Manual for Therapists

Adaptive Pacing Therapy
(APT)
for CFS/ME

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on behalf of the PACE Trial Management Group

NB This manual was used in the PACE trial by healthcare professionals to support Adaptive Pacing Therapy (APT) and is available free of charge for down-loading at www.pacetrial.org, so long as no changes are made. Any use of this manual should acknowledge the PACE trial (www.pacetrial.org). This treatment should only be delivered by appropriately qualified healthcare professionals, who have received appropriate training and continued supervision in the use of APT. 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 APT 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.

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There are additional landscape appendices.
- Therapists Landscape appendix
  - Timing of sessions excel sheet
- Participants Landscape appendices;
  - Energy Grid
  - Weekly Plan
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Abbreviations

APT	Adaptive Pacing Therapy
CBT	Cognitive behaviour therapy
SSMC	Standardised Specialist Medical Care
GET	Graded Exercise Therapy
CFS	Chronic Fatigue Syndrome
RN	Research Nurse
DNA	Did not attend
ME	Myalgic encephalomyelitis/encephalopathy
PACE	Adapted **P**acing, Graded **A**ctivity, **C**ognitive behaviour therapy: a Randomised **E**valuation
UTA	Unable to attend

Use of the APT therapists' manual

The manual has been devised to give you a clear indication of what to cover in each session and to give an indication of what phase of the treatment process the patient and you are in.

The pink sheets divide the manual into the 3 phases of treatment.

The yellow sheets are the session plans and content for each of the 15 sessions of treatment. The space between the list of handouts is an indication of which might be used during the session and those that the participant will use at home.

The participant will receive the full handouts booklet in session 1; however a number of the handouts may have to be photocopied for daily use.

Participants may request that handouts are photocopied onto coloured paper as black on white for some people with CFS/ME may be difficult to read. It is suggested that each participant have a ring binder for ease of using and storing all information.

The participant handouts for specific sessions are appended to this manual. All participant handouts will be available to the therapist on computer for ease of duplication as required.

All sessions will be tape recorded and the duration of the session noted. A therapist record will be kept on each participant. The therapist will also note their own reflections on sessions and the treatment process (forms to assist in this process are in appendix 2). Relaxation sessions may also be taped and given to the participant for home use.

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.

The Pace Trial:

Short title of trial:

Pacing, graded **A**ctivity, and **C**ognitive behaviour therapy; a randomised **E**valuation

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 (SSMC)

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 l 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 determine 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 APT/ CBT/ GET

	SIMPLE ADAPTIVE PACING (APT)	**INCREMENTAL PACING (GET)**	**COMPLEX INCREMENTAL PACING (CBT)**
Model	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**

PACE Trial: Differences between APT / CBT / GET

Strategy / Method	**APT**	**CBT**	**GET**
Works from a pathological assumption	√		
Works from a deconditioning assumption		√	√
Aim 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/aims 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	√		
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	√	√	√

Rationale and Model of Adaptive Pacing Therapy

This manual outlines adaptive pacing therapy (APT) for CFS/ME to be used in the PACE trial. Pacing for CFS/ME is based on the descriptions of pacing that have been used for chronic pain for many years (Neilson et al 2001, Hanson 1990, Fey & Fordyce 1983). The principle behind the treatment is to help the person with CFS/ME to manage their level and pattern of both activity and rest to maximise function whilst avoiding an exacerbation of symptoms. The aim is to provide the best conditions for natural recovery to occur. A lessening of activity-associated symptoms is regarded as evidence of recovery which may permit an increase in activity.

The theoretical justification for pacing in CFS/ME is based on the idea that the disease limits available energy. Consequently it has to be expended wisely. This has also been described as an "energy envelope" in which the person with CFS/ME must remain if they are to avoid exhaustion. The pacing therapy used in this trial is based on that reported as useful by people with CFS/ME and collated by the patient organisation Action for ME (AfME 2002, 2003).

MODEL OF CFS/ME USED IN PACING

The concept of fixed limits

The basic underlying concept of adaptive pacing is that CFS/ME is an organic disease that the person can adapt to but cannot change. CFS/ME is regarded as limiting the persons' available energy. Exceeding the available energy causes an exacerbation of fatigue and other symptoms, often after a time lag. The limited energy is often described as a bank account, which may be overdrawn. If the person with CFS/ME has overdrawn the account they will inevitable have to "pay back". Pay back may be delayed so that excess activity today may result in greater fatigue tomorrow. Another analogy is the "envelope theory" (Pesek et al 2002). The exponents of this theory propose that if the sufferer's energy expenditure exceeds the energy available (the energy envelope) they will develop fatigue – the aim therefore is to keep within the envelope of available energy.

A similar model was described in the recent CFS/ME working group report on CFS (2002) as follows:

> "*Pacing is based on the envelope or glass ceiling theory of CFS/ME which suggests that energy is finite and limited, and that the best way for a sufferer to manage their illness is to live within this envelope i.e. not constantly break through the ceiling (some advise never going beyond 70% of a sufferer's perceived energy limit)*".

Activities that require energy

It is important to note that people with CFS/ME often report that a range of activities make demands on energy and lead to exacerbation. These include physical activity, mental activity and also emotional demands.

The available energy increases with recovery but cannot be increased by increasing activity.

The underlying hypothesis is that if people with CFS/ME use their energy wisely, they will facilitate recovery and their limited energy will increase gradually. Consequently they may then be able to do more. Pacing can therefore improve coping and provide the conditions for natural recovery but does not fundamentally change the course of the disease.

MODELS OF TREATMENT

Pacing and chronic pain

Activity pacing means planning and limiting activity. It has been a primary component of chronic pain self-management programmes since their inception (Birkholtz et al 2004, Hanson 1990, Fey & Fordyce 1983) and is currently considered to be a key requirement for adaptive pain management (Nielson et al 2001). When used for chronic pain the aim is to avoid unnecessary activity induced exacerbations of pain. Hence: An important issue discussed with sufferers is how they pace themselves when engaging in various physical activities. Many attempt to continue doing certain activities at the same pace as they did before the onset of their pain condition. As a result they often experience an acute exacerbation of pain become discouraged and sometimes abandon the activity altogether. The person with pain taking appropriate rest breaks and performing tasks at a slower speed can often prevent exacerbation of pain (Birkholtz et al 2004). The appropriate use of rest breaks needs to be emphasised, since many individuals continue to engage in physical tasks until pain sensations force them to stop. By this time it is too late. Instead, people should stop before pain increases. For example if the person experiences significant increases in pain after sitting at a workbench for two hours, they should take a break after an hour and half or so. Knowing when to stop comes from experience (a trial and error process) over time (Hanson 1990).

Pacing and CFS/ME

There have been a number of supporters of adaptive pacing for chronic fatigue syndrome. One description included as part of a type of adaptive therapy is described as follows *"This approach seeks to enhance physical function and quality of life by monitoring energy, fatigue and activity levels and then making adjustments in daily activity that minimise fatigue and improve perceived energy*"(Friedberg & Krupp 1994). APT may also involve lifestyle modification: *"Suggestions were given to direct life style changes compatible with the activity limitations imposed by the illness. Usually this meant reducing the work load of a job or at home, declining selected social invitations, scheduling regular rest intervals, and controlling exposure to stressful events*" (Friedberg & Krupp 1994).

The essence of pacing is that the person with CFS/ME uses self-management of their level of activity in order to avoid exacerbations of symptoms and disability (AfME 2002). The CFS/ME Working Group report (2002) described adaptive pacing as follows:

> "*Pacing is an energy management strategy in which sufferers are encouraged to achieve an appropriate balance between rest and activities. This usually involves living within physical and mental limitations imposed by the illness and avoiding activities that exacerbate symptoms or interspersing activity with planned rest. The aim is to prevent sufferers entering a vicious cycle of over activity and*

> *setbacks, whilst assisting them to set realistic goals for increasing their activity when appropriate*".

Pacing is based on developing awareness not only of the symptoms but also more subtle indicators that herald a future exacerbation of symptoms (listening to your body). It is also about becoming aware of the effect of activity or lack of rest on disability. Activity is undertaken in planned limited amounts alternated with periods of rest. There is an emphasis on not over-spending the limited amount of energy available by using a variety of strategies such as doing one thing at a time, choosing low energy activities and using energy saving devices. The main key to effectively managing symptoms is limiting the amount of energy expenditure. Examples of how patients' describe this are,

> *"stopping what you are doing when the warning of fatigue starts"*
> *"Knowing how much to do before resting, If feeling better resisting the temptation to overdue activity which results in exhaustion"*
> *(188 & 225 AfME 2003)*

The aim of pacing

The aim of pacing is to avoid symptom exacerbations whilst achieving as much as possible with limited energy. In particular, to establish sustainable activity levels that avoid the "bust and boom" pattern so often seen when people with CFS/ME attempt too high a level of functioning. Too much activity or too much rest can each be unhelpful (AfME 2002).

By enabling the person to gain more control of their activity and symptoms pacing is intended to give the person with CFS/ME a sense of control over the illness.

Important strategies used in pacing

- *Establishing a baseline*

Many people with CFS/ME get into an activity pattern of oscillation between activity and inactivity – this has been called "boom and bust". Here the person with CFS/ME alternates from relative symptom free rest to activity-induced symptoms. A key initial strategy in pacing therefore is to become more aware of this pattern by keeping records of activity and symptoms to seek to establish a more stable and sustainable pattern of activity. Baselines may sometimes need to start at a very low level.

- *Dealing with pressures to deviate from pacing*

The aim is to discuss how to manage pressure from self and others to deviate from pacing programme. The person with CFS/ME is encouraged to find ways to keep within limits

- *Anticipating exacerbations*

The person with CFS/ME is educated to become aware of their limits and to anticipate what activities will exceed them. One way is to “listen to the body” and become aware of early warning signs, then to set limits rather than wait until severe symptoms exacerbation have occurred. A related strategy is to rest when a period of increased demands is anticipated.

- *Proper rest*

Pacing emphasises not only limiting activity but also interspersing it with proper rest. Many people with CFS/ME say they do rest but more careful attention to their symptoms and activity shows that they are not truly relaxing. Pacing therefore involves practising relaxation to achieve proper rest.

- *Alternating activities*

It is noted that people with CFS/ME may become fatigued because they have persisted too long with an activity. One way to avoid this is to limit activity and to ensure that activities are interspersed with periods of proper rest. Another that may enable the person with limited energy to achieve more is to alternative activities. For example changing from a physical activity to a mental activity.

- *Increasing as able*

This form of pacing does not necessarily imply that the person with CFS/ME must permanently remain at a fixed activity level. As natural recovery occurs the person with CFS/ME may find that they feel able to increase activity – but only if the envelope increases in size. When such recovery occurs the person may establish a new baseline. Activity is not increased in order to “push the envelope” but rather follow its natural expansion. However appropriate aims and priorities can be set and then activity built up as tolerance increases.

Balance plays a key part in throughout the process (AfME 2002):

- ➢ balance between activity and rest/ relaxation,
- ➢ balance between physical and mental tasks,
- ➢ balance between work and leisure, and
- ➢ balance between needs and wants.

The important APT considerations are;

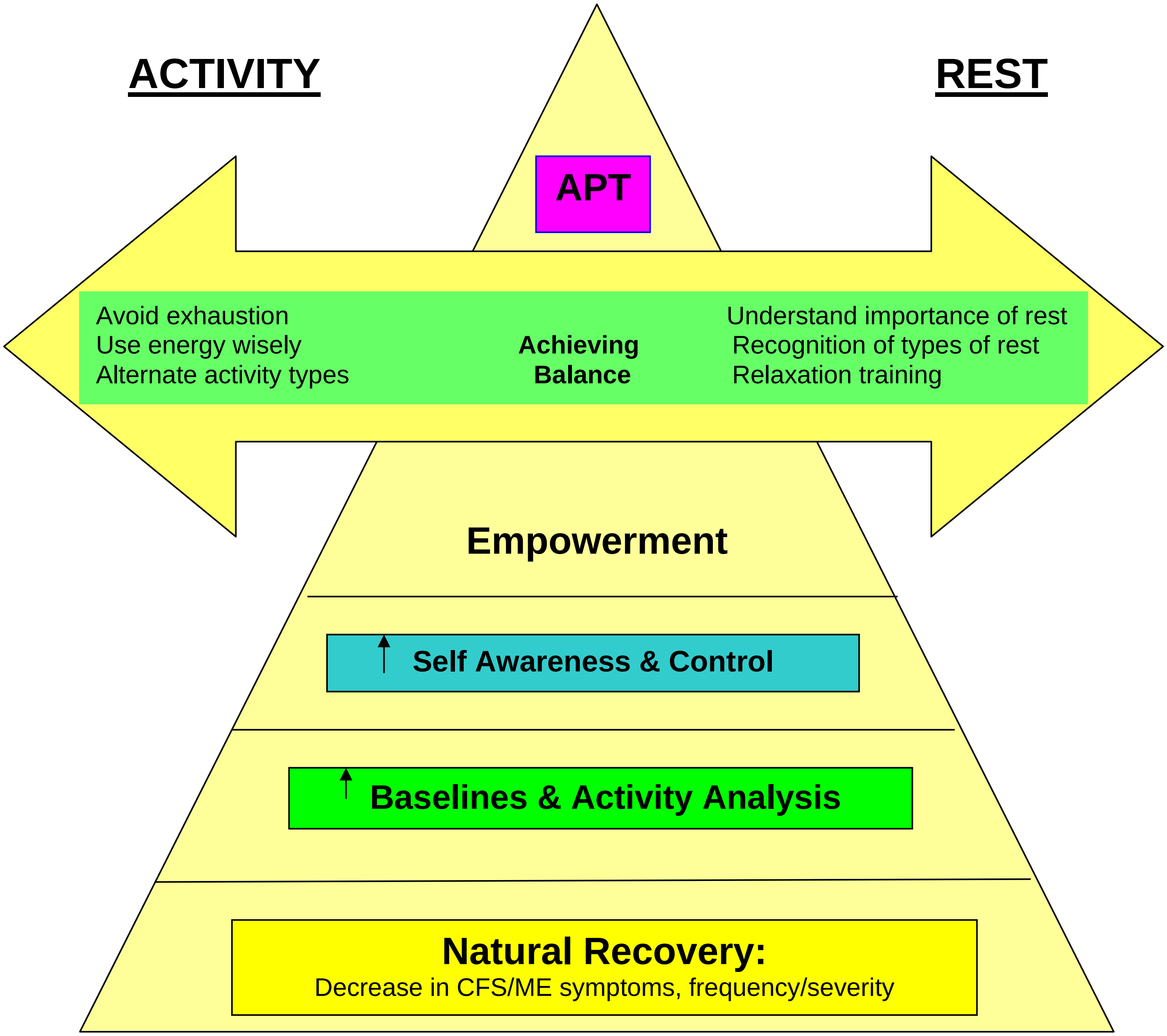
- Individualising treatment
- Flexible discussion of issues and APT model
- Encouraging
    - o Listening to their body
    - o Alternating rest and activity
    - o Understanding and using rest and relaxation
    - o Doing one thing at a time
    - o Understanding and using Activity Analysis
    - o Evaluation of activity priorities
    - o Consideration of how ergonomics and body mechanics impact on activity
    - o Choosing low-energy activities
    - o Using energy saving devices
    - o Maintaining activity levels within the energy envelope
    - o The 70% rule – never going beyond 70% of a person’s perceived energy limit.
    - o Increasing when the person feels their are able

The following diagrammatic model aims to reflect the concept of the APT model visually. It is used as a participant handout at the beginning, through treatment and at the end of treatment.

The Adaptive Pacing Therapy Model of CFS/ME

The Energy Envelope

Successful Energy Management



ACTIVITY

REST

APT

Avoid exhaustion
Use energy wisely
Alternate activity types

Achieving Balance

Understand importance of rest
Recognition of types of rest
Relaxation training

Empowerment

↑ Self Awareness & Control

↑ Baselines & Activity Analysis

Natural Recovery:
Decrease in CFS/ME symptoms, frequency/severity

What APT is not

APT is distinguished from the other two supplementary therapies by its theoretical model. Whilst a variety of generic therapy techniques can be used it is important that it remains distinct from the other supplementary therapies namely graded exercise therapy (GET) and cognitive behaviour therapy (CBT).

These notes therefore help to demarcate what is the boundary of acceptable practice in APT.

A). APT is distinct from graded exercise therapy.

In APT you do not;

- Give a rationale for the use of exercise
- Plan an increasing physical exercise programme
- Give or use a rationale of de-conditioning
- Use exercise within the session
- Monitor the physiological effects of exercise using heart rate monitors

B). APT is distinguished from CBT as follows.

In APT you do not;

- Focus on the participant's thoughts or beliefs as a target for therapy
- Focus on goals and achieving increases in function
- Focus on the use of evidence to systematically challenge thoughts and beliefs about CFS/ME.

C). Distinguishing APT from Standardised Specialist Medical Care

In APT you do not;

- Give the rationale for other therapies
- Refer to other therapies
- Advise on prescribed medications

If these issues arise the participant should be referred back to their specialist medical practitioner.

