process, which if overlooked could result in non adherence on the part of the participant.

A copy of all of the records that both the therapist and the participant will need to complete during CBT can be found in the appendices. The page number of each appendix can be found on page 108.

A manual has also been written for the participants of this trial. It contains all of the information that you will be covering with them during their course of CBT. It also contains blank diaries that can be photocopied, if necessary, between sessions.

Any comments or suggestions of how to improve this manual would be gratefully received.

UNDERSTANDING CFS/ME

This section aims to help you to understand the basics of CFS/ME. It also illustrates the differences between treatments offered in the PACE trial and finally outlines the CBT approach.

It contains the following:-

- Background information about CFS/ME
- Summary of different treatments
- A cognitive behavioural model of understanding CFS/ME
- CBT approach to CFS/ME

BACKGROUND

What is Chronic Fatigue Syndrome (CFS) Myalgic Encephalomyelitis/Encephalopathy (ME) (CFS/ 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 similar or identical conditions. For brevity we will consider them together here as CFS/ME.

What are the symptoms?

Common to these illnesses are the 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 patients 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, anaemia and severe depression) and medical and psychiatric assessments are required to exclude these other conditions. The term CFS/ME has been reserved for patients in whom characteristic fatigue and other symptoms cannot be explained by other diagnoses.

What is the cause?

No specific cause for CFS/ME 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 patients with CFS/ME. It is possible that different factors apply to different patients.

TREATMENTS TO BE COMPARED IN PACE TRIAL

Short title of trial:

Pacing, graded Activity, and Cognitive behaviour therapy; a randomised Evaluation

Long title of trial:

A randomised controlled trial of adaptive pacing, cognitive behaviour therapy, and graded exercise, as supplements to standardised specialist medical care versus standardised specialist medical care alone for patients with the chronic fatigue syndrome / myalgic encephalomyelitis or encephalopathy

The aim of this trial is to compare four forms of management, all of which may be regarded as forms of pacing; standardised specialist medical care alone and standardised specialist medical care plus one of three forms of supplementary therapies that all involve activity management in patients with CFS/ME.

All three supplementary therapies and specialist medical care have been variously described. We have standardised each of them for the purpose of the trial by focussing on what are the theoretical basis and core features of each intervention. The aim is to make them both optimal treatments and clearly distinct.

Standardised specialist medical care

All participants will receive this treatment.

Essence

The essence of SSMC is good quality medical care. SSMC does not involve advocacy of a particular form of management or therapy and advice given will be compatible with any therapy that the participant is receiving (APT, CBT, GET or SSMC alone). SSMC alone does not involve seeing the participant on a frequent basis to deliver a version of one of the therapies in the trial (APT, CBT and GET).

Aim

The aim of SSMC is to provide an optimal supportive medical relationship, to offer advice regarding symptom relieving medication, to support basic self-management and co-ordination of care.

Theoretical Model

The assumption of SSMC is agnostic to the nature of the cause and best treatment of CFS/ME. It assumes that participants are able to improve with a combination of validation of their illness experience, simple advice, prescribed medications and time (with or without an additional supplementary therapy).

Procedure

There is a manual to guide the doctors in the provision of SSMC. The participant is given a diagnosis, accurate information and advice (within the limits of our knowledge) symptomatic medication and a therapeutic relationship with an empathic understanding doctor. A positive diagnosis of CFS/ME is made and an explanation of the condition that is consistent with the Patient Clinic Leaflet. The participant is given general advice on managing activity, stress and coping with the illness that is consistent with the Patient Clinic Leaflet:

- *Avoid extremes of activity.* Many people with CFS/ME get into a pattern of being very active and then very inactive. It is better to give yourself a pattern of activity that you can keep going. This may be a lower level of activity than you are used to.
- *Set a daily level of activity.* It will help to set a simple level of activity that you do every day. Stretching exercises, for example, will minimise the weakening effects that creep up if you don't use your muscles for a time.
- *Make only gradual changes to your activity level.* If you feel you can increase your level of activity, and not everyone does, make changes carefully and gradually. A sudden increase in activity may make your symptoms worse.

- *Try to reduce stress in your life.* When we are ill, stresses such as excessive work demands don't help us. If you can reduce these stresses, it will help you recover.

Should a participant ask for advice on how to manage their day to day activities in a particular way that is consistent with one of the supplementary therapies, and they are receiving SSMC alone, then the doctor can use the Patient Clinic Leaflet as a means to provide an overview of the general principles of such an approach, and can mention that there are self-help books and guides available. If they are already in a supplementary therapy arm of the trial, they should be advised to discuss this with their therapist, so long as they have not completed their therapy.

Medication may be prescribed for specific symptoms (such as simple analgesia, hypnotics and antidepressants) if agreed and indicated. Whilst SSMC may include referral to other doctors or healthcare professionals (such as a dietician for weight reduction or an orthopaedic surgeon for back pain) if there is a clear clinical need. It does not include the referral of the participant to other therapists for treatment of the CFS/ME itself, including those delivering therapies similar to those being evaluated in the trial (APT, CBT and GET).

Delivery

The administration of SSMC in this trial will be by a trained doctor who has had training in the SSMC manual and specific experience and training in treating patients with CFS/ME.

Simple, non-Incremental / Adaptive Pacing Therapy (APT)

This is a strategy widely used and described for patients with pain and advocated for patients with fatigue. It has however been subject to little systematic evaluation. Many patients report it to be helpful, however, and it has been recommended by a recent Government working party as one of the treatments of choice for CFS/ ME.

Essence

The essence of simple pacing is the monitoring and planning of activity with the aim of balancing rest and activity in order to avoid exacerbations of fatigue and other symptoms.

Aim

To stabilise the symptoms and activity with the anticipated benefit of: (a) maximizing what can be achieved within a limited amount of energy; (b) preventing exacerbation of symptoms and disability; (c) enabling participants to plan activities; (d) providing the best environment for the body to naturally recover; (e) allowing gradual increases in activity as the participant feels able.

Theoretical Model

The assumptions of simple pacing are that it is beneficial to stabilise activity and to balance rest with activity. An analogy of balancing the energy “account” to avoid overdrawing it is often used. Symptoms are regarded as warning signs to be “listened to”. It is assumed that the symptoms reflect a pathological disturbance, which is not reversed by undertaking increases in activity. Rather the assumption is that ignoring fatigue and other symptoms risks activity induced exacerbations of the illness and consequently impeding natural recovery, whereas good pacing will maximize the chance of natural recovery and hence improve function in the long term. Activity is therefore planned so as to balance activity and rest. The aim is to maximise what can be done on the one hand but to limit activity related exacerbations of symptoms on the other.

Procedure

The manual includes the following components: (a) The participant is helped to monitor their activity and their energy using simple self-ratings. (b) By learning about the relationship between what they do and how they feel, the participant is more able to plan their pattern of rest and activity; (c) The process is an iterative one whereby level of energy and other symptoms and activity are monitored; activity is planned and then modified in the light of its effect on symptoms. (d) The participant is encouraged to do as much as they are able within the limits imposed by their knowledge of what risks exacerbating symptoms.

Delivery

The administration of adaptive pacing therapy in this trial will be by occupational therapists who will have had training in the therapy manual and specific experience and training in applying the therapy to patients with CFS/ME.

Complex Incremental Pacing /Cognitive Behavioural Therapy (CBT)

This is the most complex treatment. It involves elements of simple pacing to stabilise activity, graded increases in activity, as with simple incremental pacing, and also directly addresses participant's beliefs and fears about their symptoms and functioning. CBT differs from GET by directly targeting cognitions and related behaviours and it differs from APT by encouraging the participant to extend their physical functioning beyond their current ability.

Essence

The essence of CBT is helping the participant to change their interpretation of symptoms and associated fear, symptom focussing and avoidance. Participants are encouraged to see symptoms as temporary and reversible and not as signs of harm or evidence of fixed disease pathology. In this way it is anticipated that they will gain more control of their lives, as they, and not their symptoms, dictate what they do.

Aim

The aim of this treatment is to change the behavioural and cognitive factors, which are assumed to be partially responsible for perpetuating the participant's symptoms and disability, and to help the participants to develop strategies for dealing with other factors, physical, emotional, social or financial, that may also be impacting on their illness.

Theoretical Model

The model emphasises the importance of the participant's understanding of their illness and their interpretation of symptoms. For example they may interpret symptoms as a warning sign to reduce activity. Fear of symptoms and consequent avoidance of activity

associated with symptoms is central. This model also acknowledges that the participant's beliefs and behaviours are influenced by available information and attitudes of families and friends and that these may also need to be addressed. The model assumes that physiological (fatigue), cognitive (fear of engaging in activity) and behavioural responses (avoidance of activity), are linked. Therefore by modifying one response it is anticipated that changes occur in the other responses. For example, increasing activity (behaviour) may gradually reduce the fear (cognitions) that activity leads to worsening of symptoms.

Procedure

The manual has the following components: Initial stabilisation of activity and rest, establishing a regular sleep pattern and then graded increases or changes in activity to work towards planned goals. CBT also actively addresses the participant's understanding of their illness which may involve challenging unhelpful beliefs, e.g., about symptoms or activity that may be preventing recovery.

Delivery

The administration of CBT in this trial will be by a trained therapist, usually a mental health professional, who has had training in CBT and specific experience and training in applying CBT to patients with CFS/ME.

Simple Incremental Pacing /Graded Exercise Therapy/ (GET)

GET involves the basic element of simple pacing to stabilise the participant's physical activity, followed by gradual and planned increases in physical activity or exercise, leading towards an increase in the ability to undertake physical exercise and activity. GET differs from CBT by not directly targeting cognitive factors and from APT by encouraging the participant to extend their physical functioning beyond their current ability.

Essence

The essence of GET is to help the participant to gradually engage and participate in physical activity and aerobic exercise. It involves a careful assessment of the participant's current physical capacity, and mutual negotiation of meaningful functional, physical goals. A baseline of physical activity is agreed and commenced, at a manageable low level of intensity. The duration of the physical activity/exercise is then increased slowly and carefully, at the right time for each participant. Once managing 30 minutes of low intensity activity/exercise, e.g. walking, they will be assisted in gradually increasing the intensity of their activity/exercise, by keeping a careful record of their activity/exercise and monitoring their heart rate. It is their planned physical activity, and not their symptoms, that determines what they are asked to do, although activity is mutually reviewed on a regular basis and plans may be adjusted depending on general health and symptoms.

Aim

The aim of this treatment is to reverse the physical inactivity that helps to maintain CFS/ME, and to re-engage the participant in physical activity. The overall objective is to help a participant to become independent in the integration of physical activity and exercise into their every day lives.

Theoretical model

GET assumes that CFS/ME is perpetuated by deconditioning (lack of fitness), reduced physical strength and altered perception of effort consequent upon reduced physical activity. A normal process of adaptive change in the body is assumed to occur as a consequence of rest or a reduction in physical functioning, i.e. weakening of muscles, reduction in fitness, ('use it or lose it') and altered perception of effort. Activity can then produce symptoms as a result of these negative changes, as the body is attempting a physical activity beyond its current capacity. These changes are thought to be reversible, and thus improving fitness and physical functioning will alter perception of effort, enable the body to gain fitness and strength, leading to a reduction in symptoms and an increase in activity capacity ('use it and gain it'). Preliminary research suggests

that reduced symptoms arise from simply doing a GET programme, rather than necessarily getting fitter, whereas improved function is related to getting fitter and stronger. Participants are encouraged to see symptoms as temporary and reversible, as a result of their current physical weakness, and not as signs of progressive pathology. A mild and transient increase in symptoms is explained as a normal response to an increase in physical activity.

There may be other mechanisms involved in the success of GET apart from reversing deconditioning, including elements of habituation, and positive effects of re-engagement with important activities. GET has also been shown to improve sleep, cognition, and mood; factors that are also likely to perpetuate the condition, although these are not directly addressed by the treatment.

Procedure

The manual includes the following components: A baseline of physical activity is agreed and commenced, at a manageable and low level of intensity. The duration of the physical exercise is then increased slowly and carefully, at the right time for each participant. Once managing 30 minutes of low intensity exercise a day, e.g. walking, they will be assisted in increasing the intensity of their exercise, by keeping a careful record of their exercise and not exceeding their target heart rate. Planned physical activity, and not symptoms are used to determine what the participant does. The level of activity is mutually reviewed on a regular basis and plans adjusted depending on the participant's current health and symptoms.

Delivery

The administration of GET in this trial will be by a trained exercise therapist, usually a physiotherapist, who has had training in the GET manual and specific experience and training in applying it to patients with CFS/ME.

SUMMARY TABLE OF SUPPLEMENTARY THERAPIES

	SIMPLE ADAPTIVE PACING (APT)	INCREMENTAL PACING (GET)	COMPLEX INCREMENTAL CBT)
<i>Model</i>	Pathology	Physiology + behaviour	Physiology + behaviour + cognition
Ingredients of therapy	Balance activity and symptoms	Planned increases in activity on basis of physiological tolerance	Planned increases in activity with challenging of understanding of symptoms
Stabilise activity	Y	Y	Y
Planned increases in activity	N	Y	Y
Direct challenge of cognitions	N	N	Y
Specific encouragement of aerobic exercise	N	Y	N

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.

What factors contribute to the development of CFS/ME?

There is a growing body of evidence that is suggesting that a number of factors may be involved in triggering the illness.

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.

What factors perpetuate CFS/ME?

Just as there are many factors involved in triggering CFS/ME, there are also many factors that are involved in sustaining it. According to this model, the symptoms and disability of CFS/ME are perpetuated predominantly by unhelpful illness beliefs (fears) and coping behaviours (avoidance). These beliefs and behaviours interact with the participant's emotional and physiological state and interpersonal situation to form self-perpetuating vicious circles of fatigue and disability. Although it is acknowledged that lack of physical fitness may play a part in exercise induced symptom production, physical fitness is not central to this conceptualisation of the syndrome.

1. ***Fear about activity making the illness worse***

People with CFS/ME commonly experience increased pain or fatigue after any activity and this may naturally be read as a sign of doing harm. These thoughts can then lead to safety behaviours e.g., avoiding activities and resting for too long. Resting for long periods can impede recovery by reducing activity tolerance and reducing fitness.

2. ***Avoidance of activities***

People with CFS/ME may start to avoid activities for fear of making their symptoms worse. However, stopping doing things on a regular basis can lead to a loss of confidence in being able to do them. For example, they may have stopped socializing with particular friends, managing their home, doing exercise etc; resuming these activities may provoke fear and lead to further avoidance.

3. *Over-vigorous activity alternating with resting for long periods*

Some people refer to this as a “boom and bust pattern”. This refers to doing too much at times followed by resting for long periods. This pattern inadvertently makes the problem worse in the longer term, as it is difficult to establish any type of routine.

4. *A 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.

5. *Symptom focussing*

The symptoms commonly experienced by people with CFS/ME are both distressing and debilitating. They will often pay a lot of attention to their symptoms which may result in an exacerbation of symptoms and lead to further avoidance.

6. *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 financial difficulties, worries about keeping a job, difficulty in maintaining studies or feelings of social isolation due to a reduced ability to socialize. These difficulties can understandably trigger feelings of frustration, helplessness and loss of control over life. 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.