Therapists Preparation and tools

General Points to ensure Adherence to Protocol

- Please complete the record of attendance (Appendix 2) for *every* contact that you have with participants, whether it is a planned session, unplanned phone call etc. This will ensure that an accurate record of contact is kept.
- If participants are too ill to attend an appointment, telephone sessions may be given. However, it is important to record this session in detail in the trial session record (Appendix 2).
- Cancellations or DNA's should be rearranged within 5 working days if possible.
- Telephone contact between sessions should be handled on an individual basis. It is not banned, but should be discouraged. To ensure that details of unplanned phone calls are recorded, please complete the unplanned phone call record (Appendix 2).
- If a participant no longer wants to participate in the trial, i.e., they withdraw their consent, the centre leader or research nurse should be informed on the same day, if possible. The centre leader or research nurse 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 audio/ or video taped with the participant's consent.
- The writing of reports and letters to referring agents should be completed as per normal practice for your centre. These are usually done at discharge.
- Any serious concerns or worries about the participant such as deliberate self-harm, significant and prolonged illness progression, a severe adverse event should be discussed with the centre leader immediately, so that the relevant course of action can take place.

Supervision and Reflective Practice

Clinical supervision for discussion of cases will be provided by the therapy lead for APT at least once a month by phone and a minimum of 4 times a year face to face as a group. Email contact can be as frequent as required.

Formal booked 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 your reflective diary and reflective review of session (Appendix 2). If after each session you reflect on the session this will help you highlight issues that you may want to discuss in supervision.
- Tape all clinical sessions (with consent), and send tapes for supervision
- Clinical notes can be bought to the face to face meetings for the purpose of supervision
- Keep a record of what has been discussed in supervision

You will be encouraged to actively reflect on your sessions and make suggestions for improvements: either your own delivery of the manual, or the way in which you handle any challenges. You will be encouraged to use a Reflective Practice sheet after each session.

You will also be encouraged to maintain good contact with your GET, CBT and APT peers, to provide mutual support and to ensure that all therapists benefit from your ideas and learning. You will also be encouraged to make good use of email contact. Peer coaching, whereby therapists support one another's learning, will be encouraged where appropriate.

Knowledge and skills required

There are a number of elements and skills within therapy that will be generic to each treatment arm such as, empathy, warmth, rapport, supportive encouragement, interactive communication, active engagement between therapist and participant, problem solving, involvement of family members (where appropriate), and liaison with employers, other health professionals and other outside agencies. An example of referral to other professionals in APT is that it would be appropriate for you to refer to a community occupational therapist for the provision of energy saving devices and/ or equipment dependent on needs of the participant.

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 limitations. 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. In order to maintain participant’s engagement throughout treatment, it will be important that you continue to use the APT model.

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. It is usually 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. 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 APT programme. Acknowledging the challenges associated with sticking to a 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. For example if a participant called their illness ME don't attempt to challenge this, ME or CFS is an appropriate term to use.

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 APT model to their illness. Agreeing an agenda for each treatment session, asking for their input in making suggestions for their activity/ rest 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.

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 targets that you set with participants, it is essential 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.

Problem Solving

Many events occur in life which influence our decisions and our plans, and may provide obstacles in adhering to the principles of APT. Pressure to engage in activities outside the participant's current energy envelope, or which get in the way of rest periods; come from a variety of sources. Problem solving is one strategy which can be utilised in relation to this issue.

Problem solving is something we all do on a daily basis in relation to the tasks we need to perform. When introducing this process to participants it is helpful to be as clear and concise as you possibly can, as this in itself can provide an immediate solution to the problem as it avoids ambiguity, prevents misunderstandings and helps resolve any misconceptions.

However, problem solving and communicating solutions to others is a skill that can be developed. It may prove useful to use time within sessions to practice these skills through rehearsal and role play. The use of role play in a session can assist in working through barriers to treatment or pressures to deviate. Another useful communication technique to assist in problem solving is the "broken record" technique – where you repeat the question or statement frequently within a session to emphasise a discussion point.

Identify the problem

- What needs to be done?
- What are the steps involved?
- What are the energy requirements of each step and the task as a whole?
- Who and what else is involved? When thinking about the actual problem it is worth identifying anybody else involved. What part if any do they play in generating the problem? What help, practical or emotional, can/can't they provide? Do they know and understand the principles of APT, and if not is it important that they do so?

What are the available solutions?

- Brainstorm tried and tested solutions (what has previously worked). Revisit solutions that may have previously been written off as unusable or impossible. Use your imagination and be creative, even the most outlandish possibilities are worth considering.
- Can any of these potential solutions be modified in any way? Use your knowledge of activity/task analysis. If you were to utilise the support of others or were to undertake only a smaller component of the task would this allow you to remain within the energy envelope?

Prioritise

- Prioritise solutions according to the help and resources available.
- Discuss possible solutions with others involved informing them of your needs and what can/can't be done within your current level of available energy. Saying NO and/or delegating are okay as this recognises your own needs as well as the needs of others.

Select the most acceptable and workable solution

- Try it out. Does it allow you to adhere to the 70% Rule? Are there any signs of symptom exacerbation?
- Review and re-select as necessary. The right solution on one occasion may be the wrong solution at another time.

Practice the strategy

- Use of role play
- Summary & feedback

Evaluate the effective strategy and re-visit the problem cycle

<u>Remember tackle one problem at a time</u>

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 APT 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 APT.
- 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 and/ or systematically challenge thoughts and beliefs about CFS/ME.

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
- 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 the APT 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 APT. You may try to cover the following points in the first couple of sessions.

- To complete all records, e.g. daily diaries
- 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.

Helping participants to become their own therapist

The overall aim of therapy 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 APT model and rationale for treatment.
- Repeating the rationale for APT 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/ rest programme as soon as possible.
- Agreeing set-back plans before participants are discharged so that they are aware of potential problems and feel confident in managing an increase of symptoms.

Involving a relative or friend in a therapy session

Participants may find it helpful to have a partner, relative or friend to attend a session with them. It can provide them with support and encouragement, particularly when they are experiencing difficulties with their APT programme. Participants sometimes like to have a person who is very involved, e.g. someone with whom they can discuss their understanding of the APT model and any problems on a daily or weekly basis. Some participants 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 relative or friend attend one or two sessions

- Ask the participant whether they would like their relative or friend to attend an appointment with them, so that they can hear about what APT involves and how they can help.
- Ask the participant to suggest that the person reads the section at the back of the participant's manual for partners, relatives and friends.

If a friend or relative 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 partners, relatives and friends if they have not already done so.
- Discuss with the participant how they would like the person to help them.
- Discuss practical ways that they can help the participant, e.g. phoning them.
- Discuss the importance of giving the participant praise for all of their efforts, e.g. filling in diaries, balancing rest and activity, taking rest, completing homework tasks etc.
- Ask them to be aware of the participant's activity/ rest programme, so that as well as praising their efforts, they can also discourage them from over doing activities beyond their energy envelope.

Managing Potential Difficulties

Participant asks you not to record the session

If a participant asks you not to tape a session, ask them the reason why and remind him/her why you are taping. If necessary switch the tape off for a five minute period, but record content in writing and try to get permission to switch on again as soon as permissible.

Attendance issues

a. Participant is unable to attend a session

If it is unclear as to why a participant has not attended, the therapist should attempt to contact them in order to ascertain any reasons for this, and to encourage attendance at the next arranged session (complete form from appendix 2). If for any reason the participant is not able to attend a session, try to replace the missed appointment with another one within five working days. This could be by telephone if the participant is unable to attend at the hospital. The number of sessions not attended and reasons for non-attendance must be recorded in the participant's therapy record.

b. It seems appropriate to alter the session timings or intervals

Both the number of sessions, and the intervals between them, can be altered with mutual agreement. The reasoning behind the changes needs to be recorded in therapy records. If both the participant and therapist agree that the next session is redundant and unnecessary, then that session may be omitted. This may occur if the participant is doing particularly well, for example, and is applying principles independently to good effect. If a participant is completely and consistently recovered before the end of APT, the remaining sessions, apart from the 15th booster session at 35 weeks, may be omitted.

c. The participant is having difficulty travelling in to the hospital

Telephone contact between sessions should be handled on an individual basis and is not banned, but should not be encouraged. It is a better alternative than dropping the therapy session altogether.

CBT/GET conflicts

a. Therapist realises they have mistakenly given a CBT or GET intervention

It is perhaps inevitable that therapists will find that they have mistakenly given a cognitive interpretation, or encouraged a form of exercise, especially with the first few participants as they are learning.

A therapist should not be worried about admitting these problems; in fact, difficulties should be shared with the team to allow all to learn from this. This will allow difficulties to be resolved, and strategies devised for next time.

Action: Continue the session but discuss with APT leader after session

b. Participant asks advice on other management strategies e.g. diet / stress management

Explain that the trial does not allow you to give any specific advice on these issues, as in the trial you are trying to give a clear consistent version of APT and that it may not be helpful to deviate into other aspects. Refer the participant to the specialist medical practitioner for further advice.

Setback issues

a. *Therapist is not sure if this is a CFS/ME setback*

Discuss with APT leader in supervision or centre leader.

b. *Participant has a cold/cough/other new or active infection*

As CFS/ME symptoms can be sometimes be similar to symptoms of a cold/cough/new or active infection, it is important to obtain information as to the nature of the symptoms. A raised objective temperature (using a thermometer, not reliant upon subjective assessment), sneezing, sputum production may be clearer indicators than common CFS/ME symptoms such as sore throat, fatigue, body aches, dizziness etc.

If the participant appears to have a new or active infection, then they should be encouraged to rest and recommence their activity/ rest programme as soon as they are feeling better.

Unforeseen or new medical issues

a. Therapist identifies a need that cannot be managed in APT sessions

Such as anxiety, panic attack, medical concern etc. It will be important to ascertain whether this need will interfere with APT. Discuss with clinic doctor, centre leader or APT therapy leader.

b. *Participant becomes unwell during treatment session*

- Treat any severe distress or medical problem fully without constraint
- Discuss with centre leader
- Document session clearly
- Consider whether the event is related to treatment or independent causation
- Incident reporting should continue as per your Trust policy

Technical difficulties:

Tape recorder malfunctions

- Continue with session
- Try to resolve problem after session
- Record in notes
- Replace by next session if possible

Difficult questions relating to trial

a. Participant asks for opinion on issues read in press etc

Can give factual info re: APT only. Cannot ask participant what they think (CBT), but can suggest they discuss with clinic doctor.

b. Participant expresses doubt over APT as result of reading press/other

Can give factual info re: APT only. Cannot ask participant what they think (CBT) but can suggest they discuss with clinic doctor.

c. Participant has been advised not to continue APT by an outside influence

Contact centre leader and discuss with APT lead.

Frequently Asked Questions, comments and issues

There are a number of questions that participants may ask during treatment. Below are a number of those potential questions and the possible responses you could consider to bring the person back to the APT model.

Is this a cure?

- Be honest, the answer is no
- Aim of APT to enable/ facilitate a natural recovery response
- It's strategy to balance activity and rest, avoiding symptom exacerbation whilst achieving as much as possible within limited energy
- Aids natural recovery
- Recovery is achieved by balancing rest and activity within an energy envelope

How do I deal with a setback?

- Adjust any programme if there is an adverse reaction rather than increase your activity
- Main advice = rest
- Make realistic goals
- Listen to your body
- Re-consider balance
    - Activity versus rest
    - Physical activity versus mental activity
    - Work versus leisure
    - Needs versus wants

Revisit patient quotes as indicated in the manual and advise to re-read the Adaptive pacing model of CFS/ME handout from session 1.

Activities make my symptoms worse?

- Consider if gone beyond the "energy envelope" (the 70% rule)
- Re-assess baseline
- Re-assess balance between rest and activity
- Are you doing too much or too little? Look again at structure of day.
- Are you having too much rest? Re-assess balance between rest and activity
- Revisit having an awareness of the "warning signs". "Listening to your body"
- Consider alternating activities – changing from a physical to mental i.e. not doing one activity for too long

What is an exacerbation of symptoms?

- When the symptoms have increased beyond your normal range
- Symptoms level stops you doing your baseline

What about further investigations?

- Re-emphasize self management technique/ approach
- All other treatments agreed to be suspended

What do I do on a bad day?

- Rest, relax, sleep
- Consider reasons (if any) for “bad” day i.e. overdoing mental or physical activity
- Re-assess baseline

What do I do when I have an infection (cold, Flu?)

- Rest, relax, sleep
- Go to bed
- Treat appropriately
- Lower your activity level

My muscles and joints hurt as a result of activity

- How much is acceptable – “listen to your body”
- Review baseline
- Re-consider the envelope theory and the 70% rule.

My fatigue is worse

- Were changes made that were too quick, too much?
- What happened this week, especially 48 hours ago (physiological effect)?
- Re-assess balance/ energy envelope
- Consider cumulative impact of over doing it (bust/ boom)
- Have you gone beyond the 70% ceiling?
- Re-evaluate goals
- Use charts and handouts

My illness is physical?

- Yes
- Recovery is achieved by balancing rest and activity (pacing), listening to your body and any warning signs. By pacing you will maximize your chance of natural recovery and improve your function in the long term.

I'm going on holiday – What do I do?

- Where possible stay within your daily routine
- Try to balance rest and activity
- Consider your energy envelope
- Listen to your body

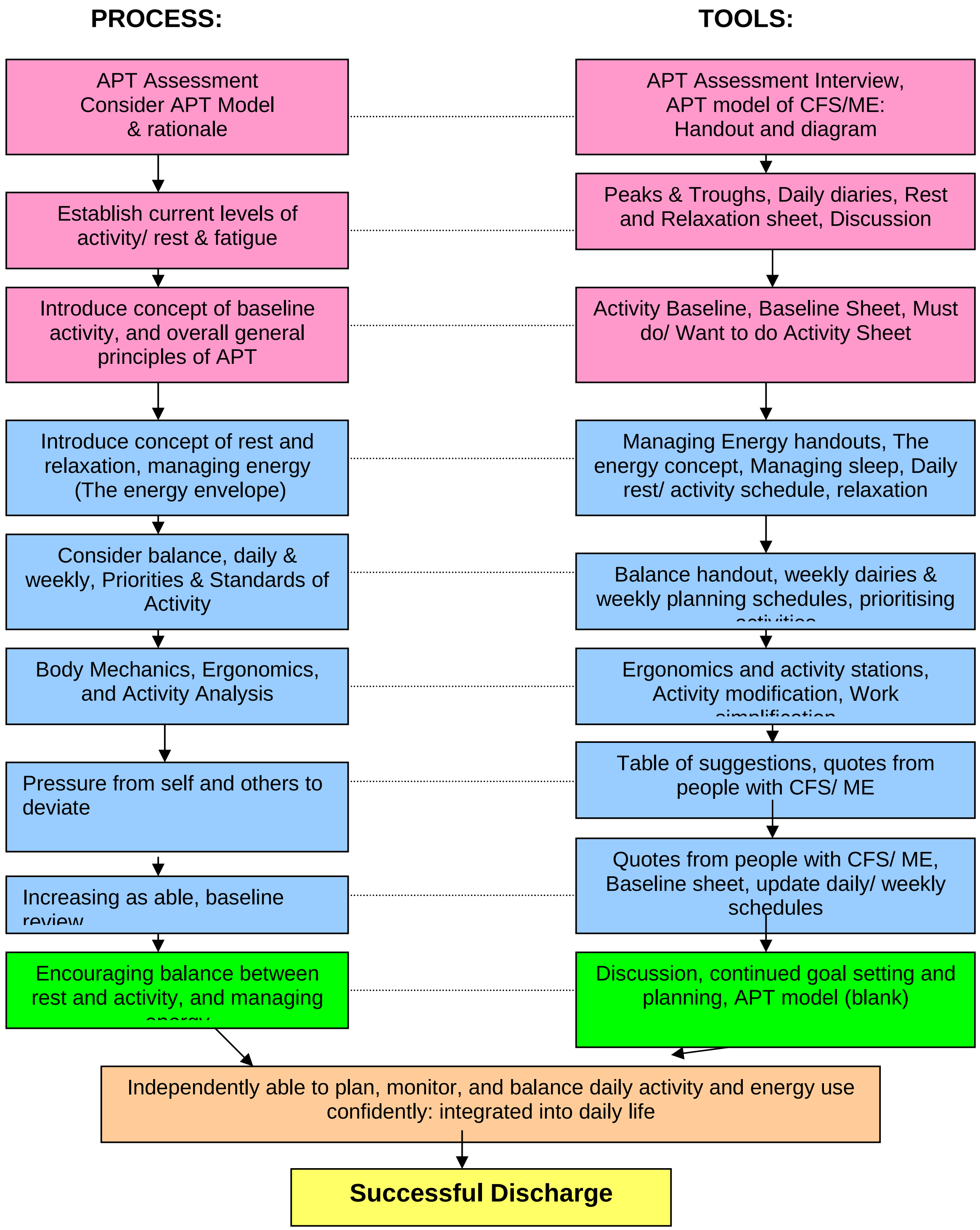
Non- concordance with homework

- Discuss why – feedback over week, months
- Re-emphasize the importance of self-management in APT
- Re-visit important strategies and elements of pacing to focus thoughts (Model of APT handout from week 1 in particular).

What if someone cries during the session?

- Be empathic, warm, re-assuring
- Check out if the session needs to end
- Once stopped crying continue with session if possible
- Record in notes

THE APT PROCESS



OUTLINE OF TREATMENT

There will be fourteen treatment sessions (the first of 90 minutes then all 50 minutes duration) given over five months. The first four sessions will be weekly and subsequent sessions at two weekly intervals. There will be a 15th session as a follow up 3 months following treatment end.

All sessions will be tape recorded and the duration of each session will be noted (see appendix 2 for suggested forms for note writing and recording of information).

Treatment falls into 3 main phases:

- *Assessment, engagement & teaching the principles of pacing*
- *Establishing self-management and control of symptoms (Active Treatment)*
- *Ending treatment and preparing & planning for the future*

Remember to ensure that you allocate time each day for note writing and reflection between individual participant sessions.

A Summary of sessions and phases given over 5 months is shown in the table overleaf.

Summary Table of Phases and Sessions for APT.

Session Number	Week No approx	Time (mins)	Summary	Homework
PHASE ONE: Assessment, engagement and treatment rationale				
1	1	90	• Detailed interview • Review of what is CFS/ME • Introduction to the APT model and rationale	• Activity and Fatigue rated daily diary • Weekly rest/ relaxation diary
2	2	50	• Review Model • Discuss Peaks/ Troughs, Bust/\Boom • Baseline Activity and sheet • Discuss rest/ \relaxation	• Daily Diaries • Baseline Sheet • Must do/ Want to do • What is Rest?
3	3	50	• Review diaries & fatigue • Discuss managing sleep and energy • The 70% rule • Schedule activity/ rest	• Daily rest/ activity diaries • Energy expenditure Grid • Energy Envelope
PHASE TWO: Active Treatment: Establishing self-management and control of symptoms				
4	4	50	• Review of model & understanding at each session • Importance of balance • Activities Lists: Self care, Productivity & Leisure • Relaxation practice • Weekly Plans • Activities in my day & week • Evaluating Priorities & Standards of Activity • Body Mechanics • Ergonomics • Activity Analysis • Activity Modification • Work simplification • Pressure from others • Problem Solving in APT • Anticipating exacerbations • Increasing as able • Baseline review • Rest, relaxation and sleep pattern review	• Activities in week & weekly plans • Actual/ Ideal Day • Actual Weekly Plans • Relaxation • Evaluating Priorities & Standards of activity • Priority Activities in week • Activity Analysis sheets • Activity Station Analysis sheets • Activity modification • Ergonomics II • Problem solving & Planning Time • Alternating rest/activity • “Listening to body” • Baseline Review
5	6	50		
6	8	50		
7	10	50		
8	12	50		
9	14	50		
10	16	50		
11	18	50		
12	20	50		
PHASE Three: Ending treatment and preparing & planning for future self management				
13	22	50	• Review APT Model • Target and Priorities review • Complete CGI • Preparation for discharge	• APT Model • Target and priorities review • Baseline sheet
14	24	50		
15	36	50	• Discharge	• Continue with daily, weekly and overall planning and implementation of APT principles

Adapted Pacing Therapy Targets & Methods

Target	Methods
Establish a baseline	a) Identify "boom and bust" patterns by keeping diaries of both activity and fatigue levels. b) Identify a manageable level of activity, which is anticipated to result in low-level symptoms, by reviewing activity-related fatigue (diaries) and trial and error. [Session 2 onwards]
Introduce proper rest and relaxation	a) Distinguish between real and perceived rest, by listing what you think of as restful and comparing to the APT philosophy. b) Learn times when rest is advisable / essential, by developing an awareness of energy diminishing activities. c) Learn and practice different relaxation techniques, and identify those most effective to you, by demonstration from the therapist, self-directed learning and trial and error. [Session 2 onwards]
Save and budget energy	a) Save energy by using rest and energy wisely. b) Budget energy by prioritising, delegating and modifying energy. c) Use the 70% rule. d) Identify the energy requirement of an activity, by monitoring how fatigued you feel via daily diaries, and spread these activities equally over the week. [Session 3 onwards]
Improve sleep	a) Learn what helps and hinders your sleep pattern, by discussion with the therapist, self-knowledge, and the observations of family / friends. b) Balance activity and rest – to ensure the body isn't over or under tired- by pre-planning your week into a schedule. [Session 3 onwards]
Live within your limits/ balance activity	a) Identify the energy requirements of an activity, by using daily diaries / fatigue levels, then find ways to adapt the activity to decrease energy needed. b) Prioritise what activities cannot be avoided, by completing a "must do would, like to do" form. As before, modify in order to expend less energy, and calculate what energy you have left for other activities. c) Spread activities evenly, by planning your week in advance. d) Save energy through rest and relaxation. [Session 4 onwards]
Use ergonomic techniques	a) Become aware of your postures and movements, by analysing your activities. b) Identify unhelpful postures and movements, by relating to fatigue levels and comparison with ergonomic techniques. c) Incorporate beneficial ergonomics into your weekly routine, by breaking down activity. [Session 6 onwards]
Devise a way to recognise energy expansion	a) Think of the last time that you had a "better" period of functioning. How did you know you had improved / what changed/ b) How long would an improved period of function continue, before extended activity / energy was attempted? [To be constantly reviewed]

Also Participant Handout

Implementation of therapy

Phase 1: Assessment, engagement and teaching the principles of pacing

The aims are to engage the person with CFS/ME in a collaborative therapeutic relationship, to establish a detailed problem analysis which identifies pattern of symptoms, activity and rest, and to ensure that the person understands the rationale for adaptive pacing. The therapist must convey to the person with CFS/ME their belief in the reality of the symptoms, distress and handicap. Since people with CFS/ME will often be particularly well informed about their illness, the therapist must be able to demonstrate a sound knowledge of CFS/ME. It is important to use a ‘somatic’ rather ‘psychological’ idiom which avoids any imputation of blame, malingering, or of the illness being "all in the mind". Because people with CFS/ME are likely to be particularly sensitive to, and fearful of, a perceived over-emphasis on psychological factors, a physical model of disease that limits energy is emphasised and used throughout treatment.

Session Structure:

After the first long session (90 minutes) sessions will be of 50 minutes duration. At the beginning of all sessions, the person with CFS/ME sets the agenda with the therapist. Other components will include enquiring about reactions to the previous session, discussion and setting of relevant homework assignments, checking reactions to, understanding and acceptance of the model of treatment and introducing the use of diaries. Sessions end with a review of session content and checking understanding.

The participant will receive the full handouts booklet in session 1; however a number of the handouts may have to be photocopied for daily use. Participants may request that handouts are photocopied onto coloured paper as black on white for some people with CFS/ME may be difficult to read. It is suggested that each participant have a ring binder for ease of using and storing all information. All sessions will be tape recorded and the duration of the session noted. A therapist record will be kept on each participant.

Session 1: Information Gathering and Treatment Rationale

- A detailed analysis of the presenting problems is made, focussing on the precise nature of and fluctuations in symptoms and incapacity and their relation to levels of activity and rest.
- The impact of symptoms and functional limitations on the person's life;
- Onset and the course of the disease.
- The person's experience of previous health care professionals and failed treatments are discussed.
- The therapist should listen to expressions of anger or frustration empathetically, and throughout the interview should convey warmth, genuine interest, and a willingness to listen and should acknowledge the reality of symptoms and the degree of distress and handicap caused.
- The person's expectations and doubts about adaptive pacing should be elicited, and the rationale for adaptive pacing explained.
- The emphasis is on effective self-management of the illness.
- Homework is discussed, and self-monitoring introduced, with a brief description of its value, and how to complete diaries.
- Significant others can be invited to join specific treatment sessions.

Handouts:

- **Interview Schedule**
- **What is CFS/ME?**
- **The Adaptive Pacing Model of CFS/ME**
- **The APT Model of CFS/ME diagram**

- **Daily Activity/ Fatigue Diary**
- **Weekly Rest and Relaxation Diary**

- **The Energy Concept: Battery diagram (might be used here or in session 2 or 3)**

Homework:

Consider adapted pacing model and record activity, rest, incapacity and symptoms in diary on a daily basis.

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 APT 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
- Identify any other problems (medical, psychiatric etc)
- Introduce the APT 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.

Each participant will have individual issues that they will wish to discuss during sessions; for example a participant may wish to focus the discussion on return to work

Chronic Fatigue Syndrome: Initial Interview

PIN: **Date of Interview**

Information Gathering and Treatment Rationale

- A detailed analysis of the presenting problems is made, focussing on the precise nature of and fluctuations in symptoms and incapacity and their relation to levels of activity and rest.
- The impact of symptoms and functional limitations on the person's life.
- Onset and course of the disease.
- The person's experience of previous health care professionals and failed treatments are discussed.
- The therapist should listen to expressions of anger or frustration empathetically, and throughout the interview should convey warmth, genuine interest, and a willingness to listen and should acknowledge the reality of symptoms, the degree of distress and limitations caused.
- The person's expectations and doubts about adaptive pacing should be elicited, and the rationale for adaptive pacing explained.
- The emphasis is on effective self-management of the illness.
- Homework is discussed, and self-monitoring introduced, with a brief description of its value, and how to complete diaries.

Can you tell me about your symptoms of CFS/ME and how it affects your life? (PROMPT: Identify pattern of symptoms in relation to activity and rest)

- Symptoms.
- Duration.
- Frequency.
- Severity.
- Fluctuations.
- Impact

Can you describe to me the onset of CFS/ME and the course of the illness since then? (PROMPT: Looking for Boom and Bust patterns, individual's thoughts as to what caused CFS,? awareness of specific triggers)

- Onset/History of Illness
- Pattern of Illness
- Lifestyle
- Illnesses
- Pressures

Have you noticed any other changes in your health?

- Appetite.
- Sleep
- Mood
- Memory
- Concentration

Have you any other health concerns? Or problems you have had to seek medical help for?

- IBS
- Fibromyalgia
- Migraine
- Rheumatism/arthritis
- Depression
- Anxiety

Can you tell me about any treatment you've had to date for CFS/ME? Including any complimentary therapies.

- Experiences of health care Profs.
- Medication. Past & Current. Any side-effects, problems or benefits noted.

Are you receiving any treatment at the moment, separate to our sessions?

Can you describe for me your current domestic situation, and if that has changed since developing CFS?

- Living situation/people you live with
- Accommodation.
- Rented/Own property.
- Responsibilities within household
- Local resources.
- Neighbourhood cohesiveness.

I'd like to know more about the impact CFS has had on your life. Can I ask about the day-to-day activities you currently manage, including use of any support on offer, comparing this to your past level of functioning prior to becoming unwell? (PROMPT: focus on current level of functioning against background of previous healthy level of functioning).

Personal care

- Household Management
- Community Management

- Leisure pursuits and methods of relaxing (What's worthwhile?)
- Education & Employment (dates, duration, difficulties encountered, level of support if required)
- Inter / intra personal skills.

Do you manage to socialise now? How does this compare with what you did previously? What did you enjoy doing?
- Support on offer through friends and family. Do you use it?
- Social Activities
- Activities used for Relaxation

What about exercise? (PROMPT: Current level of involvement and functioning against prior involvement)
- Frequency of exercise.
- Type of exercise

What do you think is causing your current difficulties?

Do you have any specific plans to resolve your current difficulties?

Have you come here today with any particular ideas or goals that you would like to discuss? (PROMPT: always relate back to APT and common focus/areas to work on)
- Short term
- Long term.

Is there anything else of significance that you feel we may have missed which you would like to discuss? Any worries or concerns?

Checklist or areas for further discussion/review as felt necessary
- Rationale for APT, discussed & handouts given
- Idea of self- monitoring introduced, description of its value in APT given
- Emphasis on effective self management, use of homework/diary sheets and keeping a record of activity and symptoms increases awareness and helps establish a more sustainable pattern of activity
- Ask for clarification of clients understanding of APT, and homework
- Having discussed APT in more detail any new expectations, doubts or concerns?

Session 2: Review pacing model and individualise to the person with CFS/ME.

- The rationale for pacing is reviewed.
- The completed daily activity sheets from session 1 are used to indicate whether a pattern of peaks and troughs (bust & boom) is apparent in the person's day.
- The model is individualised so that it relates to their experience.
- The person is asked to agree to work with the therapist on a pacing approach and to suspend any other treatments or investigations as these may interfere with pacing.
- Further self-monitoring diaries are introduced to monitor activity, rest, symptoms and incapacitates.
- The specific pacing strategies of:
  - (a) increasing awareness of symptoms and incapacity that herald exacerbations – "listening to your body", awareness of early warning signs
  - (b) limiting activities by time and establishing a baseline
  - (c) ensuring good quality rest and relaxation (use rest/ relaxation diary from session 1),
  - (d) alternating activities are described and discussed.

A patient's typical day will often look like the record shown below.

TIME	ACTIVITY
9.00 am	**Get up, Take 1-2 hours to come round, Get washed, dressed. Have breakfast. Feed dog, make packed lunches**
10.00 - 12 noon	**Do various bits of housework**
1.00 pm	**Prepare and eat lunch**
2.00 pm - 5.00pm	**Rest, often sleep**
5.00 pm	**Walk dog (sometimes)**
6.00 - 8.00 pm	**Feed children, talk to family, watch TV**
9.00 pm	**Go to bed, take 1-2 to sleep**

Handouts:

- **Bust & Boom/ Peaks & Troughs diagram (draw on in session)**
- **Baseline Activity, & Baseline Sheet**
- **Daily Diaries**
- **Summary of the general principles of APT**

- **What is rest?**
- **Activities Must do/ Like to do**

Homework:
Continue self-monitoring. Activities Must do/ Like to do

An example of a patient's (AfME 2003, 80) description is

> *"Accepting that recovery will come when you stop trying to be a superwoman/ mother. Learning to step back – say no, only do one activity a day e.g. shopping. With progress I have increased the activities undertaken".*

Session 3: Planning how to implement pacing

- Understanding and acceptance of the model for treatment is checked and discussed.
- Self-monitoring diaries are reviewed, as are the list of pacing strategies (APT Model of pacing).
- Relaxation is taught and practised. Limit daytime sleep, change to rest.
- Concept of spreading and prioritising activities introduced using completed List of Activities (must do/ would like to do) and daily diaries from sessions 1 and 2.
- Discuss the analogy of energy being like a battery, “once all the energy is used it takes time to recharge”. The “energy envelope”. The 70% rule.
- Discuss activities taking differing amounts of energy.

NB: This session may need to be longer in order to incorporate the relaxation session. The relaxation session may be taped for the participants’ home use.

Handouts:

- **Managing your energy**
- **Re-establish natural sleep pattern**
- **Baseline Sheet**
- **Energy Envelope & Bank Account diagrams**

- **Daily rest/ activity schedule**
- **Energy expenditure grid (Landscape & Portrait versions available)**

Homework: Continue self-monitoring diaries and practice of self-management strategies including relaxation

A person with CFS/ME (AfME 2003, 38) described pacing in terms of the importance of prioritising activities.

> *“Learning to prioritise activities, into which are more important and least important, to spread activities over the week not just a couple of days”*

Another (AfME 2003, 111) described the use of energy,

> *“Pacing means planning your days and only doing one high energy activity per day so if you have to go shopping one day you should leave the ironing or cleaning until the next day. It also means having complete rest a few times a day in quiet surroundings (not reading the paper or watching TV)”.*

Quote giving an alternative analogy (AfME 2003, 268)

“I use the image of a bank account. I always have to be careful not to use the overdraft. I have rest when I still have some money in my account. Otherwise the muscles I have specifically used during the activity, or the brain or the whole body starts to behave in an abnormal manner. So I try to train myself – by trial and error – to notice when there is not much “money” left and when it is the case I rest and afterwards I will have an activity that uses other parts of the body. For example an activity that requires concentration and the muscles of my hands and back should be followed by rest or relaxation and then by an activity which will use more my legs and less my hands, back etc…”

Phase 2: Practising self-management and control of symptoms

The aims of this phase are to implement pacing strategies, to monitor the effect on symptoms, encourage taking control of symptoms and empowerment.

- The person with CFS/ME is encouraged to learn what level and type of activity will lead to a symptom exacerbation and to avoid these.
- Regular rests are planned and relaxation techniques described and discussed.
- Activities are planned on the basis of time spent rather than task completed.
- Obstacles to implementing the adapted pacing programme are addressed in every session.
- This may involve lifestyle modification and challenging the expectations of self and others for excessive activity (excessive in terms of available energy).
- The person is encouraged to increase activity but only subject to tolerability (avoiding delayed symptom exacerbation and incapacity).

Session 4: equilibrium between activity and symptoms.