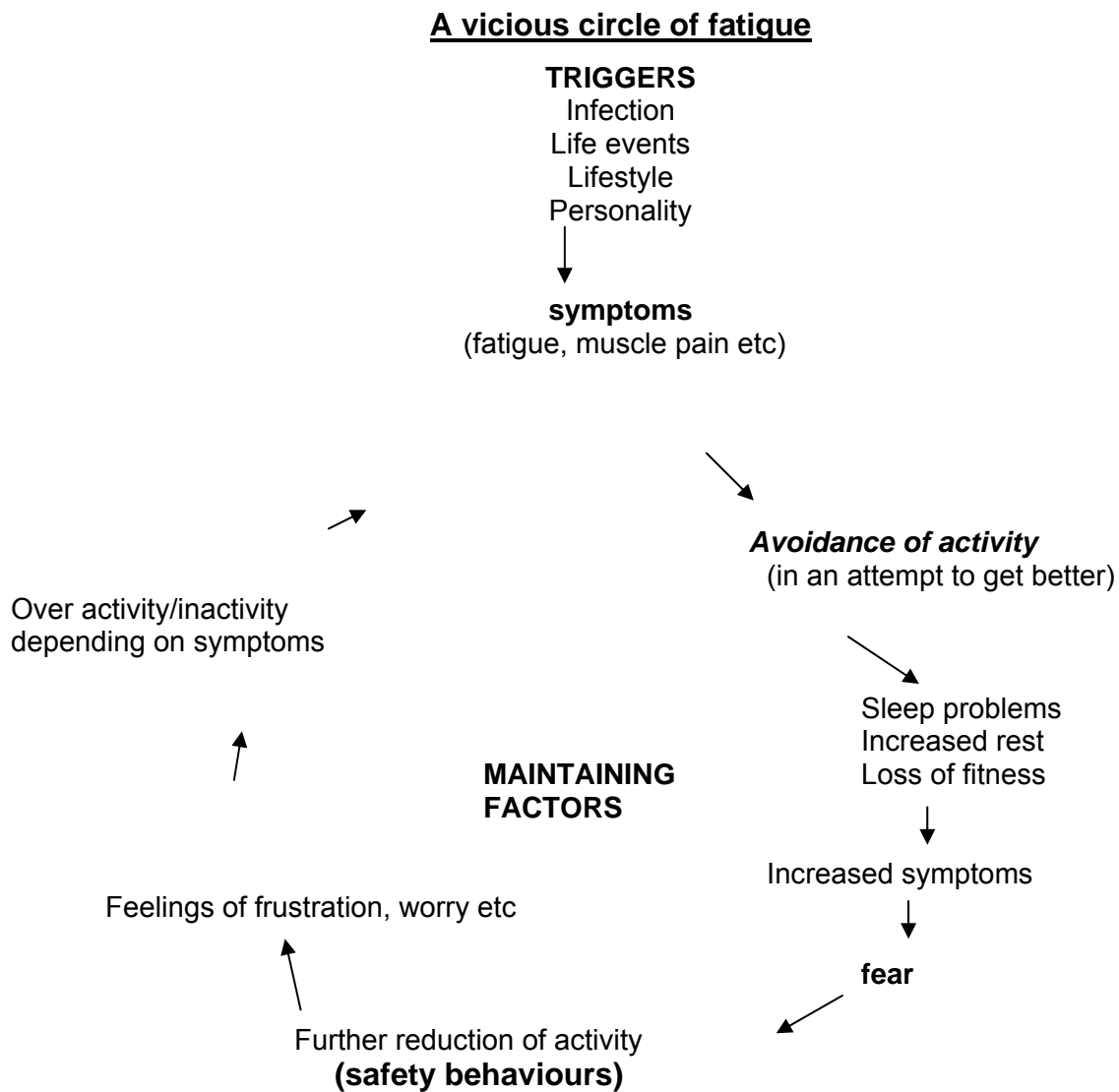
7. ***Perfectionism***

Just as personality can be a factor in contributing to the development of CFS/ME, it can also be a perpetuating factor. People who are perfectionists are likely to have more difficulty in taking breaks or rests in the day as they feel that they are “wasting” time and “should” be doing something useful. This may lead them to adopt a “boom and bust” approach to activity which makes it difficult to establish any sort of routine.

A COGNITIVE BEHAVIOURAL APPROACH TO CFS/ME

Treatment is focused on addressing the cognitive and behavioural factors that maintain the vicious circle of CFS/ME. This involves the participant becoming aware of and changing unhelpful thoughts and beliefs about their situation and altering their patterns of behaviour. There is empirical support for this model.

Factors that commonly maintain or perpetuate chronic fatigue syndrome can be illustrated in a diagram that we call a vicious circle.



AIM OF COGNITIVE BEHAVIOUR THERAPY (CBT)

Treatment aims to help participants improve their levels of functioning which in turn reduces fatigue. Treatment also aims to help participants become expert in managing their problems so that by the end of treatment they are able to maintain and build on their progress.

The main components of this approach are as follows:

- Eliciting the participant's own model of illness to establish how they appraise and cope with their situation.
- Establishing with the participant a shared multifactorial understanding of their illness that takes into account predisposing, precipitating and maintaining factors
- Using this model as a rationale to implement behavioural, cognitive and lifestyle changes, targeted at reducing the impact of maintaining and predisposing factors.
- Equipping the participant with a variety of appropriate cognitive, behavioural and problem solving skills so that they can continue to make further progress

Summary of strategies

A variety of cognitive and behavioural strategies will be discussed with participants during their CBT sessions to help them to improve functioning as a primary goal and to reduce levels of fatigue.

Cognitive strategies

These strategies aim to address unhelpful thoughts and beliefs and may involve agreeing specific behavioural experiments to test out the validity of the participants' existing beliefs.

Frequent unhelpful cognitions include:-

- fearful thoughts such as “activity will make my problems worse” , which may lead to an avoidance or reduction of activities
- perfectionist thoughts/beliefs such as “I must finish this decorating/ piece of work/tidying up before I sit down”, which may lead to a boom and bust cycle of activity and rest.

Behavioural strategies

These strategies aim to help participants to improve their functioning and sleep routine, this may involve:-

- Establishing a baseline of activity and rest
- Establishing a consistent pattern of activity and rest
- Graded activity in order to work towards specified goals
- Establish a sleep routine
- Graded exposure to situations that may cause anxiety, e.g. socializing

Problem solving

Problem solving can be used to address worries that may be interfering with the participant’s ability to make progress, e.g., work or relationship issues.

THERAPIST PREPARATION

This section aims to prepare you as much as possible for CBT sessions with trial participants. It contains the following:

- An overview of treatment sessions
- General points to ensure adherence to protocol
- Distinguishing between APT, CBT and GET
- Supervision issues
- Knowledge and skills required
- Engaging the participant in treatment: Do's and Don'ts
- How to structure treatment sessions
- Discussing what is required of the participant
- Assessment issues
- Explanation of the cognitive behavioural model
- Helping participants to become their own therapist
- Involving a relative or friend as a cotherapist
- How to set long term targets for CBT
- Information about behavioural experiments
- Managing potential difficulties

AN OVERVIEW OF TREATMENT SESSIONS

Outline of treatment

Number of sessions:

Participants will be offered up to fifteen sessions: sessions may be omitted if therapy is going well and the next session is agreed by both therapist and participant not to be necessary. If a participant is unable to attend a session in person for any reason, and the session cannot be re-arranged within five working days, this session may be held over the telephone.

Frequency of sessions:

The first 4 sessions will be weekly

Sessions 5- 14 will be fortnightly

Session 15 will be a booster session, 3 months after session 14 (discharge from active treatment).

It may be useful for both you and the participant to plan your sessions on the same day of each week and at the same time of day. You may also find it useful to plan a few sessions in advance.

Duration of sessions:

The first session will be for 90 minutes, remaining sessions will be for 50 minutes

Treatment phases:

Treatment can be divided into three main phases

1. Assessment, engagement and treatment planning (1-2)
2. Active treatment (3-10)
3. Preparation for discharge (11-14)
4. Booster session (15)

Taping of therapy sessions

This is a necessary part of the trial and participants have all consented to taping of sessions. At the beginning of each session it would be useful to remind them that you will be taping the session. If participants are unclear of the reasons, you can remind them that you are doing this for the purposes of supervision, assessment of competence, assessment of therapy differences and other research purposes.

GENERAL POINTS TO ENSURE ADHERENCE TO PROTOCOL

- To ensure that an accurate record is kept of contact with each participant, please complete the record of attendance (Appendix 1) for **every** contact that you have with participants, whether it is a planned session, unplanned phone call etc. Also, complete the trial session record (Appendix 2) after each treatment session.
- Complete the CGI (Appendix 3) for each participant at the end of treatment session 15.
- If participants are unable to attend an appointment, telephone sessions may be given. However, it is important to record this session in detail in the trial session record.
- Cancellations or DNA's should be rearranged within 5 days if possible.
- Telephone contact between sessions should be handled on an individual basis. To ensure that details of unplanned phone calls are recorded, please complete the unplanned phone call record (Appendix 4).
- If a participant no longer wants to participate in the trial, i.e., they withdraw their consent, the centre leader or deputy should be informed on the same day, if possible. The centre leader or deputy will then contact the participant to find out whether consent is withdrawn from further trial treatment only or further trial treatment and follow-up. The reason for drop-out should be ascertained if possible and passed on to the research nurse. The date of drop-out and reason (if known) should be recorded in the participant's medical notes.
- Each session should be taped. (Written consent will have already been obtained by the research nurse/psychologist).
- A letter should be written to the referral agent and other agencies at assessment, discharge and after the booster session.
- Any serious concerns or worries about the participant such as deliberate self-harm, significant and prolonged illness progression, or a severe adverse event must be discussed with the centre leader immediately, so that the relevant course of action can take place.

DISTINGUISHING BETWEEN APT, CBT AND GET

It is essential that the three supplementary therapies can be distinguished from each other by keeping the therapies consistent with their models. Please see the detailed chart below which outlines the main differences between them.

	APT	CBT	GET
Works from a pathological assumption	√		
Works from a deconditioning assumption		√	√
Aims for an improvement in function to occur		√	√
Encourage natural recovery	√		
Use diaries to identify patterns / bust and boom	√	√	√
Use fatigue scores to identify patterns / bust boom	√		
Consider increase symptoms as natural response to increased activity.		√	√
Encourage participants to listen to their body.	√		
Establish a baseline	√	√	√
Set graded goals		√	√
Goals devised by therapist and client		√	√
Goals devised by client only	√		
Encourage the choice of meaningful activity.	√	√	√
Prioritise what you can / cant do within energy limits	√	√	√
Demonstrate / practice exercise			√
Plan set activity in advance	√	√	√
Discuss sleep management	√	√	√
Discuss rest	√	√	√
Practice non-stimulating relaxation	√		

	APT	CBT	GET
Explore unhelpful thoughts		√	
Learn to challenge unhelpful thoughts		√	
Discuss the effect of stress in CFS	√	√	√
Discuss fear avoidance, and anxiety related to CFS	√	√	√
Discuss ergonomics and body mechanics	√	√	√
Discuss activity analysis and activity modification	√	√	√
Discuss potential barriers to treatment	√	√	√
Constantly review model, diaries, baseline and activity.	√	√	√
Discuss future maintenance and set backs post-treatment.	√	√	√
Use motivation as an engagement tool		√	√
Involve relatives	√	√	√

The Therapies Integrity Rating Scale

The Therapies Integrity Scale (Appendix 5) also outlines the core elements of each therapy. It will be used by independent assessors to ascertain whether the treatment you are giving is consistent with your model. A random selection of therapy tapes will be listened to and marked using this scale.

You will note that the first part of the scale is concerned with core areas, considered important for APT, CBT, and GET (covering aspects such as therapeutic alliance, rapport, generic therapy skills), while the treatment-specific sections outline the cornerstones of the individual treatments. This scale is also likely to be used throughout supervision as an aid to training.

SUPERVISION ISSUES

Clinical supervision for discussion of cases will be provided at least monthly by phone and at least four times a year on site at Kings College Hospital, London.

Supervision will provide you with the opportunity to discuss your participants and to iron out any difficulties that you may be experiencing.

In order for you to get the most out of supervision it would be helpful for you to do the following:

- Plan in advance what you hope to get out of supervision
- To complete a review of session record (Appendix 6) after each session to help you to reflect on the session and to highlight issues that you may want to discuss in supervision.
- Bring tapes of all clinical sessions to supervision
- Bring clinical notes to supervision
- Record what has been discussed in supervision in relation to your participant(s) on their review of session record.

KNOWLEDGE AND SKILLS REQUIRED

As well as a sound knowledge of the aetiology, epidemiology, consequences and available treatments of CFS/ME, a range of skills will also be necessary in order to help you to engage and work collaboratively with these people.

Engagement

In order to engage the participant in therapy, it is important that the therapist conveys to the participant their belief in the reality of their symptoms, distress and handicap. The therapist should be able to demonstrate a sound knowledge of CFS/ME as participants will generally be well informed about their illness and may have had “difficult” experiences with other professionals who may have not taken their problems seriously. People with CFS/ME are often sensitive to the over-emphasis of psychological factors. It is therefore important right from the start that an integrative model that incorporates biological factors, e.g. initiating infection, is used. It is important that you show respect for their beliefs on the cause(s) of their illness and avoid challenging them as this is likely to provoke strong emotion and will reduce the likelihood of a good therapeutic relationship being established. In order to maintain participants engagement throughout treatment, it will be important that you continue to use an integrative model and avoid promoting a rigidly dichotomous view of physical and psychological illness.

Warmth and Empathy

Empathy is something that we will hopefully tend to do with all patients without thinking about it. However, with this client group it is particularly important. Often they have had their health problems for a long time. Many of them will report at least one upsetting incident relating to a health professional, whether it is not being believed, not being taken seriously or being told it is all in their mind. Often participants will have been given conflicting advice about how to deal with their problems, leading them to a state of confusion and frustration. Some participants will feel guilty about being ill and blame

themselves for their predicament. Some participants will have had trauma in their background that may still provoke emotion.

It is therefore very important that you convey warmth and empathy at your first meeting. The assessment provides a wonderful opportunity for participants to tell their story. Often it is the first time that they will have been able to go into detail about their problems. Allowing participants to elaborate on their illness often gives them the feeling that their illness is being taken seriously, often for the first time. Acknowledging the difficulties they have encountered along the way in terms of their illness, whether related to its impact on their life or response from other health professionals, etc, is important.

Throughout your treatment sessions, it will be important that you continue to show warmth and empathise with your participant. There is no doubt that getting people to change previous routines can be difficult in a number of ways. The participant may be very fearful of changing the way they do things, fearing worsening of the symptoms. They may find that their symptoms initially worsen when starting their CBT programme. Acknowledging the challenges associated with the programme is important if you are to win their trust.

Sensitivity

Participants may not have had their illness taken seriously by previous professionals and may be concerned that you will be no different. They may think that you will be another “professional” who will tell them “to pull themselves together” etc. Participants may feel sensitive about the use of particular words, for example, asking them how often they feel *tired* can provoke anger in someone who differentiates strongly between the word *fatigue* and *tiredness*. Although you cannot forever be thinking about whether or not you are going to offend them, it is worthwhile listening to and trying to use language that is not going to be alienating. In general, it is best to use the language that the participant does to describe their symptoms.

Collaboration

Collaboration is an essential skill in working with people with CFS/ME. Up to the point of meeting you, many participants will not have been included in the management of their illness. They may not have been asked their opinion about what is wrong with them and may feel rather helpless and out of control. Collaborating throughout treatment will help participants to feel more involved in their treatment and will help them to regain some sense of control.

You will be demonstrating a collaborative style at your first meeting when you individualise the CBT model to their illness. By this we mean drawing a model together, examining factors they think have been responsible for triggering as well as maintaining the illness. Agreeing an agenda for each treatment session, asking for their input in making suggestions for their activity programme and evaluating previous sessions will help participants to feel valued and included in the treatment process.

Positive reinforcement

It is essential that you demonstrate positive reinforcement when you work with people with CFS/ME. Often, they will be very good at pointing out what they haven't achieved. It is therefore important that you emphasise and are very positive about what they have achieved. Every session you should positively reinforce all of their achievements, however small they may seem, whether it is managing to walk for a minute longer than the previous session, read for 5 minutes longer or get up 5 minutes earlier.

Establishing confidence in you as a therapist

Establishing the participant's confidence in you as a therapist is important. This is likely to occur if you utilise the skills in the sections listed above. One cautionary note, if you do not know the answer to a question, you are more likely to be respected for saying that you don't know the answer, rather than trying to answer it in a muddled way.

Encouraging optimism

Although it is important that you are realistic about the treatment targets that you set with participants, it is important that you encourage optimism about the progress that they may make with this approach. Although this has not been scientifically tested (to our knowledge), they are more likely to succeed if you encourage a positive expectation of therapeutic outcome.