- The aim is to reach equilibrium between activity and symptoms.
- Points covered are,
    - the need to anticipate fatigue,
    - the need to balance activity expenditure (both physical & mental tasks) and rest and
    - the need for good quality rest and relaxation.
- Use energy requirements grid from session 3 to consider weekly plan
- Homework diaries are given, with an explanation of how to complete them.
- Using Baseline Sheet, Must do/ want to do (session 2) & Energy Requirements (session 3) identify self care, productivity and leisure activities.

- Guided Relaxation to be included in session

A patient's (AfME 2003, 87) example of equilibrium and energy is,

> *"Recognising that ones energy is rationed! Organising the day to intersperse rest/ quiet periods with activity. Aiming as far as possible to ensure that each day has around same level of activity. It works!"*

Handouts:

- **Importance of balance & balance diagram**
- **Activities List: Self Care, Productivity, Leisure**
- **Weekly Plan (Landscape & Portrait versions available)**

- **Actual vs. Ideal Day**
- **Actual Weekly schedule (Landscape & Portrait versions available)**

Homework:

Planned relaxation and activity set at an achievable level, practised regularly and consistently. Completion of homework diaries and weekly schedule

An alternative quote (AfME 2003, 304)
"Arriving at a framework for the day – balancing rest, relaxation & activity. Integrating gentle exercises, at a sustainable level. Learning not to overdo things on those days when energy levels are increased. Breaking the habit of sleeping in the afternoon".

Another quote (AfME 2003, 312)
"Means balancing i.e. balancing periods of activity and rest plus balancing different types of activity to try and avoid causing or exacerbating symptoms. It also means working within the limits imposed by the condition, to try and avoid payback which results when I overdo things"

A further quote (AfME 2003, 52)
"Pacing involves managing your energy levels and trying to save up extra energy by stopping an activity or task before you feel you have exerted yourself and having rest periods built into your routine – even if you feel you can carry on the activity therefore giving the body a recovery time to hopefully aid healing".

Session 5: Priorities and Standards of Activity

- The rationale for treatment is re-explained as necessary.
- Consideration and re-consideration of activities undertaken in a day and week that must do/ would like to do
- Discuss the need to consider priorities to assist with balance
- Introduce idea of standards (levels) for activities

The following patient description is a useful explanation to reinforce what is meant by activity and what rest means.

> *"Spacing out all types of activities with plenty of complete rest/ relaxation between activities. All types of activities mean physical, mental and emotional. Rest/ relaxation means no TV, reading, conversation, music. Need to have eyes closed. Only doing activities if able to do them, not pushing one's self or going on too long" (AfME 2003, 116)*

Remember: now 2 weekly intervals between sessions.

General Handouts for weeks 5-12:
- **Activities in my week**
- **Weekly schedule**
- **Activities in my day**
- **Daily schedule**

Handout
- **Evaluating Priorities & Standards of Activity (including questions to ask self on priorities and standards of activity)**
- **Priority Activities in my Week**

- **Priority Activities I did in my Week**
- **Priority Activities I wanted to do in my Week**

Homework:

Planned relaxation and activity set at an achievable level, practised regularly and consistently. Completion of homework diaries; weekly & daily schedules, priorities in week (I did & I wanted to do)

Examples of quotes from people with CFS/ME on prioritising

"…To me, pacing includes prioritising some energetic activities over others, forgoing others or accepting help to achieve those I have prioritised.." (AfME 2003, 182)

"Prioritising what you need/ would like to do & allocating energy to do it. Realising that some tasks are not worth wasting energy on thus focussing on what is important to you" (AfME 2003, 192)

Session 6: Body Mechanics and Activity Analysis

- The rationale for treatment is re-explained as necessary.
- Discuss Body Mechanics and Activity Stations (with practice if appropriate kitchen, worktops)
- Introduce Activity Analysis
- Introduce Energy Conservation as a concept

Handouts:
- **Body Mechanics**
- **Ergonomics & Activity Stations**
- **Ergonomics 1-4 (photocopied diagrams)**
- **Activity Analysis**

- **Activity Analysis Sheet**
- **Activity Station Analysis Sheet**
- **Ergonomics II**

General Handouts for weeks 5-12:

- **Activities in my week**
- **Weekly schedule**
- **Activities in my day**
- **Daily schedule**

A person's explanation of activity analysis

> *"Pacing means looking at my daily activities and breaking them down (grading them) into achievable chunks, sometimes resting during a task and completing it later. Pacing and grading my activities makes it so my fatigue and other symptoms do not increase after doing an activity…" (AfME 2003, 253)*

Homework:

Planned relaxation and activity set at an achievable level, practised regularly and consistently. Completion of homework diaries and weekly & daily schedules

Session 7-12: Review model and treatment aims

- The rationale for treatment is re-explained as necessary.
- Consideration and re-consideration of activities undertaken in a day and week that must do/ would like to do
- Discuss the need to consider priorities to assist with balance

Guided Relaxation techniques are practised as required

The following patient description is a useful explanation to reinforce the adaptive pacing model,

> *"Various elements to it:*
> *1. Being more aware of how activity/ rest affect the body and altering patterns in relation to this.*
> *2. Building in rest periods interspersed with activity.*
> *3. Trying to curtail activity before exhaustion sets in.*
> *4. Switching to different kinds of activity can allow more overall activity"*
> *(AfME 2003, 89)*

General Handouts for weeks 7-12:

- **Activities in my week**
- **Weekly schedule**
- **Activities in my day**
- **Daily schedule**
- **Activity Analysis Sheet**
- **Activity Station Analysis Sheet**
- **Activity Modification Worksheet**
- **Work Simplification**
- **Energy requirements**
- **Baseline Sheet**
- **Patient Quotes**

Session 7: Activity analysis, alternating activities & activity modification

- Discuss personal aims and priorities
- Discuss alternating activities
- Introduce and discuss Activity Modification
- Discuss breaking activities down into smaller achievable tasks (activity analysis and activity modification)
- Discuss work simplification

Handout:

- **Energy requirements grid updates as activities added**
- **Activity Analysis Sheet**
- **Activity Modification Sheet**
- **Work Simplification**

Homework:

Planned relaxation and activity set at an achievable level, practised regularly and consistently. Completion of homework diaries and weekly & daily schedules

Some quotes that emphasise alternating activities and activity modification,

"Alternating different types of activity, stopping an activity before symptoms are exacerbated substantially, regular periods of complete rest/ relaxation" (AfME 2003, 321)

"Pacing means conserving energy levels, trying not to push too hard, to stop before you get exhausted. I try and break down activities to do a bit at a time rather than attempting to do it all in one go which is exhausting" (AfME 2003, 314)

Session 8: Pressure from self and others to deviate from pacing

- Discuss how to manage pressures from self and others to not deviate from the pacing programme
- Discuss and encourage how to keep within their limits
- Emphasise energy use, levels of energy, activity analysis, and modification of activities, tasks and work stations
- This is a session that a partner or friend may wish to attend

Homework:

Planned relaxation and activity set at an achievable level, practised regularly and consistently. Completion of homework diaries and weekly & daily schedules

Some quotes to assist with explaining pressures from self and others

- **Plan your time**

"It is trying to be aware of when I am starting to overdo it e.g. too long a meeting, noisy social environment. Take steps to plan my time. If one day has been quite demanding, plan to have a quiet following day. Doesn't always work due to external pressures" (AfME 2003, 281)

- **Keep to your limits**

"Pacing to me is the knowledge learnt through trial and error of how far I can go before putting myself in a relapse position. If I go out for the day on coach or car trip I need to have the next day free to recover, if I am doing any work around the house or in the garden and I suddenly feel any tiredness or muscular weakness I must stop and rest to carry on would mean I would be useless for the next day or two. I have experimented with pushing myself further but in my case this has caused a relapse. The key is to know your limits" (AfME 2003, 63)

- **Set appropriate targets**

"To know your limits. Set a small target for the day; if you complete it congratulate yourself. Don't think I have done this so I can do more, there's always tomorrow. Should be pleased with smallest of tasks, may be able to do more next day, keep positive" (AfME 2003, 123)

- **Alternate activity and rest**

"I find it helpful to alternate periods of activity with periods of rest; this pacing help maintains an even keel. Sometimes though life gets in the way or I try to meet someone else's expectations and fall into "Boom & Bust" where I do too much then have a relapse. Pacing takes patience and planning and limits everything I do every day but it seems to be how I have to try to manage my life these days" (AfME 2003, 237)

  - **Modify your activity**

"…resting at regular intervals in order to avoid relapse. Avoid the boom or bust cycle of over doing things on good days to catch up with bad days. You must conserve energy even on good days to avoid relapse" (AfME 2003, 352)

Pressure from Self and Others to Deviate from Pacing

What Helps	Associated Strategies and Tools
Keeping to your Limits	• Listen to your body and use the 70% Rule • Avoid the Boom and Bust pattern of activity • Re-visit your baseline • Is your current level of functioning within your energy envelope? • Say NO to demands/pressures from self and others
Planning your Time	• Use Daily Programme Schedule and Weekly Plan if found to be helpful • Plan ahead and incorporate periods of rest • Use time limits if necessary if you experience difficulty listening to your body • Communicate and negotiate with others • Utilise problem solving skills • Delegate as necessary, and be assertive when making requests of others • Prioritise must do/want to do activities
Use of Appropriate Targets and Priorities	• Be realistic, remember the 70% Rule and stay within your energy envelope • Be flexible and regularly review your standards and priorities • Make use of time management skills • Utilise problem solving skills • Communicate and negotiate with others • Delegate tasks/activities as necessary • Congratulate any successes in maintaining baseline
Alternate Rest and Activity	• Balance activity with periods of rest and relaxation • Balance physical and mental tasks, remembering each activities energy requirements • Balance work and leisure • Balance needs and wants
Modify your Activity	• Use ergonomic techniques, modifying tasks and workstations on a daily basis • Utilise the skills of Activity Analysis • Communicate and negotiate with others, saying NO if necessary

Also Participant Handout

Session 9: Anticipating exacerbation's

- Discuss and revisit balance
- Revisit must do/ want to do activities
- Revisit priorities and Re-set limits and priorities
- Discuss "listening to your body", warning signs
- Re-set energy levels and weekly plan
- Practise rest/ relaxation techniques as required

Homework:

Planned relaxation and activity set at an achievable level, practised regularly and consistently. Completion of homework diaries and weekly & daily schedules

Some quotes to assist with explaining anticipating exacerbation' and balance.

- **Anticipating exacerbation'**

"After an initial period of rest I have been trying to GRADUALLY build up the activities I can do. When any activity is planned I try to make sure I am well rested beforehand and allow time to recover afterwards" (AfME 2003, 60)

"Having a good idea of how much activity is possible without causing a relapse & working within my limits" (AfME 2003, 205)

- **Importance of prioritising**

"Establishing a level of activity I can maintain without a relapse that spreads it out evenly without extreme highs or lows. Jobs are broken down into small steps with rests in between. Prioritising is essential, as is the ability to leave what cannot be achieved. Planning something pleasant is included" (AfME 2003, 101)

Session 10: Increasing as Able

- Review participant's aims/ targets/ priorities
- Review progress
- Review and discuss experiences
- Re-visit the "energy envelope", has it increased?
- As homework re-visit baseline – has it changed?

Remember: *This form of pacing does not necessarily imply that the person with CFS/ME must permanently remain at a fixed activity level. As natural recovery occurs the person may find that they can increase activity – but only if the envelope increases in size. When such recovery occurs the person may establish a new baseline. Activity is not increased in order to "push the envelope" but rather follow its natural expansion. However appropriate aims and priorities can be set and then activity built up as tolerance increases (taken from page 18).*

Homework:

Planned relaxation and activity set at an achievable level, practised regularly and consistently. Completion of homework diaries and weekly & daily schedules. Relaxation carried out in session as necessary.

A number of quotes to assist with explanation of increasing as able.

Balancing activity
"About managing illness – gaining level of management/ balance where can have maximum quality of life with minimum output energy – regaining normal activity on graduated levels over period of time hopefully (or at least optimum). It's mainly about warning balance!! Not too much, not too little" (AfME 2003, 96).

Breaking down large tasks into small chunks
"Pacing to me is the measuring of energy. I look ahead for events that will use a lot of energy and plan the surrounding days so that I can conserve energy before and after. Also if I have a large task I will break it down into small chunks that can be spread over a number of days. I try to stick by the 70% rule doing only 70% of what I feel I am capable of each day. I don't drain my energy banks; I am able to increase the amount I do gradually over the months" (AfME 2003, 278).

Importance of monitoring
"Basically it means listening to your body. Adapting activities and lifestyle so that symptoms are not exacerbated and recede & gradual improvement takes place. These may mean a very drastic reduction in activities and some having to be abandoned completely initially. Both mental and physical activities must be monitored. The amount of rest and activity have to be varied slightly according to how the illness is at any given time – because it fluctuates in severity e.g. an infection exacerbates so more rests needed at such times. Use only 70% of energy in activities to allow for healing & minimise exacerbations. Keep brief notes to work out what you can and can't do to maintain progress" (AfME 2003, 354)

Session 11: Baseline Review

- Review baseline
- Review balance between,
    - activity and rest/ relaxation
    - physical and mental tasks
    - work and leisure
    - needs and wants

Handout

- ➢ Baseline Sheet
- ➢ Weekly schedule
- ➢ Daily Schedule
- ➢ Energy Grid

Homework:

Planned relaxation and activity set at an achievable level, practised regularly and consistently. Completion of homework diaries and weekly & daily schedules. Relaxation carried out in session as necessary.

A number of quotes to assist with explanation of baseline review.

"Setting a level of daily activity that is sustainable and will not cause a relapse and worsening of symptoms that can gradually be increased as my health improves. PS. I don't get it right all the time, far from it and often over do things!" (AfME 2003, 234)

"Managing activity & rest to achieve sustainable levels of activity both throughout the day & day-to-day. Establish a baseline then aim to slowly increase activity" (AfME 2003, 197).

Session 12: Rest, relaxation and sleep pattern review

- Review rest and relaxation
- Review sleep patterns

Handout

- ➢ Spider (concept map) diagram for brain storming

Homework:

Planned relaxation and activity set at an achievable level, practised regularly and consistently. Completion of homework diaries and weekly & daily schedules. Relaxation carried out in session as necessary.

Quotes to assist in explaining appropriate levels of rest, relaxation and sleep.

Alternating planned periods of rest and activity throughout the day & week so that I stop activity before becoming tired & keep within my energy limits – adapted to how my illness is at the time. Lying down for 20-30mins between tasks using more energy, listening to quiet restful music helps & stops me feeling I am doing "nothing". I include meditation and relaxation in some rest periods every day. If I stick to my programme & feel better I can achieve a little bit more than if I push on & become over-tired, and can gradually increase my activities up to a certain level." (AfME 2003, 01).

"It means not over taxing yourself. Doing tasks that aren't going to exhaust you. Knowing how your body reacts to carrying out various tasks. Listen to your body what it can cope with. Other ways to regain strength is to rest at regular intervals through the day. Not actually sleeping but being totally relaxed for about 20 minutes in a session. Body has time to regain level of ability where you can re-start to pace yourself in daily tasks" (AfME 2003, 14)

"It means having a calendar & putting all engagements on it making sure they are well spaced then I arrange what I have to do around house/ garden/ shopping to fit in again well spaced. Husband vacuums and does driving to help me out. I rest using a programme of relaxation tapes made for me 1-3 times a day. I aim to move through the day at a slow steady pace with rests" (AfME 2003, 93).

"Going slowly in everything, sitting down frequently; stopping activity before feeling exhausted. Changing plans if I feel I am not up to a certain activity. Making a point of resting at a certain time of day whether I feel tired or not" (AfME 2003, 208).

• *Phase 3: Planning for future self-management*

The aims of this phase are consolidation and planning for the future.

- The person with CFS/ME is encouraged to summarise all that they have learned and to make plans for future pacing.

Session 13: Questions & consolidation

- The rationale for treatment is reviewed and the person’s successes and setbacks in implementing pacing discussed.

Review rationale

- ➢ Review APT diagram? Give blank and ask to complete
- ➢ Review understanding of APT model
- ➢ Review basic but major principles of APT

Review person’s successes and setbacks in APT

- ➢ Discuss with the person their views on the APT journey
- ➢ Review & reflect on the daily, weekly diaries and baselines
- ➢ Reflect on personal and subjective success the person sees
- ➢ Reflect on the difficulties of using pacing/ APT
- ➢ Therapist reflection and summary of achievements

Handouts

- ➢ Blank APT model diagram
- ➢ Target Review
- ➢ Baseline Sheet

Homework:

A written summary of the treatment is produced as homework. In particular learning achieved.

Quote from a female with mild CFS/ME, who previously had severe CFS/ME.
“Learning to know your own body & its limits. Stopping physical activity before it has an adverse effect. Taking time to rest and recuperate immediately after a higher level of activity (physical & mental) to minimise adverse effects. Recognising early on when I’ve over done it & making time to recuperate so that I come up more quickly. Being prepared to push limit/ extent of activity (gently) when I feel well in order to maintain maximum health” (AfME 2003, 158)

Quote from a female with moderate CFS/ME, who previously had severe CFS/ME.
“Knowledge of what my capabilities are. Schedule over a week of things that are important for me to do either chores or social activity. Split each day with high, medium & low energy things & schedule regular rest periods in between. Feel more empowered as taking control. Helps me to avoid crashing back. If a virus or some other stress event strikes me I go straight back to lots of bed rest” (AfME 2003, 99).

Session 14: The way forward

- Review learning

Handouts

- APT model diagram
- Target Review
- Baseline Sheet

Quote on moving forward from a female with moderate CFS/ME, who previously had very severe CFS/ME.

"Worked out how much energy I could manage per day & sustain over a month with my symptoms not getting worse. From this baseline I have gradually been able to increase my activity, without symptoms getting worse. I stick to a level of activity that keeps me in my comfort zone, though sometimes I overdo it. If my symptoms reduce or I have more good days I very slightly increase my activity levels". (AfME 2003, 306)

Quote on moving forward from a female with mild CFS/ME, who previously had very severe CFS/ME.

"1. Identified needs
2. Wrote lists, prioritised, do minimum
3. Family support, help & encouragement
4. Sense of achievement when a task done
5. Accepting that you're ill, allowing rest
6. Gradually building up
7. Bring in some exercise
8. Recognising symptoms, STOP, REST, do not over do it"

Paperwork to complete after session

The Clinical Global Impression (CGI) is also completed by the therapist after this session

CGI and treatment adherence for therapists and doctors

PIN		Participant Initials	Date completed		
☐☐	☐☐☐	☐☐☐	☐☐	☐☐	2 0 ☐☐
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)?

☐☐

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?**

☐☐

Session 15: Follow up

- Session 3 months after treatment end (session 14)

- Content will vary dependent on need
- Review programme,
    - Daily plans
    - Weekly plans
    - Activity analysis and modification
    - Energy conservation & regulation
    - Use of rest & relaxation
    - Sleep pattern
    - Aims, targets & priorities
    - Balancing life

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- Packer TL, Brink N, Sauriol A (1995) *Managing Fatigue: A Six Week Course.* Arizona: The Psychological Corporation
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Appendix 1

Diagnostic Criteria

Photocopied and added

- Fukuda et al (1994) – CDC criteria
- Sharpe et al (1991) – Oxford criteria
- CFS/ ME Working group report (2001) Appendix II – Existing diagnostic criteria (adults)

Appendix 2

Tools for recording sessions and information

- *Timing of sessions (Landscape version)*
- *Record of Attendance for APT*
- *Pace Trial Session Record*
- *Unplanned Telephone Call Record*
- *Reflective Review of Session*

The **timing of sessions** *form as attached in the therapists' landscape appendix*

RECORD OF ATTENDANCE FOR APT

Example: participant did not attend their 1st session (face to face appt) due to a tummy bug, (UW) so appt was re-arranged for 10/06/04 to be conducted on the telephone

Session Number	Attendance*		Outcome	Comments
	Date	Appt Type**		
1	*7/06/04*	*FF*	*X+*	*UW*
1	*10/06/04*	*PPC*		

*Outcome Key

✓ Attended appt as planned
X Did not attend appt as planned
+ Another appt made
- Another appt not made

**Appt type

FF – Face to face

PPC – Planned Phone call

UPC- Unplanned Phone call

Reasons for non-attendance:

SB – CFS setback
UW- unwell (other reason)
WC – work commitment
FC – family commitment
TR – transport problem
UK - unknown

PACE TRIAL SESSION RECORD

Trial number __________ **Date of session** _________

Session number __________ **Attended/cancelled/DNA** __________

Outpatient 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

Unplanned Telephone Call Record

Participant 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.

Circle the appropriate number

WHO CALLED WHO?

1. Participant called, and spoke to, therapist
2. Therapist called, and spoke to, participant
3. Participant left message on answer-phone/ receptionist
4. Therapist left message on answer-phone/ with another

PURPOSE OF CALL:

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

FURTHER COMMENTS:

Please record further information, including any advice given overleaf.

REFLECTIVE REVIEW OF SESSION

Therapist name	**Date**	**Session Number**

What went well?	**What did not go so well?**
Were there any CBT/GET conflicts?	**What would be done next time to avoid CBT/GET conflicts?**

Would you do anything different next time?	**Were there any other difficulties encountered or questions you need to ask?**
Amendments to paperwork to improve clarity or usage?	
Action plan and questions to clarify for next time:	

Appendix 3

Therapist resources

- *Relaxation 1*
- *Relaxation 2*
- *Simple Relaxation*
- *Activity Analysis: Overview*
- *Possible local resources*
- *Therapy Integrity Rating Scale*
- *Important Contacts and Phone Numbers*

Relaxation 1
Warmth and Light

Imagine you are on a sandy beach in the sunshine…….There is nobody else in sight.
Try to get a picture in your mind of an ideal beach……..that you can visit whenever you want to.

You are feeling warm and comfortable……lying in the sun. As you lie on the beach…..close your eyes, and feel the warmth of the sun on your face……and the heat it generates.
Feel the softness of the sand beneath your hands….as you lie there totally relaxed.
Feel the gentle breeze blowing in from the sea………as it cools your skin pleasantly.

As you are lying there, listen to the sounds of the sea as the waves roll up onto the beach…… hear the cries of the seagull's overhead. Notice the seaside atmosphere that you can smell.
Keep relaxing, feeling the sun and the sand………and hearing the sea and the seagulls.
As you are lying there relaxing on the beach, I would like you to imagine the sun coming towards you. You are perfectly safe……………the sun does not burn you, but merely warms you.
Feel the warmth and light of the sun on your body…..making you feel warm and comfortable all over.

Draw the sun closer to you…….Draw the sun into your heart…….Feel the small ball of warmth and light spreading throughout your heart, warming all the tissues……and lighting all the dark spaces.
Feel the rays of warmth and light extending outwards in all directions……..soothing away all the tensions in your chest. Feel it warming and lighting your chest.
Your whole chest feels warm and relaxed…..light and comfortable.

Now – imagine this ball of warmth and light……this perfect sphere…….moving downwards….out of your heart……..slowly downwards, into your stomach…….to all parts of your trunk…..the entire area between your lungs…..and your pelvis………warming and lighting all the organs….and tissues of the trunk.
Enjoy the feeling of relaxation…….as all tension is soothed away…….by the healing effects of the sun. Now….all the tissues and muscles………in the chest and trunk………..are warm and relaxed….and filled with light.

As you are lying there…….feeling the calmness and comfort of the sun……imagine it moving slowly downwards……..down into your right thigh……..Feel its rays entering the tissues and muscles………warming and lighting…everything as it moves. Enjoy the sensation of warmth and light……..in your right thigh.

Once again……let the ball of warmth and light…….with its healing energy…….move slowly downwards…..down…..towards your right foot.
The rays spread outwards in all directions……. touching all parts of your right leg…..as the sun settles in your right foot…….filling the whole of your foot with warmth and light.
Your toes are filled with warmth and light…..and small beams of light shine outwards to the tips of your toes. The rays spread further outwards……..and the sun moves from the toes of your right foot……….to the toes in your left foot. The sun settles in your left foot………..and fills it with its soothing……..and relaxing energy.

Now……let the sun move upwards…….through your left leg………again its rays warming and lighting……every fibre……as it moves…..slowly upwards……into your thigh. Notice how much calmer…….how much more relaxed your legs feel……..now that you have allowed the sun to soothe them. Wherever the sun goes…throughout your body……..its energy brings comfort and relaxation. It makes you feel serene and at ease with yourself.

Once again……let the sun move slowly upwards……this time into your buttocks. Feel the warmth….driving out the tension……….leaving a feeling of relaxation…….in every part of your buttocks. The sun light floods this whole area of your body.

Slowly………the sun moves upwards……..into the base of your spine…….its rays spread right throughout your bones………Its rejuvenating rays spread upwards……….downwards………and outwards……….through every bone in your body. The rays go down……..through the bones of your legs………..up through your spine……outwards across your ribs……..and along the bones in your arms. The suns rays stretch across your body………..with their warmth and light.
Gradually……the sun rises through your spine……..upwards….and across to your right shoulder……gently massaging your shoulder…..and upper back…..as it moves on….into your right arm……and along……into your right elbow……..where its healing energy……..soothes the fibres and joints………before moving on……….and settling in your right hand.

Shafts of light…….spread into…and outwards….from your fingers.
The sun moves across your left shoulder……lighting……and warming as it goes…….leaving your arms feeling heavy……..and relaxed. As your left shoulder begins to feel warmer and more comfortable…..the ball of light and heat moves upwards….into your neck…..soothing away all the strains of the day………relieving the pressure and lightening your mood.

Enjoy that for a moment.

And now……the sun enters your head……so that your whole body feels uplifted and refreshed. You feel more relaxed…..and calm all over. Your whole body is touched by warmth…...and light. The sun fills your head……….your heart………..your lungs………..your stomach…………your arms …………and your legs…………You feel invigorated.

Feel again…..the soft sand of the beach beneath you…….and listen to the sound of the sea….and the seagulls…….as the gentle breeze caresses your body……….that is being soothed……and warmed by the sun.

You can return to this place any time you chose, but for now, you are coming back to this room………focus on the mat / chair you are lying/sitting on………..Slowly open your eyes……..and when you feel ready, fully wake yourself, as this is the end of the relaxation session.

Relaxation 2
At Peace with Pain

Now, begin your journey inward to the place where there is peace with [pain] …..
You are in the midst of the swirling, screeching wind and water of the storm of pain….a giant hurricane that blows all around you.
And you will pass through this storm to a place that is like the eye of the hurricane….where there is comfort and calm within the storm. You will move towards this place without map or compass, at times keenly aware of your surroundings…at other times, just fixed on your goal, that special place within….where there is peace without pain.

You are driven by the power within you, which is greater than the fury of the storm of the pain that swirls all around…seeking that special place within.
You begin your journey and travel on and on...on and on…on and on. Until finally, you arrive at the threshold of this place within.
A wooden door stands before you….It has a deep, rich grain and appears to be completely smooth….You want to step through this door, but you notice no doorknob or handle.
You fix your eyes on the door and look deeply into the grain of the wood. At first you feel bewildered…but then you sense the door will open for you when you are ready.

You wait. You fix your eyes once again on the door…and focus on the grain of the wood. Feeling a sense of calm…of inner strength…you sense the door will open…and in an instant, it does.

You are transported past a swirling, screeching, tearing, electric, burning, pounding wall….to a place of peace and quiet…where it is calm and quiet, away from the swirling and screaming……away from the tearing and throbbing.
You remain aware of the storm, but it seems far away. Deep within you, you know that the harder the storm pounds and crashes, the harder it tears and flashes…the more secure you become in this special place.
Your breathing is calm and relaxed…slow, deep, and regular. You are feeling calm and quiet.

Now, aware of your surroundings, you notice that this place is strangely familiar …At once it is both like a place you have been before and a place that is new to you….a place where you feel peace and security...and where there are opportunities for discovery. Places within this place hold amazement and wonder.

Feeling calm and protected, you rest as if in a deep, deep sleep, yet with a feeling of mental alertness. You feel secure and peaceful, aware and focused.
Moving further and further in this journey within…you hear the sound of the wind and water rise and fall...then fade away. The storm is still swirling and

crashing...pounding and flashing. Sometimes it seems near ...other times it seems far….far away.

But, in this place, you feel safe and secure…calm and peaceful…distant and detached from the fury of the storm that swirls around you.
You are unafraid, unbent, and unhurt…and breathing in a way that is calm and relaxing….calm and relaxing…feeling a special sense of peace and security.
You awaken as if within a dream to a special discovery….to the healing, soothing power of warmth.

First, you feel warmth around you...very deep and complete…strong and thorough, feeling the warmth deep within you, feeling its soothing, healing power…calm and peaceful.
Then you notice that the storm has quietened. Less and less raindrops are falling…less and less water, swirling…less and less wind, blowing.
The warmth turns the water to steam….and evaporates the raindrops…even before they reach the ground. The sun comes out…and shines its light through the rising steam. You feel warm and soothed by the mist.
Take some time now to feel that special feeling…that soothing feeling…calm and comfortable…comfortable and relaxed.
Pause 20 seconds.

Now you become aware of another healing feeling. …Cool and refreshing…deep and strong…numbing and soothing. You are now barely aware of the storm.
Sensing cool and quiet ..a faint swirling…..now soft and gently…you see the cold transforming the water of the storm, turning it to snow.
Bright sparkling snow crystals float in the air and reflect the light ……then fall softly to the ground. A blanket of quiet white……creates a deep, deep restful sense of calm.
The whole landscape covered with snow...looking soft and smooth……makes you feel comfortable and relaxed ………calm and at peace.

Pause 20 seconds.

You will discover other places where you can find a sense of soothing and healing...Time is your friend and ally. Take the time you need to find a place of calm and quiet.

Pause 1 minute.

In a moment, you will prepare to leave your special place….But even as you think that thought you feel secure in your knowledge of the place that lies within.
Then you think about what you want to take with you……something that helped you feel calm and quiet……..that gave you a sense of relief and rejuvenation… a sense of soothing and healing.
You know that when you journey back to this special place……..you will find your way once again. You know that each time you come here…..and then

leave…… you can take something with you that will help you find calm, rest and relief.
But each journey will be different.…You will recognise some familiar terrain….but still you will take a different path.
The more you journey to your special place…..the easier it will be for you to find the way and the more secure and comfortable you will feel within this place. But most of all…..after each journey you remain secure in your knowledge about this special place that lies within.

Pause.

In a moment, I will ask you to take a deep breath and bring yourself back to the here and now.
Go ahead and take that deep breath now…….and blow it out.

Come back to the here and now……with a calm, soothing, relaxing feeling.
Keep that calm, soothing, relaxing feeling with you……..As you open your eyes…and continue to rest comfortably.

Adapted from Simple Relaxation, the physiological method for easing tension by Laura Mitchell.

Reminder (*when practicing at home*) - Positioning, body well supported, quiet environment, warm, switch off the phone, let others know are not to be disturbed. Are you comfortable?

With your eyes closed, let your attention focus on your body… and on your breathing… Take a few slow, deep breaths… inhale through your nose... pause for a moment… and then exhale slowly through your nose or your mouth, whatever feels more comfortable. Use this time to prepare your mind and your body for this period of relaxation. As you continue to breathe… slowly and regularly… you will still hear noises of life going on outside this room (give examples)… put them to one side. They are not important at this point in time. Right now we are here taking time to relax.

We are going to move round your body, following a set of instructions that ask you to move and re-position yourself. When I say stop… do just that, and register the feeling of the new position as accurately as you can. Try to concentrate on these new positions… and take time to register them, because with this knowledge you can make use of these positions at other times in your life. Initially this will require some concentration but it does become easier with practice, and over time.

As we move through this relaxation exercise I will repeat each set of instructions twice. However, do not try to memorize the exact position you are in today. The position of your body vary slightly each time you do this relaxation because you will be starting from a slightly different position on each occasion.

What is important are the orders of **1. Move and feel, 2. Stop, 3. Feel.** These never change… although as you develop skills in this particular method of relaxation you may wish to change the sequence of orders as you move round your body.

ORDERS TO THE ARMS

SHOULDERS

ORDER: Pull your shoulders towards your feet… down and away from your ears. STOP

RESULT: Feel your shoulders are further away from your ears… When you stop don't be surprised if your shoulders bounce back up slightly, that's perfectly natural… but register this new position. Your neck may feel longer.

ORDER: Pull your shoulders towards your feet… down and away from your ears. Only pull your shoulders down, do not roll them backwards or forwards. STOP. Now register this new position, feel your shoulders, they are further away from your ears and your neck feels slightly longer.

ELBOWS
ORDER: Elbows out and open. Move your upper arms slightly away from your body, not lifting them but opening up the angle at your elbows by moving your forearms away from your sides. STOP
RESULT: Feel your upper arms away from your body and the wider angle at your elbows. Register this position. The weight of both arms should be fully supported and resting.

ORDER: Elbows out and open. Move your upper arms slightly away from your body… opening up the angle at your elbows… moving your forearms away from your sides. STOP. Now register this new position by feeling. Recognize both arms are away from your body and resting on something… not glued to your sides, that there is an open angle at your elbows. Do not hurry.. feel… don't fidget. Concentrate on feeling.

HANDS
ORDER: Finger and thumbs long and supported. Try to keep the heel of your hand resting where it is and only move your fingers and thumbs. Stretch them out to be as long as possible… feeling the space between each finger… and your index fingers and thumbs. Go on stretching… feel your fingers opening out even further… and stiffening as they can stretch no further… STOP. Let your hands rest, lying on the support.
RESULT: Feel your fingers and thumbs stretched out… separated… and touching the support, nails on top… Especially feel your heavy thumbs.

ORDER: Finger and thumbs long and supported. Again, stretch them out to be as long as possible… feeling the space between each or your fingers and your thumbs. STOP. Let your hands rest, lying on the support.
RESULT: Feel your fingers and thumbs stretched out… resting on the support. Think about the surface your fingers are lying on... Is it hard or soft?.. Register the texture of the material... Is it rough or smooth?.. Does it feel warm or cold to touch?.. Take your time as you register the position of your hands, and enjoy all the sensations that are travelling up to your brain through your fingertips that at other times you are probably too busy to think about.