ENGAGING PARTICIPANTS IN TREATMENT

Do's:

- Ask what the participant would like to be called when you first meet.
- Discuss the agenda for the first session and ask the participant whether there is anything that they would like to add to it.
- Show empathy, warmth, sensitivity and understanding during the assessment process (and thereafter).
- Give a clear explanation of the CBT model using the participant's own words and examples.
- Be very positive about participant's attempts to help themselves to overcome their CFS/ME.
- Give participants the opportunity to discuss any fears or worries in relation to CBT.
- Tell the participant that you will look forward to working with them over the coming months.
- Use language that participants will understand.

Don'ts

- Challenge the participant about their illness attributions.

HOW TO STRUCTURE TREATMENT SESSIONS

The following guidelines aim to help you to structure treatment

- Read your previous session notes before the participant comes into the session
- Write an agenda on your therapist session record, of what you would like to discuss in the session.
- Gain the participant's consent for taping the session.
- After greeting the participant, discuss the agenda with the participant, suggesting your own ideas and asking for theirs.
- Prioritise the agenda with the participant.
- Remind the participant of the length of the session (50 minutes).
- Work through the agenda.
- Remind the participant when you have 5-10 minutes left, if necessary.
- Write down on your therapist session record anything that you have not managed to discuss in the session, so that it can be prioritised for the next session.
- Book the next appointment

Every session should contain the following:-

- A review of homework and the participant's diaries
- Review of model
- Time to check out the participant's understanding of any new techniques you may have introduced during the previous session
- The opportunity to discuss the participant's reactions to the previous session and any issues that you did not have time to discuss.
- An opportunity to discuss any other issues (other problems that may have come up in the previous 2 weeks)
- Time to plan homework

DISCUSSING WHAT IS REQUIRED OF THE PARTICIPANT

It is important right from the beginning that you discuss with the participant ways in which they can help themselves to get the most out of CBT. You may try to cover the following points in the first couple of sessions.

- To complete all records, e.g. self-monitoring diaries - to initially illustrate how much activity, rest and sleep they are having, and then to indicate the amount of progress with the activity programme etc.
- To commit to prioritising treatment over the coming months, with a clear understanding that what will help their progress is the changes they make in their lives in-between sessions.
- To contact you as soon as possible if they are not going to be able to attend an appointment - so that you can rearrange one for them within the time specifications of the trial protocol.
- To keep you informed of any changes in medication, other treatments etc.
- To participate in setting an agenda each session - so that all of their needs and requirements are met.
- To feel able to tell you if they are not clear on any aspect of the treatment programme.
- To attend appointments on time (wherever possible) as you may have an appointment straight afterwards and would therefore be unable to offer extra time.

ASSESSMENT ISSUES

By the time that you meet the participant, they will have been given a diagnosis of CFS/ME by an assessing doctor/ therapist in the department. The participant will have also seen the research nurse who will have confirmed their diagnosis. The participant will have been randomised to CBT of which they may have a sketchy understanding.

Although the participant will have recently had a detailed assessment, the aims of the appointment will be to:-

- Take a background history to be able to put their CFS/ME problems in context with their life
- Form a positive therapeutic relationship
- Confirm a diagnosis of CFS/ME
- Identify any other problems (medical, psychiatric etc)
- Introduce the CBT model and discuss how it might apply to them

Introduction of session

After meeting and greeting the participant, tell them that you have 90 minutes for this first session. Explain what you will be doing in the session and ask them whether there is anything in particular that they would like to get out of the session. As this is your first meeting with the participant, it is important that right from the start you demonstrate warmth, empathy and understanding.

Assessment format

Name:

What does the participant like to be called?

Date of assessment:

Age:

DOB:

Address:

Phone: *Do they have a current number where they can be reached*

GP: *Has this changed?*

Address:

Phone:

Occupation /benefits/income protection (IP):

Ask what job they are doing, or if not working, are they in receipt of benefits or IP.

Main problem

Although CFS/ME may have been diagnosed, it can be useful to open the assessment with a question such as “What is the main problem for you” This gives the participant the opportunity to “encapsulate” the whole problem before you break it down into small components. It may also reveal problems other than CFS/ME that will also be important to assess

Physical symptoms (frequency, intensity, duration)

It is important to ask participants for a complete list of symptoms. They may report feeling fatigued all of the time, and if this is the case, it is useful to determine whether the intensity of the fatigue changes. A variety of other symptoms may occur, including muscle pain, sore throats, tender glands, sensitivity to light etc and the frequency of these symptoms should be noted.

Other symptoms (Short-term memory, concentration, exhaustion following mental effort, word finding difficulty, sleep –Initial insomnia, wake in the night, early waking appetite, weight, libido)

Cognitive symptoms are common. Participants will often report errors such as slips of the tongue or forgetting the right word. Ask them about their short-term memory with questions like, “If I was to ask you what you had for lunch yesterday, would you be able to remember?” Ask about their concentration with questions like “Are you able to follow a film on television?”

Sleep complaints are common. Ask whether they have difficulties in getting to sleep, or waking in the night. (You will get more details of sleep when asking about a typical day).

It is useful to establish whether or not they have problems with appetite, this can sometimes be decreased appetite due to their fatigue or increased cravings for things like carbohydrates. It is important to establish any substantial changes in weight as this may reflect other problems that would need to be investigated. Asking about changes in libido, needs to be done sensitively. A reduced libido may be seen as a problem that can usefully be discussed in sessions.

Restricted/modified activities- work, social, sport, home, relationship

Ask participants about each of the above areas.

Work: If they are still working, is it impaired in any way? They may have given up everything else to be able to keep their work going.

Social: How has this changed? Establish whether their social network has changed, whether they go out as much or do friends visit instead

Sport: How has this changed? What can't they do that they used to do?

Home: This can substantially change for people with CFS/ME. Check out what has changed. If they are unable to clean, cook, care for the children etc, who is now doing the work?

Personal relationships: If they are in a one to one relationship, how has this changed. It can sometimes be that the relationship gets stronger, on the other hand it can cause strain on both partners.

Family relationships: The dynamics can change within the family. This is more likely to happen in the case of there being a role reversal, e.g. the husband becoming the carer etc. People with CFS/ME can feel very guilty about not doing as much with their family, or for their family as they used to do.

Typical day (getting up time, number of rests, length of activities, bed time routine)

Are some days different to other, e.g. weekends?

It is important to establish a typical pattern of their day. If the pattern is very variable, e.g. a couple of days in bed followed by two or three days of reasonable activity etc, then asking about a typical week, is more productive. Detailed questioning will help you to establish "problem" areas to target for CBT.

Ask what time they typically wake up and what time they get up. If their waking up and getting up time is variable, ask them what is the earliest and latest that they may wake up and get up. Establish the types of and lengths of activities that they do in the day,

e.g. if they go for a walk, what is the shortest/longest? Find out how many rests they take in the day. For how long are their rests? Where do they take their rests, e.g. at their desk at work, in bed etc. Do they sleep in the day, if so, for how long? Where do they sleep? Do weekends differ to week-days? Do they have a bed time routine? What is it? When they go to bed, how long does it take them to go to sleep? What do they do if they can't go to sleep? Do they wake in the night? If so, how often and for how long? Is there anything that they do on a regular basis, e.g. go to an evening class, meet a friend, etc?

Onset - (viral illness, triggers, life events) What happened after the illness? Convalescence?, too much too soon etc.

It is important to obtain as much information as possible about what was happening around and just before the time of onset. However, take care with the type of questions that you ask, as a participant who feels that their illness is directly caused by a virus may feel that you are trying to “psychologise” the illness with questions such as “was there anything stressful happening in your life at the time of onset”?. Questions such as “was there anything different going on in your life at the time?” would be a more appropriate question, or “Tell me about your life just before you became ill.” Most participants will have a clear onset associated with an illness such as flu, glandular fever, food poisoning. If this is the case, find out how they managed in the days and weeks after the illness began. Did they go to bed for a number of days, weeks, did they try to keep going despite their illness? Also what kind of management/medical advice did they get at this time?

Course and fluctuations of illness since onset

By the time that participants have an appointment with you, they may have had their illness for many months or years. Find out what the illness has been like since it started, e.g. have there been marked fluctuations (periods of feeling reasonably well

and periods of feeling very poorly);or has their illness gradually got worse/better? Find out about any particular life events e.g. other illnesses etc. Again briefly touch on advice and diagnosis at this point, as it's often an important factor in onset/maintenance.

Coping strategies- what are they doing/have they done to reduce symptoms (e.g. rest, belonging to an ME organization)

Participants will have often tried a variety of ways of coping with their symptoms. It is useful to enquire about what methods they have tried in the past as well as what strategies they are currently using, as this information may help to shed light on maintaining factors, e.g. excessive rest. Useful questions may be “What do you do when you feel excessively fatigued?” “Is there anything that you avoid for fear of making your symptoms worse Have you tried other coping strategies in the past?” It is also useful to find out the reason for using particular strategies, e.g. were they given advice to rest? Etc. Establish the effect that they think that their strategies are having on their symptoms.

Modifying factors-Is there anything that makes your symptoms better or worse? (E.g. being too hot, cold etc)

Some people with CFS/ME may note specific things that make them feel better and/worse. It is a useful question to ask as it can be useful for eliciting illness management beliefs. Acupuncture, Enada, Vitamin B, rest, when I'm not so stressed, when I'm on holiday or even when I exercise, are examples of things that people with CFS/ME report that are helpful. Stress or winter months are examples of things that sometimes make people with CFS/ME feel worse.

Overall impact of illness on your life

Although you will have detailed information about the specific effects of CFS/ME on the participant's life, asking them about the overall impact will give you insight into their attitude towards it. Although many people will say things such as "It's ruined my life"; "I have lost x number of years", some people will be more optimistic and say things such as "It's given me the opportunity to review my life"; "It's brought me and my partner closer together". They often find it cathartic to summarise the impact of their illness.

Opinions/attitudes of important others, e.g. family, colleagues, friends (too much/too little)

Ask about the opinion and attitudes of people that are close to them. Find out about their friends attitudes, have they lost friends? Are friends supportive? What are work colleagues/employers like? How about family members? Establish the level of support they get (too much/too little). For example, sometimes relatives and friends do more than may be required, e.g. all of their shopping, cleaning, cooking resulting in increased dependence of the person with CFS/ME. On the other hand they may be struggling to keep their head above water in a household where no-one helps.

If a close relative attends the assessment, then it is useful to ask them about their opinions about the participant's CFS/ME.

Mental state: Mood- energy, enjoyment, self-worth, suicidal thoughts, guilt, hope, future. Anxiety- major worries/preoccupations, panic attacks.

Alternative psychiatric diagnoses should have been excluded at the participant's initial assessment to account for their symptoms. However, it is important to perform a mental state examination to establish whether they have low mood (which is common in CFS/ME) and/or anxiety problems, which are also common in CFS/ME. They frequently report feelings of frustration about their situation and mood fluctuations, e.g. they may

feel low when particularly fatigued, or when they are not able to do something to which they were looking forward.

Care should be taken when addressing their mood as participants who have been labelled as “depressed” in the past may feel that you will draw similar conclusions. An opening question such as “It sounds as if CFS/ME has changed your life quite a lot, how does this make you feel?” is appropriate. This will then lead you into more specific questions about enjoyment, self-worth etc. A sensitive inquiry about suicidal thoughts is essential i.e. “Have things ever been so bad that you have felt like ending your life?” (Contact the on-call liaison psychiatrist for participants who you feel are a suicide risk).

When someone has been ill for a long time they will have stopped doing many of the things that they used to do. Many of these things will have ceased due to their fatigue, but there may also be a component of anxiety in their reason for avoiding certain situations. It is important to establish any phobic anxiety problems that they have, as they can be targeted in your sessions of CBT. Questions could include “Are there any situations in which you feel tense?” “Are there any situations that you tend to avoid because they would make you feel uncomfortable”, e.g. supermarkets?” “When you have been in those (specified) situations, have you noticed any symptoms that come on suddenly, e.g. a racing heart?” For participants who have noticed acute symptoms, discuss further to establish whether or not they have suffered from panic attacks

Current treatment/management of this problem- (i.e. diet etc)

Establish whether or not they are on a special diet or seeing any alternative practitioners. What do they think that the effect of these treatments has been on their symptoms?

Meds: - prescribed, homeopathic, etc

Find out the names and doses of any prescribed medication or other remedies that they are taking, either regularly or as required. How long have they been taking them? What is the effect of them?

Substances containing caffeine, e.g. tea or coffee; other substances, alcohol, cigarettes,

Most people with CFS/ME will avoid or take little caffeine or alcohol due to them exacerbating their symptoms. However, the information is useful in determining possible factors that may affect their sleep.

Previous treatments for this problem (with effect); response of other health care professionals

Participants may have seen a variety of health professionals and have tried a number of treatments. It is important to find out what they have tried with its effect, e.g. antidepressants. It is also at this point that you may establish the attitude of other professionals to their problems. Any expression of anger towards “unhelpful” people that they have consulted previously should be dealt with sensitively.

Past medical history (childhood illnesses, similar episodes of illness, operations, allergies, other illnesses)-dates, investigations and treatment

A brief overview of their medical history is necessary to establish concurrent or previous problems. It is useful to note any similar episodes of illness, treatments and outcome.

Psychiatric history (dates, treatments, therapies etc)

Enquiries should be made about whether they have ever seen a professional in relation to depression, anxiety or any other problems of this nature. Treatment dates and effects should be noted. If they have had a history of depression, careful enquiry and details of suicidal ideas/attempts should be noted.

Other problems/issues

Before moving on to discussing the participant's own beliefs about their illness and the treatment explanation, it is useful to ask whether there are any other issues or problems that you haven't discussed over the course of the assessment. Patients rarely come up with something new at this point, but may repeat a problem that they have already mentioned, e.g. a phobic anxiety or relationship problems. It would be important to acknowledge their problem and to reassure them that you can address their problem during your sessions (if appropriate). If the patient informs you of a problem that you feel that you cannot address, it would be important that you inform the participant of where they may be able to receive help or that you would liaise with the appropriate agency/GP etc.

Beliefs: about the cause of the illness and why it is persisting

Exploring the participant's beliefs about their illness is essential before you discuss the CBT model for CFS/ME. It is vital that you incorporate their own beliefs into the CBT model that you discuss with them so that they feel that their opinions matter and have been taken seriously. Participants will have been diagnosed with CFS/ME, but it is important to ask them what they feel has caused their problems and what they feel is keeping their illness going. It is useful to gain an impression of their strength of belief in the cause, particularly if they feel that it is caused by something physical, e.g. a virus. Questions such as what do you think has caused your illness? Do you consider that there may be any other factors that have contributed to your illness? What do you think is causing your symptoms now? You should listen to what they say without passing any judgement. It is important to note fearful cognitions i.e. fear of activity making their

symptoms worse leading them to stop doing things. If a participant is convinced that their CFS/ME is caused purely by something physical, e.g. an ongoing virus, you will need to carefully address their beliefs during the course of CBT to broaden rather than directly challenge causal attributions.

A purely physical attribution of illness may be a block to overcoming their CFS/ME.

Treatment explanation using CBT model

Please see page 52

Number of sessions

Remind participants that they have 15 sessions in total including this session. In order to plan for participants to have regular appointments, e.g., weekly for the next 4 sessions, fortnightly for sessions 6-14 and three months after session 14 for the booster session, give them the outline of CBT sessions form (Appendix 7). It may also be helpful for you to plan a few future dates for sessions.

Background History

It is useful to state that you have completed taking a history of their problems and that you would now like to ask them about their family and personal history to get their problems into context with the rest of their life. If you have not time to do this at the first session then it is fine to leave this part until session 2.

Family history (age, job, health, relationship)

Parents and siblings

It is useful to establish their relationship with family members. It is important to ask them to elaborate on statements such as “we get on o.k. now”, “we have never got on”

etc. Asking about the health of family members and how they cope with illness, may enlighten you further on attitudes towards illness within the family

Family psychiatric history

The presence of a psychiatric disorder, such as depression in the family, may reveal a genetic vulnerability. Questions such as “Do you know whether any of your family have suffered from problems such as depression or anxiety” would be appropriate. If the answer is yes, it is useful to get further details.

Personal history (birth, milestones, childhood, family atmosphere, school, further education, work, sexual development, relationships, partners, children)

Eliciting a detailed personal history will help you to get a picture of what sort of a child and what sort of childhood the participant had. The information may also help you to understand some of the participant’s current behaviour patterns and at a later date be useful in your cognitive work with the participant. For example, if a participant has described a boom and bust approach to activity, this would be understandable for a participant that comes from a family where you were expected to work hard or where you were criticized for not doing so.

Asking about where a participant was born and whether they achieved “normal” milestones in terms of talking, walking, crawling etc, leads nicely into this section. Finding out about family atmosphere is important. Participants may report an “idyllic” childhood, with loving and supportive parents. However, if you have gained a sense from the family history that relationships with parents had not been, or were not good, you may want to explore this further. You will usually be aware of trauma in the childhood, e.g. abuse, from referral letters or from documentation of their initial assessment. However, sometimes patients will reveal new information in their first CBT appointment particularly if they know that you are going to be working with them for a number of sessions. Any difficulties will obviously need to be dealt with sensitively and with empathy. It is useful to note their ability to make friends, whether or not they

enjoyed school, had any periods of absences and for what reason, results of exams etc. A general overview of further education and work history should be noted. Asking about sexual development and personal relationships can seem irrelevant or rather personal but it may reveal problems e.g. difficulties in relationships if there has been sexual abuse. You may have already gained information about their current partner (if applicable) earlier in the assessment. However, it is useful to note the course of their relationship and to find out details of the ages, health and any other problems relating to any children.

Pre-morbid personality and lifestyle

Rather than asking about their personality separately, you may ask about their personality during the course of their personal history. However, it is important to find out about their personality as this information may be helpful in determining some of the work that you do with your participant. For example someone who describes themselves as a hard worker or a perfectionist may hold beliefs such as “To be successful, you have to work hard all of the time” and may require more work on taking regular breaks and challenging their beliefs than someone who describes themselves as a laid-back sort of person!. They may report that their personality has changed since they became ill, e.g. that they are more laid back than they used to be, that they do not set themselves such high standards etc. Although you may have a sense of their lifestyle before becoming ill, it is useful to find out what they used to do in terms of sport, social life etc. Information about previous things they used to do may help you in your goal setting with participants.

Current situation (housing, living with, work, benefits, interests)

This section will draw together a lot of what you may already know. It may help you determine areas that will need to be addressed in your sessions. For example, it may draw your attention to problem areas such as inadequate housing, financial difficulties due to not working that may be factors that are contributing to the maintenance of their

CFS/ME. Although you will have asked about employment and benefits, it would be useful to find out, if they are not working, whether they want to return to their previous job. There is some evidence to suggest that being on benefits and/or income protection (IP) are poor prognostic factors as they are contingent upon the patient remaining unwell. Knowing about their current interests/hobbies may be helpful when you come to discuss targets for treatment.

Future plans (work, moving house, starting a family etc)

It is important to note any significant future plans as it may have an affect on treatment, e.g. one can expect a participant's fatigue to increase with a pending house move etc

EXPLANATION OF COGNITIVE BEHAVIOURAL MODEL

Discussing the CBT model and giving an individualised rationale is very important in terms of demonstrating an understanding of the participant's problems. It is useful to sit next to the participant with a large whiteboard and pen so that you can both look at the information together. It is helpful to draw an individualised vicious circle including the relevant information that has been gathered during the assessment in order to discuss the rationale of CBT. Check out every so often with the participant that what you are writing down on paper fits with their experience. When you have completed the trigger section ask them whether you have missed anything out. At the end of the maintaining factor section, check out whether there is anything else that they would add.

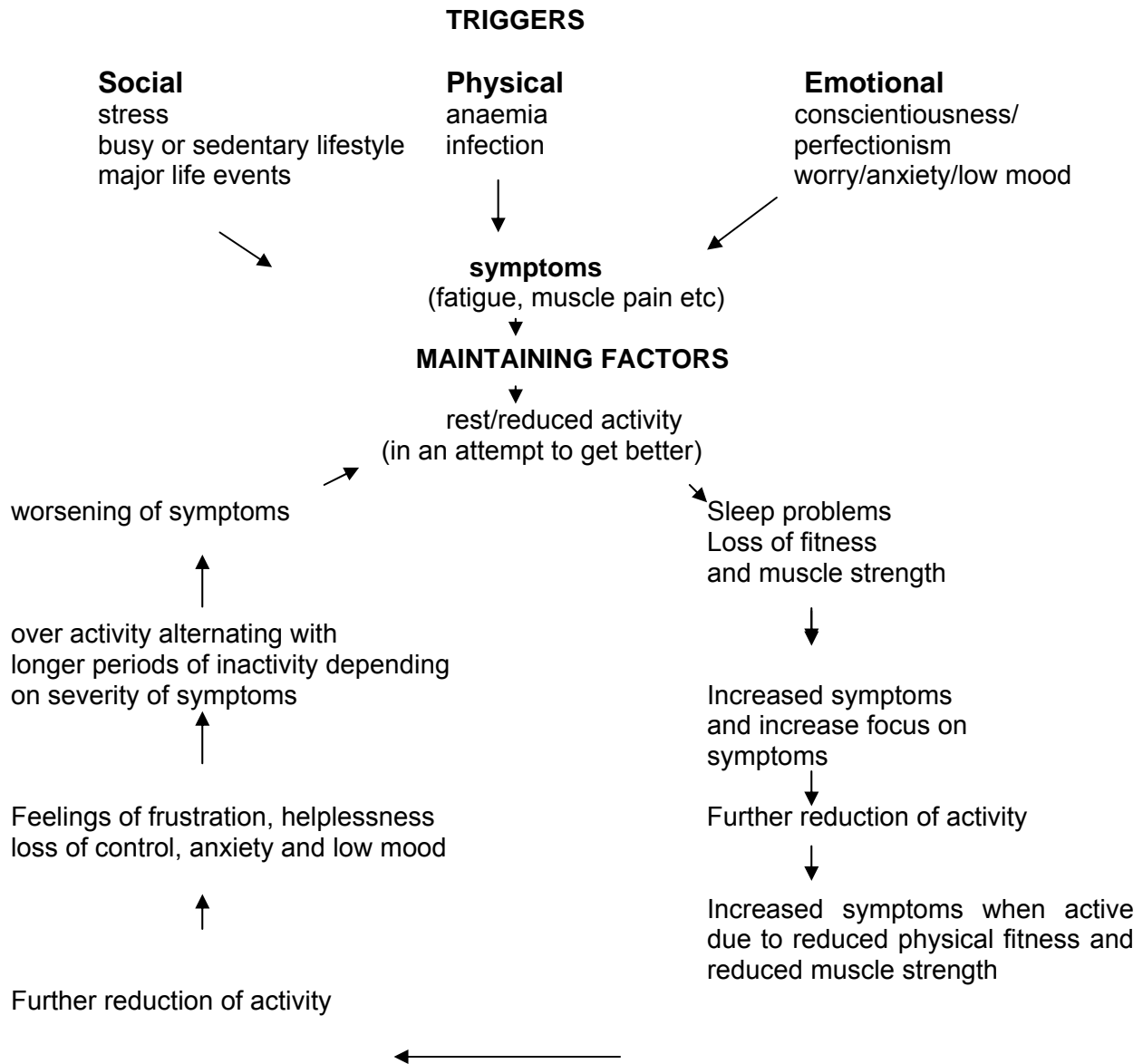
It is helpful to divide the triggers into 3 sections (social, physical, emotional) and to go through them together. Because many people with CFS/ME will report a viral illness at the onset and many may feel that that is the most responsible factor, then it is important to write down the "physical" trigger first of all. Gradually work through all of the factors that the participant mentioned around the time of onset, e.g. working hard, life events, being very physically active etc. Personality factors such as having high expectations, or feeling "stressed" or anxious may also be added.

Once you have agreed on the trigger factors which have led to the fatigue and other symptoms, you should move on to the maintaining factors. It is useful to summarise what the participant has told you, e.g. that when they became fatigued they slept for a week, then went back to work but couldn't manage, so they gave up and continued to rest for a lot of the time...etc. If participants have other ongoing problems at home, e.g. financial worries, a sick relative etc, then it is important to include these factors. Fears, unhelpful thoughts, frustrations that you have elicited from assessment should also be included, e.g. "I'm never going to get well"; "I am wasting my life", etc.

Once you have got this information down on paper, you can then discuss the roles of the different thoughts and behaviours in maintaining their problems and how CBT aims to help.

An example of a more detailed vicious circle is overleaf.

A VICIOUS CIRCLE OF FATIGUE



Below are some other important issues to briefly cover when discussing the rationale.

- CBT is a pragmatic approach which is helpful in a variety of illnesses, including chronic pain, diabetes and cancer.
- CBT aims to help people to become an expert in managing their problems.
- That when they begin to change or increase their levels of activity that they can expect a temporary increase of their symptoms.
- Eliciting the participant's own expectations and doubts about CBT. They should be reassured that their concerns will be discussed in future sessions.
- Examples of the strategies that may be used so that the participant obtains an idea of what they will be doing in the coming weeks.
- For participants who are attempting to structure their day or regulate their sleep pattern etc, positively reinforce their attempts and say that you will be helping them to build on what they are already doing.

HELPING PARTICIPANTS TO BECOME THEIR OWN THERAPIST

The overall aim of CBT is to help people to become their own therapist by helping them to become an expert in managing their own problems. Strategies to facilitate participants to become their own therapist include the following:

- Giving clear explanations about the CBT model and rationale for treatment so that participants can quickly learn about what may be maintaining their CFS/ME.
- Repeating the rationale for CBT to reinforce the model and to increase the participant's level of understanding.
- Checking the participant's understanding when discussing new strategies.
- Encouraging participants to evaluate the progress that they have made since the last session and in light of this information, to make suggestions for their activity programme as soon as possible.
- Encouraging participants to suggest most of the ideas for their programme from mid-treatment (session 7) onwards, so that they will be able to confidently increase/change activities after discharge.
- Agreeing set-back plans before participants are discharged so that they are aware of potential triggers and feel confident in managing an increase of symptoms.

INVOLVING A RELATIVE OR FRIEND AS A CO-THERAPIST

Patients sometimes find it helpful to have a partner, relative or friend to act as a co-therapist. It can provide them with support and encouragement, particularly when they are experiencing difficulties with their programme. Patients sometimes like to have a co-therapist who is very involved, e.g. someone with whom they can discuss their progress and any problems on a daily basis, will phone them to make sure that they are out of bed, etc. Other patients prefer to have a co-therapist who is less involved, e.g., they may want to talk to them about their progress on an informal basis, once a week. Some patients want to do their programme without the help of a relative etc, or do not have anyone that they feel is suitable.

For participants who do want to have a co-therapist:

- Ask the participant whether they would like their co-therapist to attend an appointment with them, so that they can hear about what CBT involves and how they can help.
- Ask the participant to suggest that the “co-therapist” reads the section at the back of the participant’s manual for partners, relatives and friends. You can also give them an extra copy, if necessary (Appendix 8)

If a co-therapist attends an appointment then it is useful to:

- Find out how much contact they have with the participant, i.e. see them once a week, live with them etc.
- Encourage them to read the information for partner’s relatives and friends if they have not already done so.
- Discuss with the participant how they would like their co-therapist to help them. (The amount of support given by a co-therapist will vary on a number of factors, e.g. time available to co-therapist, requirements of the participant etc).
- Discuss practical ways that they can help the participant, e.g. phoning them to check that they have woken up etc.

- Discuss the importance of giving the participant praise for all of their efforts, e.g. filling in diaries, going for a walk etc.
- Discuss the possibility that the participant may notice a temporary increase in their symptoms. Reassure the co-therapist that this is quite normal with a change in activity level.
- Ask them to be aware (if participant wants the co-therapist significantly involved) of the participant's activity programme, so that as well as praising their efforts, they can also discourage them from over doing activities.

HOW TO SET LONG-TERM TARGETS FOR CBT

- Inform participants that setting targets will provide them with a clear direction and focus during CBT
- Targets are things that the participant would like to be doing in the longer term, rather than something they want to achieve immediately.
- It is important that the participant has *different* types of targets to work towards to make their life as balanced as possible.
- Targets should include pleasurable activities as well as activities such as work and chores etc.
- Targets should be *realistic* and *achievable*, rather than them representing a wish list.
- Be wary of the participant being too “driven” or “ambition orientated” when setting targets. If their targets seem to be too ambitious, it is important to discuss reason why they may not be a good idea. For example, if participants want to achieve all that they were doing before they became ill, discuss the possibility that their busy lifestyle may have been partly responsible for them becoming ill in the first place.
- Inform participants that they will be able to change their targets once their initial ones have been achieved.
- It is important that all targets are *specific* in terms of:-
 - the *activity* that they wish to perform (activity).
 - how often they would like to carry out the activity (frequency).
 - the *length of time* to be spent on the activity (duration).
- Once targets have been agreed, you and the participant can both write them down on the long-term target record (Appendix 9). The participant can then keep their copy in their treatment manual and you can keep your copy in the notes.
- The participant may break down each target into manageable steps by either following the guidelines in their manual, or in a session with you.

BEHAVIOURAL EXPERIMENTS

Behavioural experiments can be beneficial in helping participants to test their negative cognitions and constructing and testing new more adaptive perspectives.

There are two broad types of behavioural experiments that can be used at various stages of therapy. One type is based on hypothesis testing, i.e. “Is it true that ...” and the other is based on discovery, i.e. “What would happen if.....”

Hypothesis-testing experiments can be used to test the validity of a particular unhelpful cognition (negative prediction). For example, “if I do not sleep in the afternoon, I will get worse”. “If I walk for more than 10 minutes I will collapse”. They can also be used to support evidence for a more adaptive cognition. For example, “If I get up at the same time each day, my sleep will gradually improve”.

Discovery experiments can be used when participants are unclear about the processes maintaining a problem, or about what might happen if they acted in a different way. These experiments can help in the development of the formulation, in designing treatment strategies and in creating and refining new perspectives. For example, a participant may be unclear about what may happen if they change what they are doing at the beginning of their course of CBT.

Examples of situations where behavioural experiments may be used

Behavioural experiments may be loosely introduced from the first session. The participant may feel wary about the whole CBT approach. One way of dealing with the ambivalence is to view the approach as an experiment and wait to see what happens over a period of time.

When you agree the first programme of planned activity and rest you can discuss the participant's prediction of what they think may happen as a result of changing the way they do things. You can continue to view changes in their activity programme as experiments

Behavioural experiments may also be used to test out the validity of the participant's existing "unhelpful" thoughts, assumptions and core beliefs. They may then be used to strengthen new, more "helpful" thoughts, assumptions and core beliefs.

Types of behavioural experiments

There are a few different types of behavioural experiments that can be used to help participants to test their negative cognitions and construct new more adaptive perspectives. These include active experiments, gathering information from other sources and direct observation. However, the most commonly used experiments in CFS/ME are active experiments which are described below.

In active behavioural experiments the participant will deliberately think or act in a different way in the "problem" situation. For example, participants may have previously sat down for a rest when they experienced symptoms following increased activity. You may ask them to keep going for X amount of minutes to see what happens. They should be encouraged to note what happens, and reflect on the implications for their thinking and behaviour in the longer term.

In certain situations where the participant feels that an experiment is going to be difficult, it can be useful to use role play. For example, if the participant has little help from family members at home, they may fear that asking someone to help may provoke a negative response. Role play could be used to practice requesting help in different ways, which may lead the participant to increase their confidence and feel more able to tackle this problem in real life.

Recording of behavioural experiments

For specific behavioural experiments it would be useful to ask participants to complete the behavioural experiment record (Appendix 10). This will enable you to review the outcome of the experiment and help you both to decide how to move forward.

MANAGING POTENTIAL DIFFICULTIES

Before embarking on CBT with patients, it is useful to think about potential difficulties that you may encounter during your sessions. We have listed possible problems that you may come across with some suggestions of how to deal with them.

Difficulties with engagement

Participants may have difficulty in engaging with therapy for a variety of reasons. We have already outlined factors that help engagement, but it is worth considering particular engagement problems and how to manage them.