ORDERS TO THE LEGS
HIPS
ORDER: Turn your hips outwards, by this I mean gently roll your kneecaps to the side. STOP
RESULT: With your thighs rolled outwards and your kneecaps facing outwards feel this new position at your hips. REPEAT

KNEES
ORDER: If you wish move your knees until they are comfortable. STOP
RESULT: Feel the resulting comfort in your knees. REPEAT

FEET AND ANKLES
ORDER: Slowly push your feet away from your face, bending at the ankle, pointing your toes. Feel the stretch down the front of your legs and across your ankles. STOP.

RESULT: The muscles in the backs of your lower legs should now be relaxed…. And your feet are dangling loosely at the ends of your legs.

REPEAT. Take your time and enjoy the sensation of your feet resting at the ends of your legs.

Before we move on take time to again check over your arms and legs, making sure your shoulders haven't crept back up towards your ears… your elbows are still out and open… your fingers are long and supported… That your hips, knees, feet and ankles, are all resting in a comfortable position before we move on.

ORDERS TO THE BODY
ORDER: Consciously push your whole body into the support. STOP.
RESULT: Feel the contact of your body on the support… feel your body lying there… feel the support holding your weight. Register how this feels.

REPEAT. Let your body rest in this position, completely supported, completely at rest.

ORDERS TO THE HEAD
ORDER: Push your head into the support. When you feel your head thoroughly supported then STOP.
RESULT: Feel the contact of your head on the support. Feel the support holding your heavy head for you. You will probably find this most comfortable. Enjoy the relief.

REPEAT

ORDERS TO THE FACE
<u>MOUTH</u>
ORDER: Drag your jaw downwards. Separate your lower teeth from your top teeth, and slowly pull the jaw down. As this happens feel the stretching of your skin over the cheeks, then STOP.
RESULT: Feel your separated teeth, and heavy jaw. Your lips may be gently touching together. Register how this feels.

REPEAT. Is your tongue fixed to the roof of your mouth? If so it is in the stress position, so gently loosen it… and let it rest in the middle of your mouth or against your bottom teeth.

<u>EYES</u>
ORDER: If you haven't already done so, and now feel safe enough, then gently close your eyes. STOP.
RESULT: Without screwing up any of the muscles around your eyes feel your upper lids resting gently over your eyes and let your eyes and all associated muscles rest. Enjoy the darkness, and the peace you have created.

REPEAT

FOREHEAD
ORDER: Begin to think of the area just above your eyebrows, and think of smoothing gently up into your hair, over the top of your head, and down the back of your neck. STOP.
RESULT: Feel your hair move in the same direction.

REPEAT. This is an extremely difficult part of this relaxation and you may want to repeat this smoothing over again, another once or twice.

Before we move on to your breathing you may want to take time to check over your body. Your arms…. again making sure your shoulders haven't crept back up towards your ears, that your neck still feels longer… your elbows are still out and open, the weight of your arms is fully supported… your fingers are long and supported… you are enjoying the sensations travelling up through your fingertips. Your legs are in a comfortable position… your hips, knees, ankles and feet are all resting in a comfortable position. Your body and head are well supported, enjoying this experience of relaxation. Your teeth are still separated and your eyes are gently closed… you have worked hard at smoothing the muscles in your forehead. Take your time and enjoy these new positions, this state of relaxation.

BREATHING

Breathe in gently… Concentrate on your chest rising and falling with each breath… As you breathe in you feel your chest rising as your lungs fill, your lower ribs moving upwards and outwards each time you inhale. Then as you exhale… again slowly… and gently…you feel your ribs fall downwards and inwards, back to their starting position. Repeat the breathing another four or five times before either again checking over your body, repositioning as necessary, or bringing this period of relaxation to an end.

Activity Analysis: Overview

Activity Analysis is a process by which an identified task is broken down into all its constituent parts.

Essentially there are eight major categories. It may be helpful to impose your own sense of progression to them.

First it is necessary to have an idea of the extent to which the following skills are required to do the task:

1) Physical:
- Muscle strength
- Joint range of motion
- Coordination (gross or whole arm/body movements vs. fine precise finger movements used in the various prehension patterns)
- Sensation- (sharp/dull, hot/cold, pressure, light touch, 2-point discrimination, kinaesthesia, - the first 3 enable us to protect ourselves, the latter help us know instinctively where one part of the body is in relation to another
- Physiological status- this includes heart rate, respiratory rate, demands on autonomic system.

2) Sensory
- Sight
- Sound
- Smell
- Taste
- Equilibrium/ balance
- Touch

3) Perceptual
Where our brain interprets the sensory information it receives and gives it meaning- problems here make remembering things more effortful. Mostly when considering perception, we mean:
- Visual processing e.g.: distinguishing spatial relationships, figure-ground, shape constancy, depth perception etc. etc.
- Auditory processing e.g.: auditory figure-ground, auditory discrimination etc.
- Motor planning e.g.: the integration of proprioceptive information and body scheme is required for accurate execution of movement.

4) Cognitive
This refers to the sub-skills of cognitive processing: i.e. alertness, recognition, attention/ concentration span, recall, ability to follow simple/complex directions, assemble and/analyse information, organize/ use information.

5) Emotional
This refers to the demands the task will place on people's affective state, + consideration of their own emotional strengths/ weaknesses

Consideration of the following factors is added to the above:

6) Social
Is this task being done by the person alone? Does the person want to do the task alone? Will other people be around? How necessary is it that others help with the task or any steps of it?

7) **Cultural**
What is the impact of any culturally derived values/behaviours on the task and the way it is to be done? (this includes factors relating to gender as well as ethnic norms).

8) Environment
What are the surroundings like in which the task will be done?
It refers to the type of area your participant will be carrying out activity in and encompasses such things as physical layout, (i.e.: the distances they will have to cover, the presence or absence of stairs/ railings etc), the equipment/ work surfaces etc that will be used or available, as well as the conditions that exist within that setting.

All of the above are then put against the context of the approach that is most suitable and acceptable to the person. Generally it seems that the most acceptable solutions are the simplest ones.

Put in a concrete context for example:

Your participant may complain of difficulty in writing letters or completing forms, you may choose to address the mechanical portions of the task before moving on to address the mental fatigue component, an example is given below;

Solutions might be any of the following,

a) change of hand grip
b) change to the type of writing implement being used
c) proximal supports/splints/braces for fingers/wrist etc
d) positioning systems
e) Augmentative communication devices (e.g. recording systems/computers, secretaries) etc.

In addition/ in place of a change to any of the following:
a) the time of day,
b) place,
c) length of time handwriting is being done for

Activities can also be broken down into their elements.

If the person with CFS/ ME wants to do the weekly shopping, it could be broken down into smaller achievable components before the whole is achieved.

Such as

a) Writing the weekly food list
b) Going for short rides in the car
c) Walking short distances
d) Going initially with someone else
e) Just doing a component of the shop i.e. the vegetables, and a friend doing the remainder whilst the person with CFS/ ME rests

And so on

Over time the person will then increase the task range as able within their energy envelope.

Possible resources and outside agency contacts

You may wish to add your own local contact resources here.

Suggested contacts/ information sources;

- **Citizens Advice Bureau (CAB)**

- **Employment and educational schemes such as Job Centre plus, Learn direct, etc.**

- **Welfare Rights**

Locality Issues

PACE Trial Therapy Integrity 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

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 discussion		considerable discussion		extensive 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 discussion		considerable discussion		extensive 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

C. 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 discussion		considerable discussion		extensive 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 discussion		considerable discussion		extensive 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

D. 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. Incremental Changes
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. Adapting Exercise/ Physical Activity
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. Physical Goals
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

<u>Finally,</u>

<u>Homework assigned/reviewed: (same for all therapies)</u>
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 to develop homework		considerable attempt to develop homework		extensive attempt to develop 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**

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.

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.

This information can be given out to individual participant as required.

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 organisation, 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 will, of course, vary according to context. However, the person with CFS/ME has considerably more legal protection and rights with regard to their employment than previously. For more details of how this affects you, the Citizens Advice Bureau is a useful source of information. Those who still have connections to a place of work can ask their union representative, human resources or occupational health departments.

IMPORTANT CONTACTS AND TELEPHONE NUMBERS

All public PACE trial enquiries should go to:

pace@qmul.ac.uk

Please do not give out any personal information to anyone not associated with the PACE trial: if in doubt, go through PACE management

Serious adverse events

In case of a serious adverse event (SAE), immediately contact the clinic doctor, the Research Nurse or the centre leader:

Local hospital cardiac arrest number:

PACE Contacts:

APT Therapy Leader:
Dr. Diane Cox – d.cox@ucsm.ac.uk
01524 384581

Local Research Nurse:

Centre Leader:

Appendix 4

Participant handouts

Summary Table of Sessions for APT.

Session Number	Week No approx	Time (mins)	Summary	Homework
1	1	90	• Detailed interview • Review of what is CFS/ME • Introduction to the APT model and rationale	• Activity and Fatigue rated daily diary • Weekly rest/ relaxation diary
2	2	50	• Review Model • Discuss Peaks/ Troughs, Bust/\Boom • Baseline Activity and sheet • Discuss rest/ \relaxation	• Daily Diaries • Baseline Sheet • Must do/ Want to do • What is Rest?
3	3	50	• Review diaries & fatigue • Discuss managing sleep and energy • The 70% rule • Schedule activity/ rest	• Daily rest/ activity diaries • Energy expenditure Grid • Energy Envelope
4	4	50	• Review of model & understanding at each session • Importance of balance • Activities Lists: Self care, Productivity & Leisure • Relaxation practice • Weekly Plans • Activities in my day & week • Evaluating Priorities & Standards of Activity • Body Mechanics • Ergonomics • Activity Analysis • Activity Modification • Work simplification • Pressure from others • Problem Solving in APT • Anticipating exacerbations • Increasing as able • Baseline review • Rest, relaxation and sleep pattern review	• Activities in week & weekly plans • Actual/ Ideal Day • Actual Weekly Plans • Relaxation • Evaluating Priorities & Standards of activity • Priority Activities in week • Activity Analysis sheets • Activity Station Analysis sheets • Activity modification • Ergonomics II • Problem solving & Planning Time • Alternating rest/activity • "Listening to body" • Baseline Review
5	6	50		
6	8	50		
7	10	50		
8	12	50		
9	14	50		
10	16	50		
11	18	50		
12	20	50		
13	22	50	• Review APT Model • Target and Priorities review • Complete CGI • Preparation for discharge	• APT Model • Target and priorities review • Baseline sheet
14	24	50		
15	36	50	• Review of programme and progress • Discharge	• Continue with daily, weekly and overall planning and implementation of APT principles

PACE Trial Participant Information

Chronic Fatigue Syndrome (CFS) and Myalgic Encephalitis/Encephalopathy (ME)

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

What are the symptoms?

Common to these illnesses are symptoms of physical and mental fatigue, usually made worse by exertion. Other symptoms may include difficulty with memory and concentration, muscular and joint pain, unrefreshing sleep, headache, tender lymph glands, and sore throats. Some 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 and anaemia) and a medical assessment is needed 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 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.

PACE Trial Participant Information

The Adaptive Pacing Model of CFS/ME

The concept of fixed limits

The basic underlying concept of adaptive pacing is that a person can adapt to CFS/ME but that there is a limited amount that they can do to change it, other than provide the right conditions for natural recovery. CFS/ME is regarded as limiting your available energy. Exceeding the available energy causes an exacerbation of fatigue and other symptoms often after a time lag.

The limited energy is often described as a bank account, which may be overdrawn. If you have overdrawn the account you will have to "pay back". Pay back may be delayed so that excess activity today may result in greater fatigue tomorrow or the following day.

Another analogy is the "envelope theory" (Pesek et al 2002). The exponents of this theory propose that if the person's energy expenditure exceeds the energy available (the energy envelope) they will develop fatigue – the aim therefore is to keep within the envelope of available energy.

A similar model was described in the recent CFS/ME working group report on CFS/ME (2002) as follows:

> "*Pacing is based on the envelope or glass ceiling theory of CFS/ME which suggests that energy is finite and limited, and that the best way for a sufferer to manage their illness is to live within this envelope i.e. not constantly break through the ceiling (some advise never going beyond 70% of a sufferer's perceived energy limit)*".

Activities that require energy

It is important to note that people with CFS/ME report that a range of activities make demands on energy and lead to exacerbation. These include physical activity, mental activity and also emotional demands.

The limit increases with recovery but cannot be increased by increasing activity.

The underlying idea is that if people with CFS/ME use their energy wisely, their limited energy will increase gradually. You will then be able to do more. Pacing can improve coping and provide the conditions for natural recovery but in itself activity does not fundamentally change the course of the disease.

Model of Treatment

Pacing and chronic pain

Activity pacing means planning and limiting activity. It has been a primary component of chronic pain self-management programmes since their inception (Birkholtz et al, 2004, Hanson 1990, Fey & Fordyce 1983) and is currently considered to be a key requirement for adaptive pain management (Nielson et al 2001).

Pacing and CFS/ME

There have been a number of supporters of adaptive pacing therapy (APT) for chronic fatigue syndrome/ ME. One description included as part of a type of adaptive therapy is described as follows *"This approach seeks to enhance physical function and quality of life by monitoring energy, fatigue and activity levels and then making adjustments in daily activity that minimise fatigue and improve perceived energy" (Friedberg & Krupp 1994).*

APT may also involve lifestyle modification: *"Suggestions were given to direct life style changes compatible with the activity limitations imposed by the illness. Usually this meant reducing the work load as a job or at home, declining selected social invitations, scheduling regular rest intervals, and controlling exposure to stressful events" (Friedberg & Krupp 1994)*.

Pacing as a helpful self-management strategy for CFS/ME

The essence of pacing is that the person with CFS/ME uses self-management of their level of activity in order to avoid exacerbations of symptoms and disability (AfME 2002). The CFS/ME working group report (2002) described adaptive pacing as follows: "*Pacing is an energy management strategy in which sufferers are encouraged to achieve an appropriate balance between rest and activities. This usually involves living within physical and mental limitations imposed by the illness and avoiding activities that exacerbate symptoms or interspersing activity with planned rest. The aim is to prevent sufferers entering a vicious cycle of over activity and setbacks, whilst assisting them to set realistic goals for increasing their activity when appropriate*".

Pacing is based on developing awareness not only of the symptoms but also more subtle indicators that herald a future exacerbation of symptoms (listening to your body). It is also about becoming aware of effect of activity or lack of rest on disability. Activity is undertaken in planned limited amounts alternated with periods of rest. There is an emphasis on not over-spending the limited amount of energy available by using a variety of strategies such as,

- doing one thing at a time,
- choosing low energy activities and
- using energy saving devices.

The main key to effectively managing symptoms is limiting the amount of energy expenditure.

The aims of pacing

The aim of pacing is to avoid symptom exacerbations whilst achieving as much as possible with limited energy.

In particular, to establish sustainable activity levels that avoid the "bust and boom" pattern so often seen when people with CFS/ME attempt too high a level of functioning. Too much activity or too much rest can each be unhelpful (AfME 2002). By enabling you to gain more control of your activity and symptoms pacing is intended to give you a sense of control over the illness.

Important strategies used in pacing

- *Establishing a baseline*

Many people with CFS/ME get into an activity pattern of oscillation activity and inactivity – this has been called “boom and bust”. Here the person with CFS/ME alternates from relative symptom free rest to activity-induced symptoms. A key initial strategy in pacing therefore is to become more aware of this pattern by keeping records of activity and symptoms seeking to establish a more stable and sustainable pattern of activity. Baselines may sometimes need to start at a very low level. This will be discussed in greater depth in future sessions.

- *Dealing with pressures to deviate from pacing*

The aim is to discuss how to manage pressure from self and others to deviate from pacing programme. You will be encouraged to find ways to keep within limits.

- *Anticipating exacerbations*

You will be encouraged to become aware of your limits and to anticipate what activities will exceed them. One way is to “listen to the body” and become aware of early warning signs. Then to set limits rather than wait until severe symptom exacerbation has occurred. A related strategy is to rest when anticipating a period of increased demands.

- *Proper rest*

Pacing emphasises not only limiting activity but also interspersing it with proper rest. Many people with CFS/ME say they do rest but more careful attention to their symptoms and activity shows that they are not truly relaxing. Pacing therefore involves practising relaxation to achieve proper rest. You will be given further information on what is meant by rest and opportunity to practise various techniques.

- *Alternating activities*

It is noted that people with CFS/ME may become fatigued because they have persisted too long with an activity. One way to avoid this is to limit activity and ensure that periods of proper rest are interspersed between activities. Another that may enable the person with limited energy to achieve more is to alternate activities. For example change from a physical activity to a mental activity.

- *Increasing as able*

This form of pacing does not imply that the person with CFS/ME must permanently remain at a fixed activity level. As natural recovery occurs you may find that you feel able to increase activity – if the envelope increases in size. When such recovery occurs you will need to establish a new baseline. Activity is not increased in order to "push the envelope" but rather follows natural recovery. However, appropriate aims and priorities can be set and then built up as tolerance increases.