Fixed physical attribution of illness

Participants who hold a fixed physical attribution of their illness are likely to have difficulties engaging with a therapy that they feel is going to be looking at their “behaviour” and “thought” patterns. Holding a purely physical attribution appears to be occurring less than it used to do in clinical practice, but it still occurs. Examples of a physical attribution may include an ongoing virus, permanent damage being caused from an allergic response, damage from taking too many antibiotics, an unalterable disease, etc.

If participants are insistent that there is an ongoing “physical” problem, it is rarely helpful to directly challenge them on this point. It is important that you acknowledge that their illness is real but its effects can be reversed by the way they manage it. The way that you present the rationale for treatment will be particularly important otherwise they may feel that you are trying to “psychologise” the illness. It is particularly helpful if they are sceptical about this approach, to draw a model of illness together, to look at all the factors that may have triggered it and be involved in maintaining it. Patients often feel reassured when they are informed that CBT helps people with a wide range of health problems including cancer, chronic pain and diabetes. It can be helpful for this group of patients to try to view aspects of CBT as an experiment.

The following dialogue may help to engage participants in therapy.

Therapist

Up to now, you have been trying to manage your illness by doing things when you feel relatively ok, i.e. when your symptoms are not too bad. However, from what you have said, it seems that you can tend to push yourself too much when you have a bit of energy, resulting in you feeling exhausted and resting until your symptoms have reduced a bit. Does that sound right?

Participant

Yes

Therapist

Although this seems a logical way of doing things, it seems that you have not managed to make any substantial improvement. Would you agree?

Participant

I have tried to do things in so many ways over the years and don't really seem to have got anywhere, so yes, I suppose I agree with you.

Therapist

What I am proposing, is that I try to help you to do things in a slightly different way, i.e. that you establish a routine of doing activities and taking breaks/resting at regular times. This will help your body clock to become used to doing things at set times again. How do you think that would make you feel?

Participant

Worried. What if I don't feel like doing things at certain times. What if I feel really awful when I am supposed to be doing something, surely pushing myself will make me worse?

Therapist

I understand that what I am proposing may seem a bit worrying to you. However, how would you feel about starting with very small goals? I would suggest in the first instance is that we look at all of the activity and rest that you are having in an average week. I am going to ask you to fill in an activity diary and sleep diary for the next week and to bring them with you to your next appointment. So for the next week you will not be doing anything different, except filling in your diaries, would that be ok?

Participant

Yes, that's reasonable

Therapist

Good. Then when you come for your next appointment, we will discuss how we move forward from here, is that ok?

Participant

Yes

At the next appointment, you will be agreeing a programme of planned activity and rest with the participant. They may have difficulty accepting a programme that seems quite rigid in terms of doing things at set times. The following dialogue suggests ways of dealing with this.

Therapist

Last time we agreed that we would look at your diaries and agree how we would move forward, is that ok with you?

Participant

Yes

Therapist

Before we do that, would you say that the past week was fairly typical for you?

Participant

I would say that it was reasonably typical for me.

[If the week was not typical at all. You need to decide whether the participant can give you enough information to decide on their first programme. If not, you will need to ask the participant to complete diaries for a further week in order to get a more accurate picture to enable you to write a programme].

Therapist

*Well, thank you for completing your sleep and activity diary so diligently, all this information will really help us to establish a programme today. What I would like us to do now is to work out the amount of sleep, rest periods and activity that you had in the last *7 days and divide it by *7. This will give us an average amount of sleep, activity and rest in a 24 hour period. We can then look at how we can distribute your periods of activity and rest evenly throughout the day, and establish a sleep routine, would that be o.k.?*

*Use the number of days that the participant has been recording their diaries, it may not be exactly 7.

Participant

But what if I don't feel like doing things at set times, what if I feel really bad when I am meant to be doing an activity or getting up? Surely I am going to damage myself further?

Therapist

Would you be willing to give it a try to see what happens? It seems that at this moment you are predicting that you would feel worse. Why don't we agree to test it out to see what happens and look at it as a type of experiment? When you come back next time

we can discuss how you got on with it. If you are taking regular breaks in the day, rather than keeping active for relatively long periods, you may gradually find that you have less time when your symptoms are really severe. Also, if you develop a more regular sleep pattern, your body is likely to start getting used to it. Obviously, it will take a little while for your body to get used to doing things in a different way and you may find a slight increase in your symptoms initially. However, once your body gets used to a different routine, the symptoms will hopefully subside.

Participant

I'm willing to try it, as there does not seem to be much of an alternative.

Therapist

Good.

Feeling that a physical cause has been missed and wanting further investigations

Some participants may not hold a specific belief about what is wrong with them, but feel that despite many investigations, something has been missed. They may feel that they want to continue having investigations or try a variety of treatments until they are cured. Again, it is important to empathise with their situation, but to encourage them to hold off having further investigations until after they have completed a course of CBT.

Participant

I am feeling so exhausted, I really cannot believe that all my tests are clear. I feel sure that something has been missed. I think I might go to my GP just one more time to ask him if there are any other tests that I could have.

Therapist

I can understand that with feeling the way you do, you feel something has been missed. However, what I am proposing to do is to help you to understand why you feel

as bad as you do and also to see if we can help you to feel a bit better in the process. Would that be o.k.?

Participant

But what if something has been missed that could be easily rectified?

Therapist

From your notes I can see that you have had many tests, none of which point to a simple explanation for your fatigue. It therefore seems unlikely that someone would be able to detect an obvious cause of your problems. Although I can see the temptation of seeking further clarification of your problems, in reality what can happen is that you end up feeling more confused. I believe that your fatigue is a symptom of a bigger picture and I would like to spend some time discussing my thoughts on this matter with you. I wonder how you would feel about that?

Participant

Well, I suppose it wouldn't do any harm!

Therapist

What I suggest that we do is to get a large piece of paper and write down what we do know about your illness, including your symptoms, what was happening at the time you became ill and ways that you have been managing to deal with your illness to date. This information may help us to look at factors that may have triggered it and factors that may be involved in keeping it going. I hope this will help us to make some sense of your illness together before we move on to discussing ways of overcoming it. Would you give my suggestion a go?

Participant

Yes

Therapist

Great. Then maybe that would be a good place to start this session.

Non-compliance with diary keeping

Participants may not be very compliant with keeping their diaries; some of the reasons for this are listed below.

- Not sticking to the agreed programme.
- Not enough time to keep them properly, e.g. if they are working
- Forgetting to fill them in for a couple of days and therefore feel that there is no point in starting them again.
- Feeling that there is not enough room to write down what they are doing
- Finding them boring
- Requiring too much energy to complete.

As diary keeping is an integral part of CBT, the issues surrounding non-diary keeping and the importance of keeping diaries must be discussed with the participant. The following discussion aims to highlight the point.

Therapist

Now we have agreed the agenda for today's session, I wonder whether we could start by looking at your activity diaries?

Participant

We can do, but I haven't written much on them.

Therapist

Oh, why is that?

(Obviously what you say will depend on the participant's reason for not completing the diaries, but pointing out the importance of completing diaries is important at this stage.)

This should obviously be done with sensitivity as the participants may feel guilty about not completing them).

Not sticking to the agreed programme

Participant

There didn't seem to be much point. I haven't done much that we agreed at my last appointment, therefore there wasn't an awful lot to write down.

Therapist

I think that it would be useful for us to talk about why you did not manage to do what we agreed. There are often lots of reasons for not sticking to the agreed programme, particularly when you just start it, but its important that we try to iron out the difficulties so that it seems more manageable for the next week/two weeks. When we have done that, maybe we can recap the importance of completing diaries, we had lots to talk about at the last session and I may have not clarified their importance, would that be ok?

(You should then establish exactly what the participant has done, what they haven't done and their reasons. E.g., was the programme realistic? Did life-events get in the way? Etc. You should then problem solve to ensure that they are more likely to manage their agreed programme in the next two weeks).

Not enough time to keep the diaries properly, e.g. if they are working

Participant

I have had a really busy two weeks and just haven't had time to fill them in. I have done the odd day when I've remembered, but I'm afraid they look rather bare.

Therapist

Well, I am glad that you have managed to write something down. Maybe we can start by looking at what you have written down and then talk about how you can fit keeping your diaries into your schedule, would that be ok?

(You should then problem solve the difficulties of diary keeping. Maybe agree times to write things down, have a reminder note in work diary, keep the diaries in a place where they can be easily seen or writing down less, etc. Establish whether keeping the diaries is in fact helpful. Maybe suggest that the participant uses the target achievement record, which requires less detail, instead.

Forgetting to fill them in for a couple of days and therefore feel that there is no point in starting them again.

Participant

I managed to keep them for a few days and then forgot for a couple, so I didn't feel that there was any point in starting again.

Therapist

It sounds as if you managed well for the first few days. I wonder if it would be useful for us to look at what you have managed to complete and then to talk about why you might have forgotten to complete them.

You should then discuss the reasons for the participant forgetting to complete them, e.g. were they too busy? Did they have difficulties with the programme? Clarify the importance of keeping diaries and problem solve ways of remembering to keep diaries.

Feeling that there is not enough room to write down what they are doing

Participant

I didn't complete them, as there isn't enough room to write everything down.

Therapist

It might be a good idea for us to clarify what you need to write down in the diaries and then if the diaries still do not seem to have enough space, maybe we can devise another diary together.

(Some people feel restricted by the diary and are keen to suggest their own type of record. This is fine so long as all the written information that is required is recorded. When participants have established a good routine, they can start using target achievement records that just require a tick by their homework tasks).

Require too much energy to complete.

Participant

I am sorry, but I have been too tired to fill in the diaries. It just seems to be too much of an effort to do everything that you are asking me to do.

Therapist

I understand that, at first, keeping diaries as well as changing your routine can seem overwhelming. I wonder if it would be helpful for us to go through your homework and see if there was anything that was particularly difficult for you so that we can make it more realistic for next time. Maybe we can then discuss your difficulties with keeping the diaries and discuss ways of making them easier to complete.

(Establish the participant's main difficulties with their programme and record keeping. Establish how important the diaries are at this stage and whether they could use a target achievement record or record less on their activity diary etc).

TREATMENT SESSION PLANS

This section provides you with detailed plans for your treatment sessions with participants. The suggested plans may not always be applicable, for example you may need more than one session to complete the assessment. However, hopefully they will give you some guidance of what to cover during your 15 sessions.

This section contains the following:

- A summary of session contents
- Session action plans

A SUMMARY OF SESSION CONTENTS

Phase 1: Assessment, engagement and treatment planning

Session 1 (90 minutes)

- Set agenda
- Take history of CFS/ME problem
- Elicit participant's beliefs and coping behaviours
- Take a general background history
- Explain cognitive behavioural model
- Discuss an individualised rationale
- Outline number of sessions
- Discuss the possibility of the participant having a relative or friend to act as a co-therapist and whether they would like them to attend a session.

Homework

Complete self-monitoring diaries (activity, and sleep if applicable)

Read information about CFS, the model of understanding CFS, cognitive behaviour therapy, how to complete activity diaries and planning targets for treatment.

Ask relatives/friends to read the section for partners, friends and family at the back of the manual (if applicable).

Session 2

- Set agenda
- Review CBT model and review the rationale for treatment.
- Take a general background history (if not completed in session 1)
- Outline the contents of sessions
- Review treatment model as a way of testing out their beliefs that activity will result in long term worsening of symptoms.

- Establish a baseline of activity and rest for their initial activity programme and include planned periods of activity, rest, getting up time.
- Discuss longer-term targets for treatment and write them down.

Homework

Carry out planned activity and rest programme

Continue self-monitoring diaries

Read information about planning activity and rest and improving your sleep

Session 3

- Set agenda
- Review the participant's understanding of the model in light of information they read for homework and doing things in a more structured way.
- Review self monitoring diaries and discuss progress and problems with their first activity programme
- Discuss strategies to improve sleep, e.g. up time, worry time, bed restriction etc.
- Agree an activity programme including initial steps towards targets

Homework

Continue self-monitoring diaries

Carry out planned activity and rest programme and sleep routine

Read information on how to increase/change activities

Phase 2: Active treatment

Session 4

- Set agenda
- Review cognitive behavioural model
- Discuss how much of the activity programme the participant managed. Discuss any problems.
- Agree another activity programme.
- Introduce identifying and challenging unhelpful thoughts using participants' own examples, if they are confident with their activity pattern.

Homework

Carry out agreed activity programme and sleep routine

Continue self-monitoring diaries

Read information on: unhelpful thinking patterns

Write alternatives to unhelpful thoughts on 'new thought record'

Session 5-7

- Set agenda
- Carry out a mid-way evaluation at session 7 in order to review their understanding of the model of treatment, their overall progress and any problems etc.
- Review their progress with their activity programme
- Encourage the participant to suggest own ideas for their activity programme from now on.
- Discuss with the participant whether they would like to use target achievement records instead of activity diaries if they are managing a consistent pattern of activity and rest.
- Discuss stopping sleep monitoring diaries when the participant has achieved a more regular sleep pattern.

- Continue to review the participant's thought diaries and help them to come up with more helpful alternatives and/or action plans.

Homework

Carry out agreed activity programme

Continue self-monitoring diaries

Continue to challenge unhelpful thoughts

Session 8-11

- Set agenda
- Continue to review homework and to work towards targets
- Discuss any potential blocks that are making it more difficult for the participant to make progress, e.g. financial worries, work issues, relationship problems etc.
- Discuss techniques, e.g. problem solving, or resources that may help them to overcome these problems.
- Continue cognitive work; Review illness beliefs in light of any changes that they have made. Conceptualise any regular themes/schema and discuss ways of challenging them.
- Agree new targets if previous ones have been achieved

Homework

Read relevant information from the manual, e.g. "Blocks to recovery" or "worry and anxiety related to chronic fatigue syndrome".

Continue to challenge unhelpful thoughts

Start to complete core belief worksheets if applicable

Practise using any other techniques discussed in sessions, e.g., problem solving, exposure to anxiety provoking situations etc.

Carry out agreed activity programme

Continue self-monitoring by completing either activity diaries or target achievement records

Phase 3: Preparation for discharge

Session 12-14

- Set agenda
- Continue to review homework
- Continue discussion on increasing/changing activities in order to work towards targets
- Review model and discuss what has been learned
- Plan for the future by discussing how to maintain gains and make further lifestyle changes
- Discuss how to deal with future setbacks

Homework

Continue self-monitoring diaries

Continue graded activity and rest programme

Continue cognitive/problem-solving work if applicable

Write down ideas for management of set-back plan and targets for the next 3 months.

Phase 4: Booster Session

Session 15

- Set agenda
- Evaluate progress since discharge appointment, particularly focussing on targets
- Discuss problems that have occurred and how they have dealt with them
- Problem solve any outstanding problems
- Review their understanding of the model
- Agree further targets

SESSION ACTION PLANS

Phase 1: Engagement, assessment and treatment planning

The aims of this phase are to:

- Engage the participant in a collaborative therapeutic relationship;
- To establish a detailed problem analysis which identifies patterns of symptoms, activity, rest, cognitions and illness attributions;
- To agree specific, realistic, measurable end of treatment targets
- To ensure that the participant understands the rationale for CBT and is willing to engage in it
- To elicit their fears and expectations of CBT
- Discuss with the participant whether they wish to involve a co-therapist

Session structure

At the beginning of all sessions, the therapist will remind the participant of the length of the session (90) minutes for the first session and 50 minutes for subsequent ones. An agenda is agreed with the participant incorporating suggestions of the therapist and participant. Other components will include enquiring about reactions to the previous session, discussing and agreeing homework, reviewing their understanding and acceptance of the CBT model and introducing relevant therapeutic techniques. Sessions will end with a review of session content and checking their understanding of what has been discussed.

Session 1

As this will be the first time that you meet the participant, it is vital that you convey genuine interest, warmth and empathy throughout the session in order for the participant to feel that you have understood and believed their problems. It is important that you listen to feelings of frustrations or anger that the participant may express, whether it is in regard to previous management, effects on their life etc. It is important that you acknowledge the reality of their symptoms and the degree of distress and impairment that they are experiencing.

History of CFS/ME problem and background history

A detailed analysis of the CFS/ME problem and a background history will be taken using the assessment form at the back of this manual, (Appendix 11). For further details of assessment, please turn to page 39.

This session will involve you gaining information about the precise nature of the symptoms, levels of activity, rest and sleep, illness attributions, cognitions, overall impact of symptoms and impact on the participant's life. You will need to find out about the onset, paying particular attention to any illness they may have experienced, any particular stresses or life-events prior to becoming ill. The course and development of the illness should be discussed with attention being paid to the participant's own coping mechanisms. Factors that improve or worsen symptoms should be elicited. Response of "close" people, e.g. family, friends and colleagues should be noted. The participant's experience of other health professionals and response of any other treatments should be discussed. A general family and personal history should be taken to place the participant's current predicament in context with their life. It is helpful to elicit their personality traits and their opinion of their personal and social strengths and weaknesses.

Explanation of cognitive behavioural model

It is helpful to draw an individualised vicious circle including the relevant information that has been gathered during the assessment in order to discuss the rationale for CBT. (Please turn to the next page for further details). It is important to include the precipitating factors, e.g., illness, life-events, working excessively hard, perfectionist personality etc. It is also important to discuss the maintaining factors, e.g., erratic or reduced activities, disturbed sleep patterns, unhelpful illness beliefs and any other unhelpful cognitions etc. Other stressors that the participant may have mentioned such as financial worries, illness of a close person etc, should also be discussed as a possible factor that may be maintaining their CFS/ME. For the participant to feel involved in the process it is important that you give them the opportunity to contribute by including any factors that they feel are relevant.

Once you have discussed the factors that may have contributed to and be maintaining their CFS/ME, the next step is to apply the CBT model to their problems.

Giving an individualised rationale

You may say something along the following lines.....*Thank you for giving me such a clear account of what was happening leading up to the onset of your chronic fatigue syndrome and how you have been managing since your problems began. This information has helped me to understand your problems better and to identify some of the things that I feel we could work on to help you to feel better.* So from the diagram we've drawn together, it seems that several factors are involved in keeping your CFS/ME going. You've mentioned that (use clients examples and try to link in thoughts feelings and behaviours), e.g., you sometimes push yourself too hard and then you feel worse and have to rest for a while which makes you feel really frustrated that you can't keep going. How does that sound so far? This irregular pattern of activity and rest that you have described - what we call a boom and bust cycle - and your disturbed sleep are other factors that may be involved in keeping the symptoms going. So it's

possible that by managing all of these things slightly differently, would help you to be able to make a difference to how you feel. Would you be willing to try that?

So, in a nut shell, cognitive behaviour therapy aims to help people with CFS/ME to change certain patterns of thinking and behaviours that may be partially responsible for maintaining their CFS/ME problems.

To start with, we will work towards you having a consistent amount of planned activity and rest throughout the day based on the average amount that you are now having. So for example, rather than resting (use participant's example), e.g. in a block of 3 hours in the afternoon because you feel so fatigued at this time, you might take the same amount of rest but in 3 x 1 hour sessions.

Changing the way you do things may understandably make you feel a little worried about the effect on your symptoms. Over the weeks we will look at these thoughts together with the aim of helping you to identify more helpful alternatives which will hopefully help to reduce some of your worries/fears/anxieties etc. Once you have sustained a regular pattern of activity and rest, you will gradually increase the amount of activity that you do, in order to work towards some of the targets that you told me earlier that you would like to achieve, such as going out more with your friends, going back to work etc. Do you have any questions about what I have just said so far?

Outline number of sessions

It may be helpful for you to give participants the outline of CBT session sheet, (Appendix 7). This will inform the participant about the number of and spacing of sessions. In order to increase the likelihood of the participant attending regularly, it might be helpful for you to agree a regular time and/or day for them to attend.

Discuss the possibility of the participant having a cotherapist

Discuss with the participant whether they would like to have a friend or relative to act as co-therapist while they are doing their CBT programme. You can suggest that the co-therapist may come to one or more sessions, i.e. to hear about what CBT involves and

how they can support the participant with the programme (Please see page 57 for more details).

Homework discussion

Participants should be given their treatment manual and self-monitoring diaries to complete. (Please see Activity Diary, Appendix 12 and Sleep Diary, Appendix 13). You should explain the reason for completing the diaries and give examples of how to complete them.

Homework: Read information about CFS and how to complete activity diaries. Also read information on planning targets for treatment. Complete self-monitoring diaries. Ask “co-therapists” or family or friends to read information for relatives, friends, etc in the treatment manual, or a handout.

Session 2

In this session it is important to elicit the participant's reactions and any concerns that they have about the previous session. Any concerns should be discussed during the session.

Review CBT model and review the rationale for treatment

The treatment rationale should be reviewed with the participant and any misconceptions that they may have should be explored. For example, sometimes participants will take away a particular message about what you think has caused or maintained their problems. In this situation, it is useful to re-draw and discuss an individualised model with the participant, emphasizing all of the factors that seem relevant to them as well as those that seem relevant to you. Try to go with the participant's view as much as possible. Join with them rather than oppose them.

For participants who have a very fixed idea about what has caused their CFS/ME, e.g. a virus, chemical poisoning etc, you may need to spend more time on discussing the CBT model. Carefully discuss all of the factors however small that may have contributed to the development and maintenance of CFS/ME. It is not helpful to challenge participant's beliefs at this stage, as it is likely to anger or frustrate them which may make it more difficult for a positive therapeutic relationship to be established. It is important that you gain the participant's agreement to work within the CBT framework collaboratively with you over the next few months. It is more useful to try and broaden, rather than challenge, their illness attributions. These days most people acknowledge that even for conditions such as cancer, heart disease or diabetes, social, emotional, cognitive and behavioural factors play a part in causation and/or prognosis.

Establish a baseline of activity and rest and a regular getting up time

Self monitoring diaries are reviewed with the participant and an initial programme is agreed. Use information from the participant's activity diary to calculate the total amount of rest and activity they have in a typical week. The aim of the first programme is to regulate the amount of activity and rest that the participant has each day. Examples of initial activity programmes are on the next page. Periods of activity should be agreed at regular times and for a set duration. Periods of rest should be based on individual need and should also be taken at regular times and for a set time(s) in the morning and afternoon. In order to provide more structure, you may agree a getting up time. This is particularly important when the participant's getting up time is erratic. You may agree to take an average of the time the participant has got up in the previous week. Participants may be fearful about doing things in such a structured way and therefore care should be taken to ensure that you are spreading what they are already doing over a week, rather than increasing activity at this stage. Participants will write down what they are planning to do on the activity programme (Appendix 14), while you record details of homework on their session record. Agree that their activity programme is an experiment and ask them to predict what they think might happen. Agree to discuss their experience of the programme at the next appointment.

Important: Make sure you warn clients that a temporary increase in symptoms at this stage is nothing more than their body getting used to a new way of doing things, and that this should pass.

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

Discuss longer-term targets

In this session, it is important to agree long term targets with the participant. (Please see page 59 for more details). Participants should be encouraged to have a variety of targets, e.g. social, work related, home, exercise, hobbies, DIY etc. The targets should be realistic, i.e. intending to go back to work full time when they have been ill for many years, or to run in a marathon when they have never run before, should be discouraged. The targets should be specific and measurable, i.e. Go to the cinema weekly, rather than to go out more often. Targets should represent what the participant

would like to achieve and be a representation of recovery or improvement to the participant. When you negotiate the targets, ask the participant to write down their targets on the longer-term target record, and then either make a photocopy of this for your records, or write them down on another longer-term target record and file it in your notes. If time, discuss what steps would need to be taken to achieve each target. For example it would be unrealistic to expect someone who has been out of work for a few years to go straight back to work. It is therefore important that you break down each target into manageable steps. Each step should represent only a minimal increase or change in activity level. At all costs, sudden increases of activity should be avoided as they are likely to lead to increased symptoms, resting to recover and disappointment. The participant can write down the steps to achieving each target on their target breakdown sheet in their manual.

Homework: Carry out structured activity and rest programme, continue self monitoring diaries. Read information on planning activity and rest and improving your sleep.

Session 3

Review the participants understanding of the model

Participants will have tried to stabilize their levels of activity and rest for homework, by having planned chunks of activity and rest throughout the day at set times. They may have also aimed to get up at a regular time each day and may have cut out sleep in the day time. It is important to check with the participant that they understand the reason for doing things in such a structured way. Information that they have read for homework in the section on planning activity and rest should be discussed to enhance their understanding of the model.

Review self monitoring diaries and discuss progress with initial programme.

It is important to discuss the participant's homework in detail during this session. Ask the participant how they managed with their activity programme to get a general overview. The participant's thoughts should be elicited about doing things in a consistent way, (as opposed to, perhaps, the way they previously managed their problems). Participants may report being more fatigued than previously. It is helpful to reassure them that this is normal and is to be expected when they start doing things in a different way. After a general discussion, look at the diaries with the participant to give you a more detailed account of their progress or difficulties. This detailed information will then help you to agree changes that should be made to their programme.

The questions below may help you to gain a clear idea of how the participant has managed with their activity programme since their last appointment. The participants' answers to the questions below will help you to decide on what changes may be necessary to their activity programme for the next week. The questions that relate to planned activity and planned rest will apply to most participants, but the questions that you ask relating to sleep will depend on any sleep problem that the participant is experiencing.

- Planned activity.
 - What percentage of the time or how often did the participant manage to go for their agreed walk, read, do chores, meet a friend for coffee etc?
 - How often did they manage to do their activity for an agreed time, e.g. walk for 10 minutes, read for 30 minutes etc?
 - For activities where they did not stick to the agreed programme, were they doing them more, or, less often, for longer or shorter?

- Planned rest.
 - What percentage of the time did they manage to have their planned rests?
 - How often did they have their rests for an agreed amount of time?
 - If they did not stick to the agreed times, did they rest more or less frequently, for longer or shorter?

- Sleep
 - How often did they manage to get up at their agreed time?
 - How often did they manage *not* to sleep in the day?
 - How long did it take them to get to sleep at night?
 - How often did they wake in the night and for how long?
 - How many hours did they sleep for in total?

Discuss strategies to improve sleep.

The strategies that you discuss with participants will very much depend on the type of problems that they have. However, the most commonly used technique is sleep restriction as people with CFS/ME will often sleep for too long. This will involve you agreeing a getting up time, restricting sleep in the day time and possibly agreeing that they do not go to bed before a particular time. Other techniques such as stimulus control, worry time and developing a pre-sleep routine can be particularly helpful for people who have difficulty in getting to sleep at night. More information about techniques to improve sleep is included in the sleep section of the participant's manual.

Agree an activity programme including initial steps towards targets

Changes to the participant's activity programme should be agreed depending on how much of it they have achieved. Please see the chart on the next page for guidance. If participants have managed to achieve a high percentage of their previous week's homework, they may be able to include one or two steps towards their longer-term targets that you agreed with the participant last week. Ask participants for their own suggestions for the programme in light of what they have read and what they understand from your discussions so far.

It is important that the participant's activity programme reflects a balance of different types of activity, e.g. walks, reading, computer work, seeing friends as well as agreed periods of relaxation. Participants should be reminded that periods of relaxation as well as periods of activity should be taken at set times and for a set duration, rather than in response to symptoms.

Homework: Continue self-monitoring diaries, carry out agreed programme, read information on how to increase or change activity levels.

Guidance on when to change levels of activity

% OF SUCCESS IN ACHIEVING ACTIVITY 0 = NO SUCCESS 100 = COMPLETE SUCCESS	POSSIBLE REASONS FOR ACHIEVEMENT/ NON ACHIEVEMENT	HOW TO CHANGE ACTIVITY LEVEL
0-25%	activity level set too high an acute illness relapse of symptoms	Reduce activity level
25-50%	activity level set slightly too high.	Reduce activity level slightly, if nearer 25% achievement level, otherwise keep activity level the same
50-75%	activity level set about right	Keep activity level the same if nearer the 50% achievement level, otherwise *slightly increase the activity level.
75-100%	activity level set about right	*increase activity level, unless participant has reached ultimate target, in which case keep the activity level the same/ or start on another target

*The amount of time by which the participant increases activity, will depend on what the activity is, and the time that they are already spending on it.

Phase 2: Active treatment

The aims of this phase are to:

- Help participants to become aware of unhelpful thinking patterns, e.g. that fatigue should be responded to by avoiding or reducing activity.
- Test negative beliefs by implementing gradual behavioural change.
- Address blocks to recovery, e.g. being in receipt of benefits, ongoing stressful situations, a lack of social support etc.
- Work on any other problems brought up at assessment that may be amenable to CBT, e.g. anxiety problems.

Session structure

At the beginning of all sessions, the therapist will remind the participant of the length of the sessions (50 minutes). An agenda is agreed with the participant incorporating suggestions from the therapist and participant. Other components will include enquiring about reactions to the previous session, and from time to time, reviewing their understanding and acceptance of the CBT model. New therapeutic techniques will be introduced depending on their individual problems, e.g. problem solving blocks to recovery, addressing sleep problems etc. Participants will be encouraged to have a more active role in suggesting plans for homework. Sessions will end with a review of session content and checking their understanding of what has been discussed.

Session 4

Review cognitive behavioural model

In order to ensure that the participant understands the rationale for CBT, it is useful to review the CBT model again. Depending on their level of understanding, you may draw another diagram, or review an old one that you have drawn together. Elicit any concerns that they may have and try to allay them by further discussion.

Elicit cognitions that may interfere with homework

Ask participants about their thoughts on completing their new programme. Discuss any thoughts that they mention that you feel may interfere with their ability to carry out their homework as a way of re-introducing cognitive therapy.

Examples of unhelpful thoughts include the following:

1. *I will feel worse if I get up at the same time each day if I haven't slept well the night before*
2. *I will hurt more, if I go for a walk every day.*
3. *I can't rest when there is so much to do.*

Depending on time available and the level of participant's understanding, either;

- a. Introduce the unhelpful thoughts diary (Appendix 15).
Write down examples of their unhelpful thoughts, situations in which they may occur and emotions that they may provoke.**

Or

- b. Introduce the new thoughts diary (Appendix 16)
Write down examples of their unhelpful thoughts, situations in which they may occur, emotions that they may provoke and discuss alternatives.

Examples of alternative to the unhelpful thoughts include the following:

1. *I don't know that I will feel worse, and in the long run, I may feel better.*
2. *I may hurt more to start with, but I remember before I had CFS/ME that I ached more when I increased exercise and it gradually lessened, the same may happen again.*
3. *When I took lunch breaks at work I found that I managed better in the afternoon. Maybe the same will apply at home if I take regular breaks!*

****If you do not have time to discuss in detail how to challenge unhelpful thoughts in this session, make sure that you at least mention coming up with alternatives. This is important as participants may feel more distressed if they are just writing down their unhelpful thoughts.**

Homework: Carry out agreed activity programme; continue self-monitoring diaries, read section on unhelpful thinking patterns and depending on how much you managed to discuss in session, either ask the participant to;

- a. Complete the unhelpful thoughts diary. Ask them to record examples of situations in which they experienced an unpleasant emotion or mood change, and to write down as exactly as possible what was going through their mind at the time on the unhelpful thoughts diary, or
- b. Complete the new thoughts diary. Ask the participant to record examples of situations in which they experienced an unpleasant emotion or mood change and write alternative, more helpful thoughts on their new thoughts diary.

It is important to point out that it can be hard to identify unhelpful thoughts at first. Inform the participant that recording unhelpful thoughts may heighten their awareness of their problems and temporarily make them feel worse. Participants should be advised that if this happens, they should perhaps spend ½ hour a day writing down their unhelpful thoughts and make sure that they identify alternatives from the start. They should also be encouraged to discuss their difficulties with their co-therapist (if they have one), or a family member or friend.

Session 5-7

Review of self-monitoring diaries and discussion of homework

The homework that has been carried out since the previous session will be discussed in detail with the aid of the self-monitoring diaries. It is important to elicit the participant's reactions to their homework and how much of it they managed. Any difficulties they have had in adhering to their programme should be tackled by using a collaborative problem solving approach. If it appears that targets have been set too high, they should be adjusted accordingly. For example, if a participant has agreed to get up at 8.30a.m, but has got up after 10.00am each day, it would be more realistic to agree that they get up at 9.30a.m. When participants are managing to achieve targets on a regular basis, e.g. 75% of the time, then they should be increased. Participants should be reminded that with an increase in their targets, they may notice an increase in symptoms.