Balance is the watchword throughout (AfME 2002):

- Balance between activity and rest/ relaxation
- Balance between physical and mental tasks
- Balance between work and leisure
- Balance between needs and wants

References:

- Action for ME (2002) *Guidance on the management of CFS/ME* Wells: AfME
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- *CFS/ME Working Group Report*. (2002) London: DoH
- Fey SG, Fordyce WE. (1983) Behavioural rehabilitation of the chronic pain sufferer. *Annuls of Reviews in Rehabilitation* 3:32-63.
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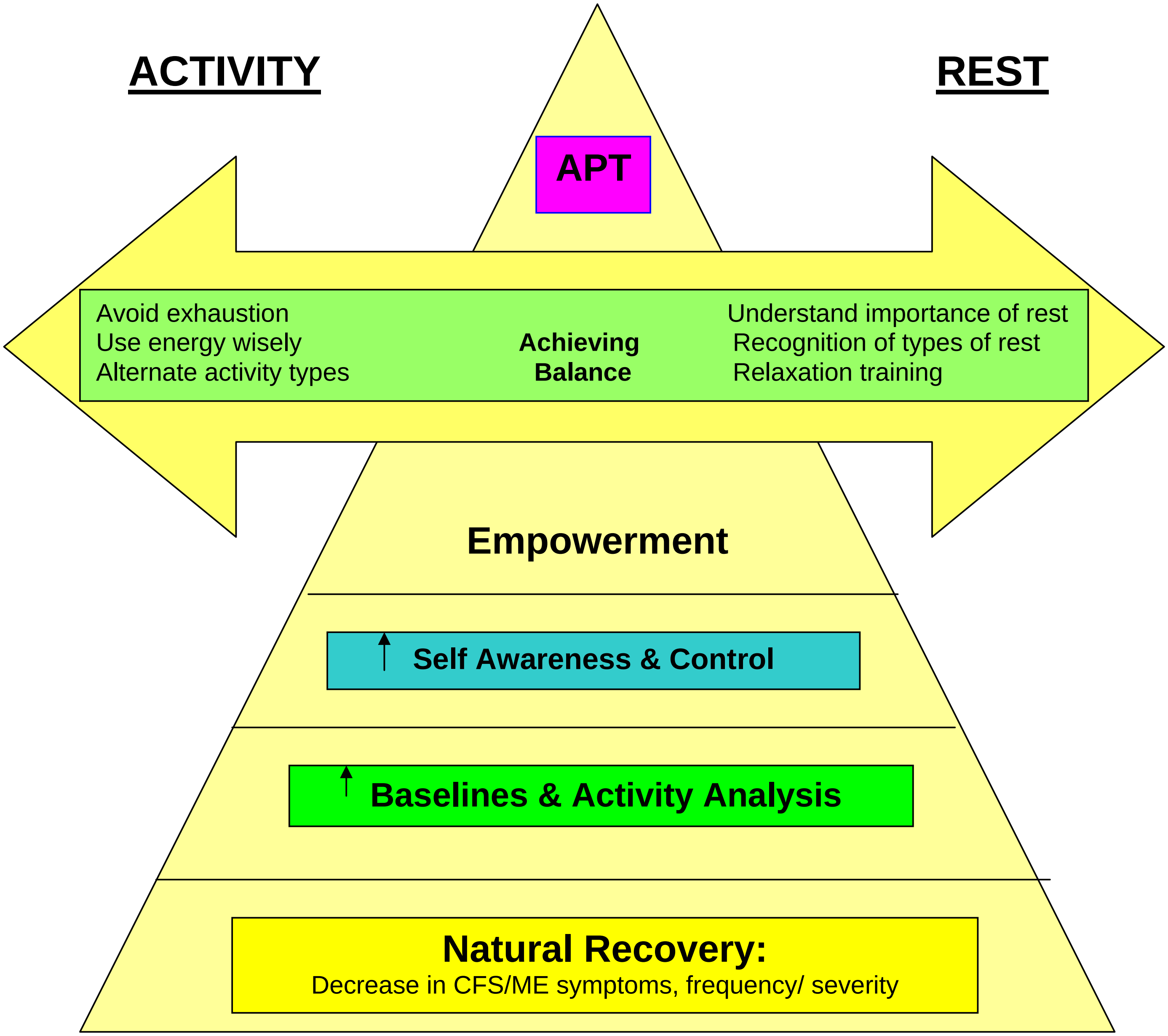
Participant Handout

The Adaptive Pacing Therapy Model of CFS/ME

The Energy Envelope

Successful Energy Management



ACTIVITY

REST

APT

Avoid exhaustion
Use energy wisely
Alternate activity types

Achieving Balance

Understand importance of rest
Recognition of types of rest
Relaxation training

Empowerment

↑ Self Awareness & Control

↑ Baselines & Activity Analysis

Natural Recovery:
Decrease in CFS/ME symptoms, frequency/ severity

Participant Handout

CFS/ ME Daily Diary

Date/ Day:

Time	**Activity**	**Fatigue level** 0 – none 10 – maximum fatigue

Adapted from Cox DL (2000) *Occupational Therapy & Chronic Fatigue Syndrome* London: Whurr

Participant Handout

Rest and Relaxation

Date:......................................Name:...

During the week list all the activities you do to rest and/ or relax

Day	Type of rest/ relaxation	Duration in minutes
Monday		
Tuesday		
Wednesday		
Thursday		
Friday		
Saturday		
Sunday		

Participant Handout

Bust & Boom

Peaks & Troughs

People often describe a see-saw effect to their symptoms

This can be on a daily, weekly and monthly basis.

The process is,

- When feeling better do more in an attempt to catch up
- Feel worse, symptoms increase,
- Do less , “rest”
- Feel better and so on

This can also be described as an over activity/ under activity cycle

The diagram below shows this.

Adapted from Cox DL (2000) *Occupational Therapy & Chronic Fatigue Syndrome* London: Whurr

Participant Handout

General Principles of Adapted Pacing

Summary

- ***Listening to your body***
- ***Alternating rest and activity***
- ***Doing one thing at a time***
- ***Choosing low-energy activities***
- ***Using energy saving devices***
- ***The 70% rule***
- ***Achieving Balance***

ACTIVITY BASELINE

A comfortable level of activity that can be managed on a regular basis, without experiencing an increase in symptoms (Cox 2000).

Participant Handout

DATE: **NAME:**

Baseline Sheet

A *baseline of activity* is a comfortable level of activity that you can manage on a regular basis, without experiencing an increase in symptoms.

What would be your own baseline at present?

____

Reproduced with kind permission of Whurr Publishers from Cox DL (2000) *Occupational Therapy & Chronic Fatigue Syndrome* London: Whurr

Participant Handout

List of Activities

Date:......................................Name:...

During the week list all the activities you must do and would like to do

Must do activities	**Would like to do activities**

Adapted from Packer et al 1995 *Managing Fatigue*

Participant Handout
Rest, Relaxation & Stress

LEARNING TO RELAX

Rest & Relaxation

Throughout daily life, ***activity*** needs to be balanced with ***rest***. We cannot function without adequate rest. However, rest can mean different things to different people. Some people may suggest that rest means sleeping or perhaps just sitting down and “not doing anything”. Others may suggest that rest means being able to relax. When the term rest is used in your individual programme it means ***relaxation***.

What is Relaxation?

Prior to becoming ill you may have found reading, watching TV, or talking to friends on the telephone a good way to unwind. Now however, due to the “overactive brain” or “sensory overload” phenomena experienced in CFS/ME, the concept of relaxation needs to be redefined.

Anything that stimulates or over stimulates the brain either in terms of physical or mental effort is termed ***activity***. Thus talking, watching TV, reading and even eating are regarded as activities. Relaxation should focus not just on resting the body, but also on resting the mind.

Relaxation aims to achieve a state of minimal neurological (brain) activity. On a continuum between wakefulness and sleep the X indicates the point at which relaxation occurs.

It is important to try ***not*** to go to sleep during a relaxation session. The only exception is the use of relaxation to assist with sleep at the end of the day. As you begin to implement the techniques you may well find that your sleep patterns improve, due to a more helpful balance of **rest** and **activity** throughout the day. Sleep will be discussed with you more fully in session 3.

What is Recreation?

Recreational activities are what you may have previously described as relaxation. These are “the stress relievers”, for example going to the pub after a busy day at work to unwind, watching the TV, and gardening. In the main, they tend to be the activities you find enjoyable and that give you pleasure. Recreational activities are important in daily life and will, in time as your body allows, need to be reintroduced as part of your programme of rest and activity.

What is Rest?

Rest is a way to bank and restore energy. It can be preventative and restorative. Resting before you are too fatigued can prevent the onset of more severe fatigue. You will need to take short, frequent rests, and always alternate activity and rest.

STRESS

What is Stress?

Stress can be anything that disturbs your status quo. This can be mental or physical. When this happens your body reacts in various ways in order to try to restore its balance and you may experience a variety of symptoms.

What are Stressful Events?

A stressful event can be anything that you perceive as threatening, change in your life or disturbing emotions. Examples could include a car crash, divorce, moving house, prolonged difficult relationships, bringing up children alone, change of role in the home, examinations, work pressure, overwork. The list is endless. The actual event triggering stress will depend on the individual, but the most important thing is to be able to identify it and to recognise its effects on the body.

What reaction can stress cause?

The body's first reaction to stress is a surge of adrenaline and steroids. This prepares the body for a "flight or fight reaction". For example, if you narrowly missed having an accident - you may feel tense, sweaty, have a dry mouth and your heart rate increases. The feeling goes away if the stress is removed.

If the stress does not go away - for example continuing arguments with a partner or child or a busy lifestyle or a chronic illness - then the early reactions can become permanent.

If stress continues for a long time, the body becomes unable to maintain its balance and may "break down". This may take the form of chronic conditions such as migraine, high blood pressure and stomach upsets.

What role can stress play in CFS/ME?

Stress may be involved in two ways.

1. It may help to cause or trigger the illness. For example people under stress are more vulnerable to infections. This is because stress alters your body's immune system.

2. Once the syndrome is established stress may be the cause of some of the symptoms. Certain complaints such as nervousness, muscle tension, especially in the neck region and upper spine, palpitations and sweating - are all symptoms common in CFS/ME.

What can I do about stress?

There are two things you can do;

1. You can try to identify and remove sources of stress in your life.
2. You can help your body to maintain its balance and prevent symptoms of stress. This can be done in various ways. These include learning the difference between recreation and relaxation and the importance of effective relaxation through the use of techniques such as breathing exercises and relaxation.

How to Relax

Creating a feeling of relaxation (rest) incorporates being able to “switch off” both physically and mentally. There are a number of strategies you can use to help you to achieve this. For example;

1. Breathing Exercises
2. Listening to soft relaxation music
3. Following a guided relaxation technique

However, relaxation is a skill. It needs to be learnt. Initially the aim is to relax in a quiet environment where you feel comfortable and free from distraction. The techniques once established can then be used in alternative environments, for example; at work, on the bus etc.

It is important to establish a rest schedule into your daily routine. A minimum of three ½ hour rests daily is recommended. Remember the golden rule is to rest before you get tired!

Why is it important to control my breathing?

Stress can cause your breathing pattern to alter. You may begin to breathe more quickly, taking shallow breaths - this is called **hyperventilating**. If the stress is prolonged, hyperventilating may become a habit and you may not even be aware of your new breathing pattern. This may cause or exacerbate some of the symptoms of Chronic Fatigue Syndrome. A quick test to see if you are hyperventilating is to try to hold your breath. If you cannot hold your breath for more than 10 seconds then you may be hyperventilating.

Over-breathing causes many of the symptoms of hyperventilation. This causes the blood chemistry to alter, which then produces symptoms such as chest pain, palpitations, anxiety and panic. In turn, these symptoms are a new source of stress and cause more hyperventilation. A vicious circle then starts. If you can control the depth and pace of your breathing and so stop these symptoms then you can begin to relax. The following are some examples of breathing exercises and relaxation techniques you can try.

How can I control my breathing?

First be *aware* of your breathing. The following procedure will help you become more aware of how you are breathing. You can do this sitting, standing or lying.

- Place one hand on the top of your chest.
- Place your other hand at the bottom of your rib cage, over the triangle formed where your ribs separate.
- Breathe normally and see which hand moves the most.
- If the top hand moves the most then your breathing is likely to be shallow, using only your upper chest and associated with stress.
- If the bottom hand moves more then you are breathing using your diaphragm, which means your breathing is deep, and your lungs are filling with air. This is associated with relaxation.

Abdominal (Diaphragmatic) Breathing Exercise

1. Note the amount of tension you are feeling then place one hand on your abdomen right beneath your rib cage.

2. Inhale slowly and deeply through your nose into the "bottom" of your lungs - in other words send the air as low as you can. If you are breathing from your abdomen, your hand will rise. Your chest should move only slightly while your abdomen expands.

3. When you have taken in a full breath, pause for a moment and then breathe out slowly through your nose or mouth, depending on your preference. Be sure to exhale fully. As you exhale, allow your whole body to just let go. (Picture your arms and legs going loose and limp like a rag doll).

4. Do 10 slow full abdominal breaths. Try to keep your breathing smooth and regular, without gulping in a big breath, or letting your breath out all at once. Remember to pause briefly at the end of each inhalation. Count to 10, progressing with each exhalation.

The process should go like this;

Slow inhale........Pause.......Slow exhale - count 1
Slow inhale........Pause.......Slow exhale - count 2
Slow inhale........Pause.......Slow exhale - count 3

and so on up to 10. If you start to feel light headed whilst practising abdominal breathing, stop for thirty seconds while you breathe normally and then start again.

Five minutes of abdominal breathing will have a pronounced impact in reducing anxiety or early symptoms of panic.

How long should I do breathing exercises for?

Breathing exercises are aimed at giving you control over your breathing. Once this is achieved you should return to your natural breathing rhythms. If you continue to concentrate on your breathing you will become “over aware” of it and this could bring back the feelings of stress.

Points to Remember about Rest & Relaxation

1. Start resting in a comfortable position, such as semi lying or sitting. If possible chose a quiet place free from distractions. Pull the curtains, dim the lights or wear an eye mask.

2. Make sure you are warm as body temperature can dip during relaxation.

3. Try to keep to the regular times suggested.

4. Think about your breathing, try to breathe deeply and slowly.

5. Observe your body; take notice when it tells you it is tense or relaxed.

6. Pace activities, plan rest, plan your schedule

7. ***Enjoy it!!***

Adapted from Cox DL (2000) *Occupational Therapy & Chronic Fatigue Syndrome* London: Whurr

Participant Handout

Managing your Energy

Think of your available energy as being like a battery (see diagram overleaf).

If you use it all up at once and drain the battery you have to wait for the battery to re-charge.

If you use some but always keep some in reserve, and regular top ups (rest) you are more likely to be able to do the activities you want to do and not increase your symptoms.

So you need to think about

Banking Energy

Save it where you can by,

- Resting
- Spending energy more efficiently

Budgeting Energy

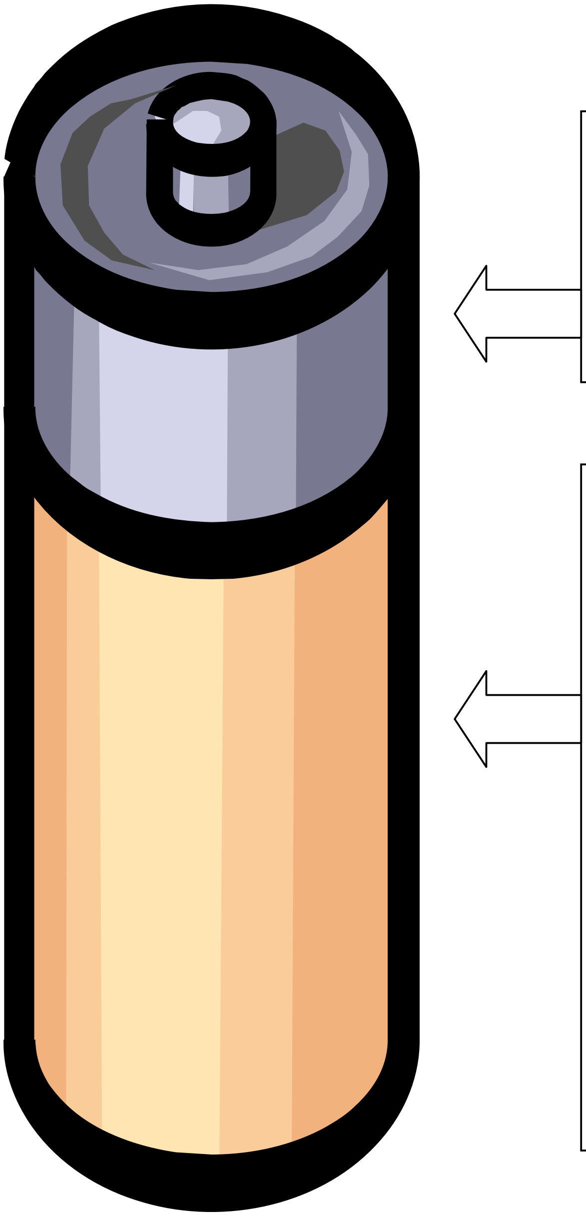
Plan energy expenditure by,

- Examining priorities
- Examining standards
- Making active decisions

Adapted from Packer et al 1995 *Managing Fatigue*

Participant Handout

The Energy Concept



Available Energy

This is all you may have available to you, for the rest of the day / week.
Once this has gone, you will have to recharge, in order to regain new energy.