Discuss using target achievement records and stopping sleep diaries

When you are satisfied that participants are managing a consistent level of activity and rest, you may introduce the possibility of them using target achievement charts, i.e., (Appendix 17) which are less time consuming to complete. Rather than record everything they do in the day, participants can write down their programme on the left side of the chart and simply tick each target when it is achieved.

Cognitive Work

Cognitive work involves checking the understanding of what they have read from the section of unhelpful thinking patterns in the treatment manual. The link between thoughts, feelings (emotional and physical) and behaviour will be discussed using their own examples. It is important to initially focus on thoughts related to homework difficulties and then to thoughts on symptoms, rest, sleep, illness attributions, self-esteem, performance and expectations. Participants will be taught how to identify unhelpful patterns of thinking (thinking errors), find evidence for and against their unhelpful thoughts, generate a number of alternative thoughts and write an action plan.

The effectiveness of the alternative thoughts will be reviewed by measuring their belief in their unhelpful thoughts before and after generating alternatives. How they felt emotionally will be compared from how they felt at the time of their unhelpful thought to how they felt after generating alternatives. Their action plan will be discussed in terms of how effective it was in helping them to break negative patterns of thinking.

Participants will be told that challenging unhelpful thoughts is a skill and requires a lot of practise. Difficulties that participants have with any aspect of their cognitive work will be explored. A common problem is a difficulty in identifying unhelpful thoughts; this can be addressed by discussing the meaning of upsetting events. Guided imagery can be helpful in recreating specific situations and emotions in order to identify thought content. Participants who have difficulty in generating alternatives or who do not find the process beneficial in making them feel any less upset will need further time for discussion. It can be helpful to go through the section “How to challenge your unhelpful thoughts”, in the participants manual. This section suggests different questions to help them to develop alternatives, such as “what is the actual evidence that this thought is true?”; “Have I had experiences that this thought is not true all of the time?” It is important that alternatives are elicited from the participant wherever possible so that they can learn to re-evaluate their thinking for themselves.

Mid-way evaluation

It is useful to carry out a mid- treatment evaluation at session 7, in order to check the participant’s overall understanding of the model of treatment, how they feel they are progressing, any general problems that they have in regard to the programme and issues that need to be addressed in the remaining sessions. In order for the participant to feel as confident as possible about continuing working towards targets after the end of the programme, they should be encouraged to generate their own ideas for their homework as much as possible.

Homework: Carry out agreed activity programme, self-monitoring diaries and challenging and recording thoughts on new thoughts record.

Session 8-11

Review of self-monitoring diaries, homework and progress towards targets

This will be a continuation of what you have been doing in previous sessions. Homework will be reviewed with the aid of self-monitoring diaries. Problems with homework will be discussed and solutions agreed. Homework for the next appointment will be discussed with the emphasis on the participant generating ideas wherever possible. New targets will be agreed when the participant has been achieving goals consistently. Rest will be gradually decreased as their tolerance allows.

Discuss potential blocks to recovery

Participants may be following their agreed programme diligently, but may be experiencing difficulties in making progress. If this is the case, it is useful to identify and discuss possible reasons. There may be some very obvious reasons for their lack of progress, e.g. a total lack of support from a partner, ongoing stressful situations or having another illness on top of their CFS/ME. Sometimes the reasons are less obvious. For example, if a participant is in receipt of benefits, or income protection (IP), this may inadvertently lead them not to push themselves too hard. This may result from a feeling of having to prove that they are “still ill” in order to keep their benefits. Another example would be that getting better sometimes means facing things that may have been difficult in the past, e.g., meeting people socially, being responsible for the running of the home, their work, paying bills etc. Also if a participant has been ill for a long time, they may have lost their confidence in their ability to do a variety of things, e.g. travelling alone, meeting new people etc. It is important that you tackle the participant’s lack of progress in a sensitive manner. The way in which you help the participant to overcome these difficulties will depend on the “block” that is identified.

Addressing worries, stress and anxiety associated with CFS

Understandably, many participants, particularly those who have had CFS/ME for some years, will have lost confidence in their ability to do certain things. These may be minor things, e.g. making phone calls, to major things, such as working. It is important to normalise any worries that they may experience and to discuss the reality of losing confidence in our ability to do things when we don't practice something regularly. Giving your own personal examples can highlight this point well, particularly if the participant can identify with them in some way, however be careful with this! Examples could include, starting a new job, meeting up with friends they haven't seen for a long time etc. Participants may also be indecisive about what they want to do in the future, or may feel particularly worried about something that is happening in their lives. In order to address these problems, the following strategies may be discussed:

- Problem solving- to help them decide on what they want and how to go about getting it, e.g. what work to do, what to do about relationship problems, what sort of course to do.
- Gradual exposure to situations which cause anxiety , e.g. situations that they have not been in for a while or at all, e.g. socializing, travelling on public transport or starting a course at college.
- Responsibility Pie - to look at a problem / situation in a more realistic way, e.g. feeling responsible that they did not meet work-related targets.

Problem solving forms (Appendix 18) and exposure task records (Appendix 19) can be found at the back of this manual.

For participants whose worries cause them to feel physically anxious, rather than a mild concern, it is helpful to discuss with them the cognitive behavioural model of anxiety. Discuss the physiological aspects of anxiety that give rise to unpleasant symptoms, e.g. an increase in nerve activity and adrenaline production can precipitate feelings of

weakness and exhaustion that can add to the fatigue and muscle ache of chronic fatigue syndrome. Discuss the participant's thoughts in relation to their worries and encourage them to challenge them as discussed in earlier sessions.

Ask participants to read the section on "addressing worries, stress and anxiety associated with CFS" in the manual.

Being in receipt of benefits or income protection (IP)

If this is something that has not already been addressed, it is important to address it at this stage. People with CFS/ME are sometimes very keen to come off benefits and it does not cause them too many problems, maybe because they have another source of income. However, it can raise a lot of issues for other people and can be a source of great anxiety.

Evidence from research trials has indicated that patients who are in receipt of benefits or permanent health insurance do less well than those who are not in receipt of them. In reality, benefits and IP can help patients financially in the short-term, but prove to be an obstacle to getting better in the long term. In order for benefits or IP to continue, patients have to have regular check-ups in order to prove that they are still ill. This can understandably be very distressing for patients and be an active factor in maintaining their condition. For some patients, returning to work can be very frightening as it may have been a major contributing factor to them becoming ill in the first place. Obviously for some patients, work is not an option due to the severity of their symptoms.

For more information on work related issues, please see Appendix 20. There is also a section in the participants' manual on work, courses and resources that you may ask them to read.

Benefits

Participants may feel trapped by their benefits, i.e. some benefits will stop being paid if they earn more than £20.00 a week. Participants may find the prospect of stopping benefits and working the number of hours required to earn more than their benefits would pay quite daunting. They can also be very fearful that if they come off benefits and have a relapse, they will not be able to receive benefits again. It is therefore useful to spend time discussing their fears and discuss different options. If they are keen to come off their benefits, it is useful to discuss steps to be taken to increase their ability to work, e.g. by doing some voluntary work, or 'permitted work'.

IP

For participants who are in receipt of IP, it can be worth discussing the advantages and disadvantages of being on it. For participants who feel clear that they do not wish to return to that job, it may be useful for them to discuss the possibility of resettlement options with their employer. For participants who wish to return to their previous job, but feel unable to work the hours that they used to do, you could suggest that they discuss a graded return to work, or part-time work. For participants considering a return to work it is helpful to suggest that they build up their stamina and confidence in their ability to work again, e.g. by doing some voluntary work. For participants who want to leave their job, it is worth discussing different options with them and getting them to look at different alternatives for homework.

It is helpful for you to offer to write to employers, insurance companies, be involved in meetings with their occupational health department or what ever is necessary to help participants to meet their work-related goals.

Cognitive Work

Cognitive work should continue as in previous sessions. The content of their thought diaries should be reviewed. Suggestions to enhance their ability to identify unhelpful thoughts, increase their awareness of thinking errors, generate alternatives and write action plans should be discussed. The role of unhelpful thoughts in terms of blocking

recovery should be discussed, e.g. “I’m not going to register at college because if I can’t go on a regular basis, I will let other people down”. Any regular themes that occur should be discussed with a view to identifying unhelpful core beliefs. Themes may include not being good enough, (related to perfectionism); never getting well again etc. The cognitive work that you do with the participant will depend on the individual. Sometimes participants find it very helpful to draw out a diagram of how their core beliefs may have been formed and maintained, others may be happy with a general discussion. If core beliefs or assumptions (rules that guide behaviour) are identified, it would be helpful to draw the participant’s attention to section 2 of “tackling unhelpful assumptions and core beliefs”, in the participant’s treatment manual. Participants would need to find evidence that doesn’t support their unhelpful core belief and do behavioural experiments to test their beliefs. When their strength of belief relating to their core belief is diminished, they would need to identify a more helpful core belief. They would then need to strengthen their new belief by finding evidence to support it.

The following work sheets for participants to complete may be found at the back of the manual:- Identifying core beliefs about a. me (Appendix 21); b. others (Appendix 22); c. the world (Appendix 23); Diagram of how core beliefs may be formed and maintained (Appendix 24); Challenging core belief record (Appendix 25); New core belief record (Appendix 26)

Homework: Carry out agreed activity programme, self-monitoring diaries (either activity diaries or target achievement charts); challenging and recording thoughts on new thoughts record. Read any new information from the manual, e.g. blocks to recovery; work, courses and resources; worry, stress and anxiety related to chronic fatigue syndrome; tackling unhelpful assumptions and core beliefs. Practise using any new techniques discussed in sessions, e.g. problem solving or exposure to anxiety provoking situations. Complete cognitive work sheets related to core beliefs, if applicable.

Phase 3: Preparation for discharge

The aims of this phase are to:

- Maintain and consolidate progress so far
- Promote the idea of the participant being their own therapist by ensuring that they can confidently set a programme for themselves and are able to monitor their own progress and make further gains once sessions have ended.
- Ensure that the participants lifestyle will facilitate their recovery, e.g. that their life is as balanced as possible in terms of time to do things that they enjoy as well as things that have to do, e.g. chores etc.
- Agree goals for participants to work towards over the coming months.
- Develop participants' confidence in their ability to identify warning signs of a set-back and how to manage any set-back effectively.

Session structure

The structure of sessions will be similar to that of phase 1 and 2. An agenda is agreed with the participant incorporating suggestions from the therapist and participant. Other components will include enquiring about reactions to the previous session, reviewing their self-monitoring diaries and reviewing their homework. Participants understanding and acceptance of the CBT model will be discussed. Therapeutic techniques that have been implemented will be discussed to ensure the participants understanding of them. Participants will be encouraged to suggest their own homework plans to promote their confidence in moving forward without a therapist. Sessions will end with a review of session content and checking their understanding of what has been discussed.

Session 12-14

Preparing for the future

The priority of the last few sessions is to ensure that the participant feels confident about being able to make further progress and deal with potential problems, without help from the therapist. It may be worth emphasising that the follow-up periods is when many clients make the majority of their improvement and that the end of treatment should therefore not be seen as the end of the recovery.

Checking the participants understanding of what they have learned during sessions, is important. Ask them to complete the “evaluation of progress” record (Appendix 27) as this will highlight their understanding of the CBT model and areas that they need to work on after discharge. All of the techniques that have been implemented during CBT should be discussed with a view to evaluating their usefulness and ensuring that participants feel confident about using them in other situations. For example, if participants have used problem solving in relation to work issues, they should feel able to use the technique in resolving other problems.

Participants should have a clear plan of what to work towards between session 14 and their booster session, and should write it on the targets for booster session, (Appendix 28). It is important to discuss how participants plan to work towards these targets, e.g. how often to increase their level of activity as well as ensuring that they feel confident in monitoring their progress. Patients sometimes find it helpful to continue to use the activity diary or target achievement record. Others find that the record of progress (Appendix 29) is better as it requires less detail. It may be helpful to suggest that participants make a regular time each week to think about their progress in the previous week, to enable them to make realistic plans for the following week. If a relative or friend has been involved in their treatment programme they may like to set a regular time to speak with them about their plans.

Management of set-backs

Participants who have experienced a set-back during treatment i.e. an increase of symptoms may have learned some useful strategies to help them to overcome any future set-backs. However, if a participant has made steady progress throughout treatment, with no set-back, then it is important to discuss practical ways of dealing with them, should they occur. For all participants, it is useful to discuss potential triggers to set-backs, e.g. viral infections, life events, if they stop using techniques that you have discussed during session etc. Each participant should be asked to complete a “preventing set-back” form (Appendix 30), to be discussed in session. It is important to emphasise that a set-back does not mean that they are going back to square 1 and it can in fact help them to understand their CFS/ME better and enhance the way they deal with it in the future.

Homework: Review what has been learned during treatment. Complete evaluation of progress, targets for the next 3 months and think about triggers for set-backs and ways of managing them using the preventing set-back form. Continue to work on any outstanding problems, e.g. challenging core beliefs, exposure to situations that cause anxiety etc. Complete an activity diary for 1 week before coming to the booster appointment.

BOOSTER SESSION

Evaluate progress since discharge appointment

Discuss the participant's progress since their discharge appointment. Discuss how they have managed with the targets that you agreed for them to work towards. Review the activity diary that they should have completed for 1 week before their appointment as this will help you to check whether they are maintaining a planned consistent programme of activity and rest. If the diaries show prolonged periods of activity or rest, or an erratic sleep pattern etc, discuss the participants' reasons and agree plans to overcome these problems.

Discuss problems that have occurred during the past 3 months.

Discuss any problems that they have encountered during the previous 3 months. These may be related to their CFS/ME or other problems. Discuss strategies that they have used in order for them to overcome their problems. Common problems include: - not achieving targets, having a set-back.

Problem solve any outstanding problems

For any outstanding problems that the participant feels they have been unable to overcome, generate some alternatives with the participant and try to agree a plan to enable the participant to be able to resolve the problem.

Review their understanding of the model

As this will be the last time that you will be seeing the participant, it is important to check their understanding of the model and to resolve any misconceptions.

Discuss further targets

If participants have reached some of their targets then it is useful to discuss others that they would like to work towards over the coming months.

REFERENCES

- Sharpe M, Hawton KE, Simkin S, Surawy C, Hackmann A, Klimes I, Peto T, Warrell D, Seagroatt V. Cognitive behaviour therapy for the chronic fatigue syndrome: a randomized controlled trial. *BMJ* 1996;312:22-6.
- Deale A, Chalder T, Marks IM, Wessely S. Cognitive behaviour therapy for chronic fatigue syndrome: a randomized controlled trial. *Am J Psychiatry* 1997;154:408-14.
- Deale A, Hussain K, Chalder T, Wessely S. (2001) A randomised controlled trial of cognitive behaviour therapy for chronic fatigue syndrome: a five year follow up. *American Journal of Psychiatry*. 158; 12; 2038-2042.
- Sharpe M. Cognitive behavior therapy for functional somatic complaints. The example of chronic fatigue syndrome. *Psychosom* 1997;38(4):356-62.
- Chalder T, Butler S, Wessely S. In-participant treatment of chronic fatigue syndrome. *Behavioural and Cognitive Psychotherapy* 1996;24(4):(pp 351-365).
- Surawy C, Hackmann A, Hawton KE, Sharpe M. Chronic fatigue syndrome: a cognitive approach. *Behav Res Ther* 1995;33 (5):535-44.
- Joyce J, Hotopf MH, Wessely S. The prognosis of chronic fatigue and chronic fatigue syndrome: a systematic review. *QJM* 1997;90(3):223-33.
- Petrie KJ, Moss-Morris R, Weinman J. The impact of catastrophic beliefs on functioning in chronic fatigue syndrome. *J Psychosom Res* 1995; 39(1):31-8.
- Sharpe M, Hawton KE, Seagroatt V, Pasvol G. Participants who present with fatigue: a follow up of referrals to an infectious diseases clinic. *BMJ* 1992;305:147-52.
- Ray C, Jefferies S, Weir WR. Coping and other predictors of outcome in chronic fatigue syndrome: a 1-year follow-up. *J Psychosom Res* 1997;43(4):405-15.
- Sharpe, M., Chalder, T., Palmer, I., & Wessely, S. (1997). Chronic fatigue syndrome: a practical guide to assessment and management. *General Hospital Psychiatry* 19, 195-199.
- Chalder T. (1997) Cognitive Behavioural treatment for participants with chronic fatigue syndrome. *British Journal of Therapy and Rehabilitation*. 4; 12, 655-658.
- Deale, A., Chalder, T., & Wessely, S. (1998). Illness beliefs and treatment outcome in chronic fatigue syndrome. *Journal of Psychosomatic Research* 45, 77-83.
- Reid, S., Chalder, T., Cleare, A., Hotopf, M., & Wessely, S. (1999). Chronic fatigue syndrome. *Clinical Evidence* 2, 397-405.

Reid, S., Chalder, T., Cleare, A., Hotopf, M., & Wessely, S. (2000). Chronic fatigue syndrome. *British Medical Journal* 320, 292-296.

Ridsdale L, Godfrey E, Chalder T, Seed P, King M, Wallace P, Wessely S. (2001) Chronic fatigue in general practice: is counselling as good as cognitive behaviour therapy? A UK randomised trial. *British Journal of General Practice*. 51; 19-24.

Chisholm D, Godfrey E, Ridsdale L, Chalder T, King M, Seed P, Wallace P, Wessely S. (2001) Chronic fatigue in general practice: Economic evaluation of counselling versus cognitive behaviour therapy. A UK randomised trial. *British Journal of General Practice*. 51; 15-18.

LIST OF APPENDICES

Page	Appendix.
109.	1. Record of attendance
110.	2. Trial session record
112.	3. CGI and treatment adherence for therapists and doctors
114.	4. Unplanned phone call record
115.	5. PACE Therapies Rating Scale
121.	6. Review of session record
122.	7. Outline of CBT sessions
123.	8. Information for relatives, partners and friends
129.	9. Long-term target record
130.	10. Behavioural experiment record
131.	11. Assessment form
138.	12. Activity diary
139.	13. Sleep diary
140.	14. Activity programme
141.	15. Unhelpful thoughts diary
142.	16. New thoughts diary
143.	17. Target achievement chart
144.	18. Problem solving
145.	19. Exposure task record
146.	20. Work, courses and resources
152.	21. Identifying core beliefs (about me)
153.	22. Identifying core beliefs (about others)
154.	23. Identifying core beliefs (about the world)
155.	24. Diagram of how core beliefs may be formed and maintained
156.	25. Challenging core belief record
157.	26. New core belief record
158.	27. Evaluation of progress
159.	28. Targets for booster session
160.	29. Record of Progress
161.	30. Preventing a set-back

TRIAL SESSION RECORD

Trial number _____ **Date of session** _____

Session number _____ **Attended/cancelled/dna** _____

Face to face appointment _____ **Telephone appointment** _____

Duration of session _____ **Other contact (brief call, etc)** _____

Agenda

Session content

Homework plans

Points for discussion for next session

Action to be taken by therapist (e.g. contact GP; send a letter)

Therapist signature

CGI and treatment adherence for therapists and doctors

PIN		Participant Initials			Date completed			
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Centre	Participant	Fore.	Midd.	Sur.	Day	Month	Year	

The following is a global impression of change scale. Please rate this scale including all of the various therapeutic factors.

1. Overall, how much has the participant changed since the start of the study (please tick only one box)?

Very much better	
Much better	
A little better	
No change	
A little worse	
Much Worse	
Very much worse	

2. How well has the participant adhered to the treatment – did the participant actually implement what had been negotiated in the therapy sessions (please tick only one box)?

Completely	Very well	Moderately well	Slightly	Not at all
------------	-----------	-----------------	----------	------------

3. To what extent did the participant accept the model of therapy? (Please tick only one box).

Completely	Very well	Moderately well	Slightly	Not at all
------------	-----------	-----------------	----------	------------

4. Sessions received

- a. How many therapy sessions with you **in total** has the participant received (include face-to-face sessions and telephone sessions, but not administrative calls i.e. to re-arrange appointments)?

<input type="text"/>	<input type="text"/>
----------------------	----------------------

- b. Of these, how many were conducted over the telephone (do not include administrative calls)?

- c. How many hours and minutes in total of treatment were given (do not include administrative calls)?

 Hours minutes

5. How many planned sessions did NOT occur?

Of these:

- a. How many were cancelled because of your being unable to attend?

- b. How many cancellations or DNAs were instigated by the participant (e.g. travel problems, sickness, family commitments)?

- c. How many therapy sessions were cancelled by mutual consent (i.e. both you and the participant *agreed that the session was unnecessary*)?

6. How many unplanned phone calls took place (phone calls regarding treatment issues, do not include administrative calls)?

7. How many sessions were attended by a relative (not partner) of the participant?

8. How many sessions were attended by a friend of the participant?

9. How many sessions were attended by the participant's partner?

UNPLANNED PHONE CALL RECORD

Trial number: _____

Date: _____

This sheet is only to record unplanned phone calls; if the call was arranged to replace a face-to-face treatment session, then use the trial session record rather than this sheet.

WHO CALLED WHO?

- Participant called, and spoke to, therapist
- Therapist called, and spoke to, participant
- Participant left message on answer phone/ receptionist
- Therapist left message on answer phone/ with another

PURPOSE OF CALL:

(Tick all appropriate boxes and add further comments if necessary)

- 1. To rearrange an appointment
- 2. write new appointment date in record of attendance
- 3. Is appointment within 5 days?
 - a. Yes
 - b. No
- 4. To explain a DNA/cancellation (add to attendance record)
- 5. To request advice (add clear notes below)
- 6. To follow up a DNA
- 7. Was any therapeutic advice given?
 - a. Yes (write full notes below)
 - b. No
- 8. Other reason, please specify _____
- 9. Duration of call _____

FURTHER COMMENTS:

Please record further information, including any advice given.

Therapist signature

PACE THERAPIES RATING SCALE

A. Alliance and facilitative conditions scale:

1. Supportive encouragement:

Was the therapist supportive of the client by acknowledging the client's gains during therapy, or by reassuring the client that gains will be forthcoming?

1	2	3	4	5	6	7
not at all		some		considerably		extensively

2. Convey expertise:

Did the therapist convey that she/he understood the client's problems and is able to help the client?

1	2	3	4	5	6	7
not at all		some		considerably		very much

3. Therapist's communication style:

How interesting is the therapist's style of communication? (Consider (1) the vividness of her/his language; (2) the originality of her/his ideas; (3) the liveliness of her/his manner of speaking).

1	2	3	4	5	6	7
dull, uninteresting	less interesting	than average	more interesting	than average	very interesting	interesting

4. Involvement:

How involved was the therapist?

1	2	3	4	5	6	7
very detached		somewhat detached		mainly involved		very involved

5. Warmth:

Did the therapist convey warmth?

1	2	3	4	5	6	7
not at all or very little		some		a lot		very much

6. Rapport:

How much rapport was there between therapist and client (i.e. how well did the therapist and client get along?)

1	2	3	4	5	6	7
total absence of rapport		some rapport		considerable rapport		excellent rapport

7. Empathy:

Was the therapist empathic towards the client (i.e. did she/he convey an intimate understanding of and sensitivity to the client's experiences and feelings)?

1	2	3	4	5	6	7
not at all		some		considerably		extensively

8. Patient self-discloses thoughts and feelings:

1	2	3	4	5	6	7
not at all		somewhat		quite a bit		very much so

9. Patient expresses strong emotions:

1	2	3	4	5	6	7
not at all		somewhat		quite a bit		very much so

10. Patient works actively with therapist's comments:

1	2	3	4	5	6	7
not at all		somewhat		quite a bit		very much so

11. Patient shows confidence in therapy and therapist:

1	2	3	4	5	6	7
not at all		somewhat		quite a bit		very much so

12. Patient and therapist agree on the kind of changes to make:

1	2	3	4	5	6	7
not at all		somewhat		quite a bit		very much so

13. Patient and therapist share same sense about how to proceed:

1	2	3	4	5	6	7
not at all		somewhat		quite a bit		very much so

14. Patient and therapist agree on salient themes:

1	2	3	4	5	6	7
not at all		somewhat		quite a bit		very much so

B. CBT scale:1. Rationale for behavioural procedures:

Did the therapist provide a rationale which emphasised the importance for the client of undertaking specific activities in order to alleviate the client's symptoms?

1	2	3	4	5	6	7
not at all		some		considerable		extensive
		discussion		discussion		discussion

2. Practising/planning alternative behaviours:

Did the therapist work with the client to plan, or to practice alternative overt behaviours for the client to utilise outside of therapy?

1	2	3	4	5	6	7
not at all		some		considerably		extensively

3. Rationale for cognitive procedures:

Did the therapist provide a rationale which emphasised the importance of evaluating the accuracy of the client's beliefs and changing inaccurate beliefs in order to alleviate the client's fatigue?

1	2	3	4	5	6	7
not at all		some		considerable		extensive
		discussion		discussion		discussion

4. Recognising cognitive errors:

Did the therapist help the client to identify specific types of cognitive distortions or errors (e.g. all-or-nothing thinking, over-generalisation) that were present in the client's thinking ?

1	2	3	4	5	6	7
not at all		some		considerably		extensively

5. Searching for alternative explanations:

Did the therapist help the client to consider alternative explanations for events besides the client's initial explanations for those events?

1	2	3	4	5	6	7
not at all		some		considerably		extensively

6. Maintaining gains:

Did the therapist encourage the continued use after the end of therapy, of the skills the client had acquired during therapy?

1	2	3	4	5	6	7
not at all		some		considerably		extensively

Adaptive Pacing Therapy Scale

1. Rationale for balancing activity:

Did the therapist provide a rationale which emphasised the importance for the client of balancing activity?

1	2	3	4	5	6	7
not at all		some		considerable		extensive
		discussion		discussion		discussion

2. Practising alternating physical and mental activities:

Did the therapist work with the client to plan and or practice alternating physical and mental activities outside of therapy?

1	2	3	4	5	6	7
not at all		some		considerably		extensively

3. Rationale for energy conservation and expenditure:

Did the therapist provide a rationale which emphasised the importance of energy conservation and expenditure|?

1	2	3	4	5	6	7
not at all		some		considerable		extensive
		discussion		discussion		discussion

4. Discussion about the importance of prioritising certain activity:

Did the therapist discuss with the client the importance of prioritising activity?

1	2	3	4	5	6	7
not at all		some		considerably		extensively

5. Discussion about the importance of activity analysis and modification:

Did the therapist help the client to analyse and/or modify specific activities?

1	2	3	4	5	6	7
not at all		some		considerably		extensively

6. Importance of rest and relaxation

Did the therapist teach and practice rest and relaxation techniques with the client?

1	2	3	4	5	6	7
not at all		some		considerably		extensively

Graded Exercise Therapy Scale**1. Rationale for use of exercise or physical activity:**

Did the therapist provide a rationale which emphasised the importance and benefits of exercise or physical activity?

1	2	3	4	5	6	7
not at all		some		considerably		extensively

2. Discussion about the content of a physical exercise programme:

Did the therapist discuss the content of a physical activity or exercise programme with the participant?

1	2	3	4	5	6	7
not at all		some		considerably		extensively

3. Monitoring the physiological effects of exercise:

Did the therapist discuss ways of monitoring the physiological effects of exertion (heart rate/Borg rating scale) with the participant?

1	2	3	4	5	6	7
not at all		some		considerably		extensively

4. Did the therapist emphasis the importance of incremental, progressive changes in physical activity or exercise?

1	2	3	4	5	6	7
not at all		some		considerably		extensively

5. Did the therapist discuss how the participant could adapt their exercise or physical activity according to their changing circumstances or goals?

1	2	3	4	5	6	7
not at all		some		considerably		extensively

6. Did the therapist discuss, review or refer to the patient's physical goals?

1	2	3	4	5	6	7
not at all		some		considerably		extensively

Finally,

Homework assigned/reviewed: (same for all therapies)

Did the therapist or client develop one or more specific assignments for the client to engage in between sessions?

1	2	3	4	5	6	7
did not		some attempt		considerable		extensive
		to develop		attempt to		attempt to
		homework		develop		develop
				homework		homework

Overall, how would you rate the therapeutic alliance?

1	2	3	4	5	6	7
very poor		fair		good		excellent

Was this therapy session:

Adaptive Pacing Therapy	1
CBT	2
Graded Exercise Therapy	3

REVIEW OF SESSION RECORD

Date:

Session number:

For supervision purposes, it would be helpful if you could complete this record after each of your treatment sessions

What went well?	Were there any difficulties?
Questions to raise in supervision	Feedback/advice from supervision

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.

LONG-TERM TARGET RECORD

Please write down below a few targets that you would like to work towards during your course of CBT. As well as ensuring that you have a *variety* of targets to work towards including some *pleasurable* ones, try to make your targets SMART!

- *Specific* - stating exactly what, how much, when, where and with whom
- *Measurable* - how far, how long for and how often
- *Achievable* - Are the targets realistic?
- *Relevant* - Are the targets relevant to your life?
- *Time-related* - The targets have a specific time-frame

Target 1

Target 2

Target 3

Target 4

Target 5

Target 6

BEHAVIOURAL EXPERIMENT RECORD

CFS ASSESSMENT

Name: **Date of assessment:** **Name of Therapist**

Age:

DOB:

Address:

Phone:

GP:

Address:

Phone:

Occupation /benefits/PHI:

Main problem

Physical symptoms (frequency, intensity, duration)

Other symptoms (Short-term memory, concentration, exhaustion following mental effort, word finding difficulty, sleep -Initial insomnia, wake in the night, early waking appetite, weight, libido)

Restricted/modified activities- work, social, sport, home, relationship

**Typical day (getting up time, number of rests, length of activities, bed time routine)
Are some days different to other, e.g. weekends?**

**Onset - (viral illness, triggers, life events) What happened after the illness?
convalescence?, too much too soon etc.**

Course and fluctuations of illness since onset

Coping strategies- what do you do/have you done to reduce your symptoms (e.g. rest, belonging to an ME organization)

Modifying factors-Is there anything that makes your symptoms better or worse? (e.g., being too hot, cold etc)

Overall impact of illness on your life

Opinions/attitudes of important others, e.g. family, colleagues, friends (too much/too little)

Mental state: Mood- energy, enjoyment, self-worth, suicidal thoughts, guilt, hope, future. Anxiety- major worries/preoccupations, panic attacks.

Current treatment/management of this problem- (i.e. diet etc)

Meds:- prescribed, homeopathic, etc

Substances containing caffeine, e.g. tea or coffee; other substances, alcohol, cigarettes,

Previous treatments for this problem (with effect); response of other health care professionals

Past medical history (childhood illnesses, similar episodes of illness, operations, allergies, other illnesses)-dates, investigations and treatment

Psychiatric history (dates, treatments, therapies etc)

Other problems/issues

Beliefs: about the cause of the illness and why it is persisting

Treatment explanation using CBT model

Number of sessions

Family history (age, job, health, relationship)

Parents and siblings

Family psychiatric history

Personal history (birth, milestones, childhood, personality, family atmosphere, school, further education, work, sexual development, relationships, partners, children)

Premorbid personality and lifestyle

Current situation (housing, living with, hobbies, interests)

Future plans (work, moving house, starting a family etc)

ACTIVITY DIARY
(See landscape appendices)

SLEEP DIARY
(See landscape appendices)

ACTIVITY PROGRAMME

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

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%)

NEW THOUGHTS DIARY

See landscape appendices

TARGET ACHIEVEMENT CHART

(See landscape appendices)

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

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.

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:

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 ()

That may occur in the above situations and reinforce core belief

Behaviour in response to thoughts

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. _____

NEW CORE 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. _____

EVALUATION OF PROGRESS

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 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; work etc)

TARGETS FOR BOOSTER SESSION

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

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

RECORD OF PROGRESS

(see landscape appendices)

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 minimise set-backs and to try to prevent set-backs from occurring in the future, we would like you to complete this form.

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

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