Used Energy

This is energy that has already been used in the day / week. Energy can be used in –

- **Self Care activities**

Showering.

- **Productivity activities**

Shopping.
Cooking.
Employment / Education
Housekeeping.

- **Leisure activities**

Reading.
Swimming.
Socialising.

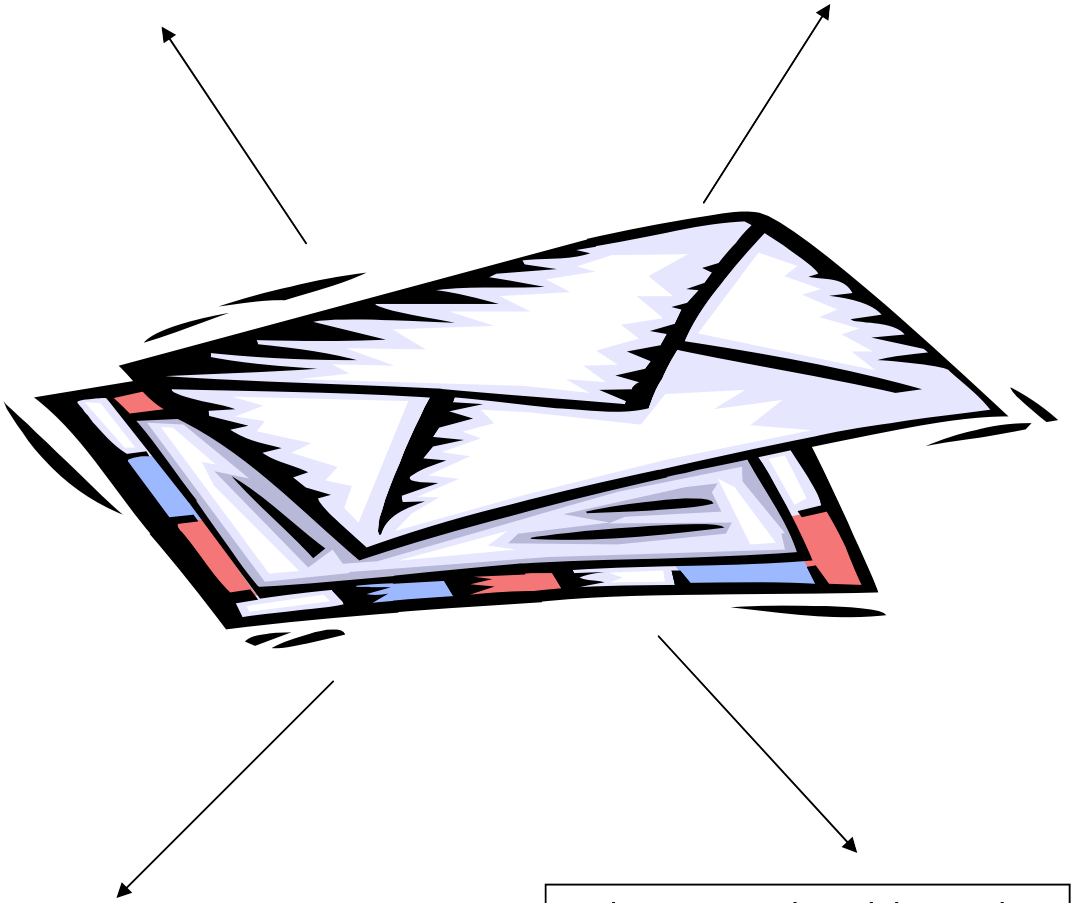
Participant Handout

A quote from a female with moderate CFS/ ME who had previously been severe (AfME, 2003, 17).

"[You need to] ...recognise the existence of a personal energy. Exceed it, leads to worsening of ME [CFS] and needs a week to get back to baseline. Operating within the energy bank maximises daily living within the constraints. Knowing the miles per gallon needed for light, moderate and heavy activities and only doing what can be done. Using experience and inner sensor to keep things as balanced as possible. Listening to body and mind and learning from past experience. 2 plus 2 can only be 4".

Participant Handout

The Energy Envelope



The energy envelope is your energy perimeter that your activities need to fit within

If you have too many or few activities within your envelope, a “Boom Bust” pattern of activity can occur

Too many activities may burst your envelope and potentially enhance CFS/ME symptoms

Doing too much activity, and experiencing exacerbated symptoms, may affect the body’s ability to recover naturally.

Participant Handout

Managing your Sleep

HOW TO IMPROVE YOUR SLEEP

Difficulty sleeping is frequently a problem in CFS/ME and you have probably found that your sleep is not nearly as refreshing as it was before you became ill. Common difficulties include, sleeping too much, difficulty falling asleep and broken sleep. Sleep patterns can also become disrupted, from taking short naps during the day, to being awake all night and, asleep during the daytime.

There are several factors that can influence sleep and can contribute to irregular sleep patterns; no balance between rest and activity, daytime sleep, and inability to get to sleep at night.

Drinking too much coffee and tea may also cause difficulty with sleep for some people with CFS/ME. These both contain caffeine, which is a stimulant, and can keep you awake. Try to change to decaffeinated coffee and tea if you have sleep problems and limit your intake. It may be helpful not to drink caffeine beverages after mid afternoon. Try drinking more mineral water, fruit juice or herb/fruit teas.

As you re-balance your activity and rest, you may notice an improvement in your sleep pattern. However, sometimes when the abnormal or broken sleep has become habitual, it can be difficult for your body to return to a normal pattern. You may find the following points helpful in considering your sleep needs.

1. Establish a balance between rest and activity

Pacing emphasises not only limiting activity but also interspersing it with proper rest. Many people with CFS/ME say they do rest but more careful attention to their symptoms and activity shows that they are not truly relaxing. Pacing therefore involves practising relaxation to achieve proper rest. The information you have been given and the opportunity to practise various techniques should help you understand what is meant by rest and develop your ability to relax. Over time this may mean you no longer need to sleep during the day.

2. Prepare for Sleep

Avoid activities which will keep you alert such as studying, work related projects, decision making and include some sort of relaxation, such as having a warm bath, or doing a relaxation exercise prior to sleep. Develop a routine before going to bed which will act as a signal for your body that it is preparing for sleep, such as locking up, and brushing teeth.

3. Create an appropriate Sleep Environment

In order to re-establish regular sleep patterns, it is important for some people that your bed and bedroom become associated with sleep, not activities like watching television or writing letters. At times, when you can't get to sleep or you wake up, don't toss and turn, get up and do something and then go back to bed and try again. In addition try to take your rest periods in an environment not associated with sleep i.e. a chair or sofa, so “bed” starts to equate with sleep.

4. Daytime Activity

Try not to sleep during the day if you can, rest instead. However, there will be times when you feel sleep is appropriate during the day. The important thing is to start listening to your body and reading the early warning signs, and to rest when anticipating a period of increased demands.

Adapted from Cox DL (2000) *Occupational Therapy & Chronic Fatigue Syndrome* London: Whurr

Participant Handout

DATE: **NAME:**

CHRONIC FATIGUE SYNDROME
DAILY PROGRAMME SCHEDULE

Time	Activity or Rest

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Participant Handout

Energy Requirements

What category does the ACTIVITY fall in to? How much does the ACTIVITY cost you in terms of energy needed?

Low	
Medium	
High	

A landscape version of this handout is provided in separate participant handouts landscape appendices

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Participant Handout

The Bank Account

The bank account uses energy like money,
Just like an account, you know how much energy is available

If you have a limited amount of energy, then you need to budget and spend wisely.

If you use up more energy than you have, you become “overdrawn”

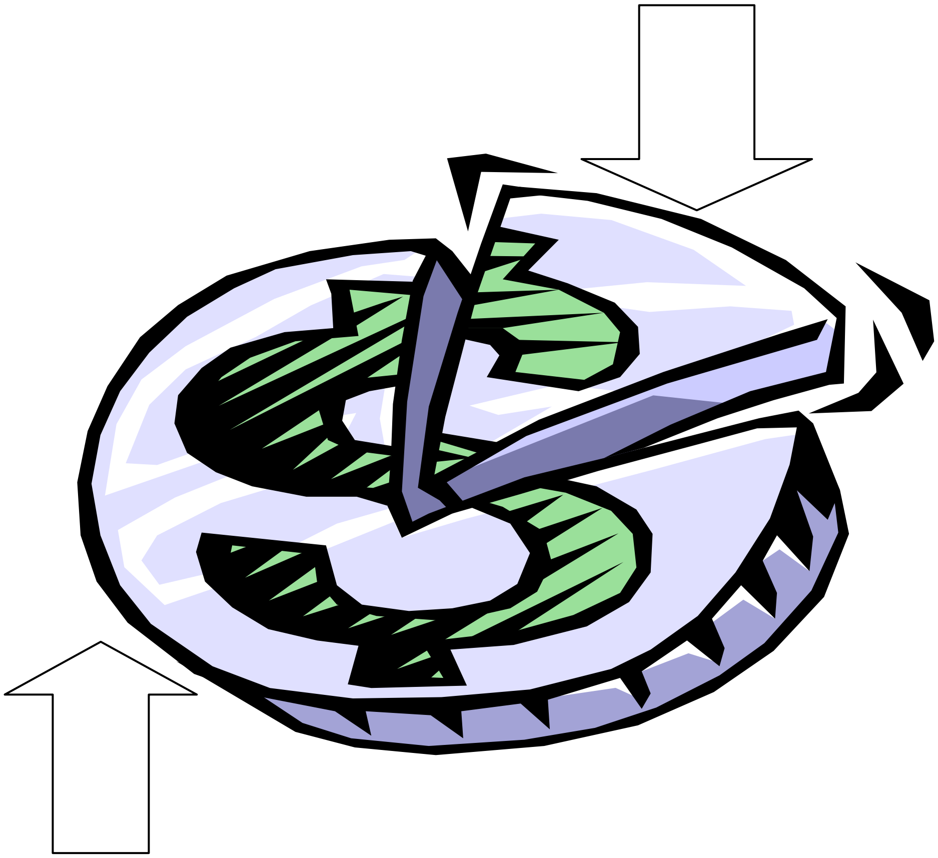
Energy “overdraft” means you having to pay back the energy - usually with interest

Participant Handout

The Bank Account

In APT, a bank account can be used to describe energy like money.
Your bank manager is your body – and you will learn to listen, when it tells you there is no more energy left.

<u>The Energy Overdraft</u>
This happens when you use energy outside of your energy envelope. When you spend energy you don't have, you go into overdraft, and have to "pay it back"



<u>The Energy Account</u>
This is energy you have available.
By saving energy, and expending it wisely, you can maximise your energy level and quality.

Participant Handout

The importance of Balance

Occupational Therapy emphasises the importance of a balance among self-care, productivity and leisure activities.

Self-care refers to basic daily activities

Productivity refers to work, housework, volunteer work, and childcare.

Productivity,

- Is necessary to lifestyle
- Gives structure to the day
- Gives social contact
- Gives a sense of accomplishment

Leisure refers to activities free from obligation, activities done by choice.

Leisure can,

- Decrease stress
- Give enjoyment and pleasure

All of these are important for health.

Rest is important if you want to take part in productivity and leisure. A balanced life requires enough rest to allow for more than just self-care. Without activities in the productivity and leisure categories little satisfaction from life is derived.

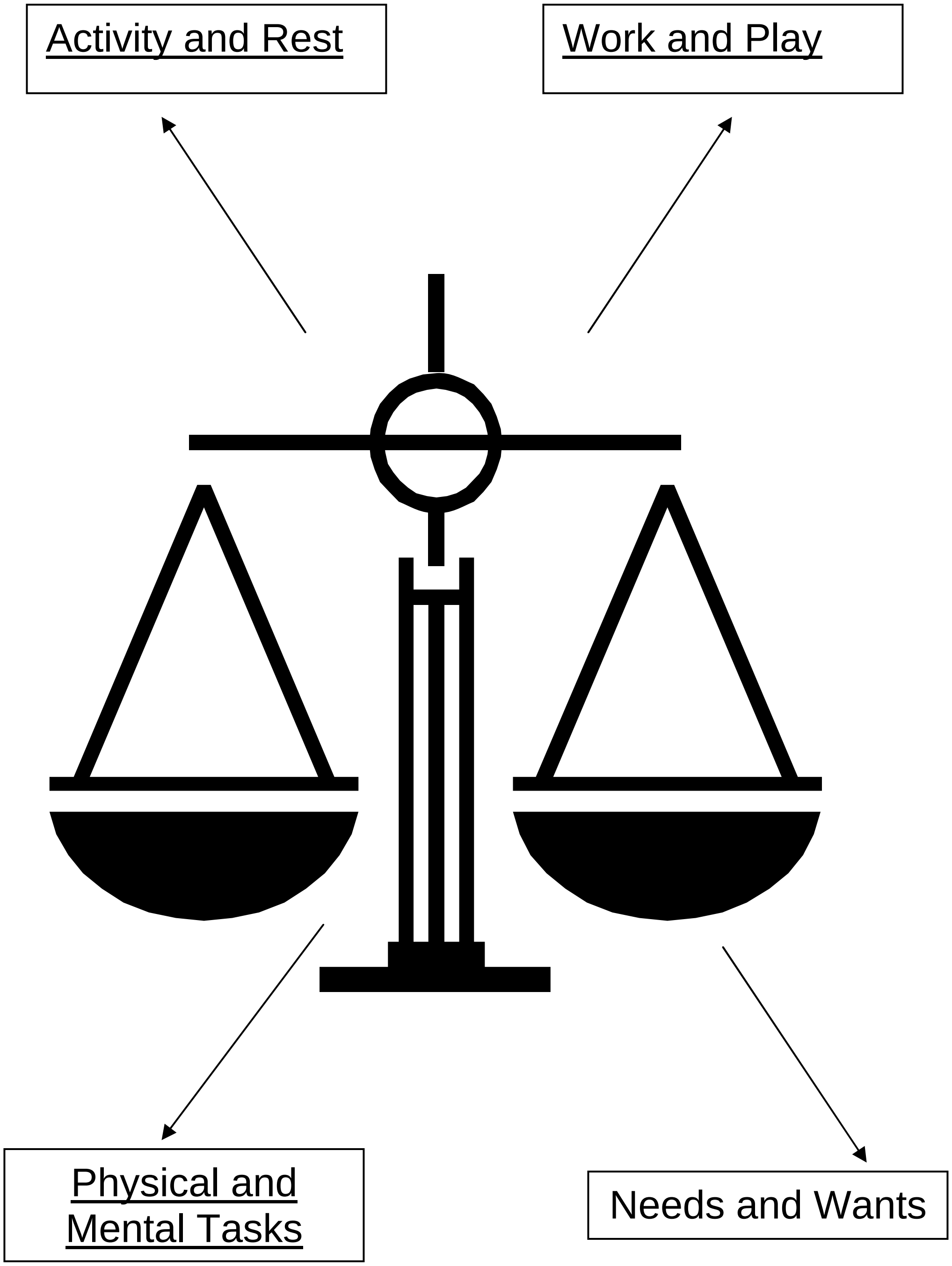
So **Balance** is the watchword throughout the management of CFS/ME:

- Balance between activity and rest/ relaxation,
- Balance between physical and mental tasks,
- Balance between work and leisure, and
- Balance between needs and wants.

Adapted from Packer et al 1995 *Managing Fatigue*

Participant Handout

Balance



Participant Handout

Activities in my Week

Date:....................................Name:...

<u>Self Care</u>
<u>Productivity</u>
<u>Leisure</u>

Adapted from Packer et al 1995 *Managing Fatigue*

Participant Handout

Chronic Fatigue Syndrome: Weekly Plan

Times							
Monday							
Tuesday							
Wednesday							
Thursday							
Friday							
Saturday							
Sunday							

A landscape version of this handout is provided in separate participant handouts landscape appendices

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Participant Handout

Actual vs. Ideal Day

Time	Actual Day	Ideal Day
7:00 am		
8:00 am		
9:00 am		
10:00 am		
11:00 am		
12:00 Noon		
1:00 pm		
2:00 pm		
3:00 pm		
4:00 pm		
5:00 pm		
6:00 pm		
7:00 pm		
8:00 pm		
9:00 pm		
10:00 pm		

Adapted from Packer et al 1995 *Managing Fatigue*

Participant Handout

Chronic Fatigue Syndrome: Actual Weekly Schedule

Times							
Monday							
Tuesday							
Wednesday							
Thursday							
Friday							
Saturday							
Sunday							

A landscape version of this handout is provided in separate participant handouts landscape appendices

Participant Handout

Evaluating priorities and standards of an activity

Priority is the importance placed on an activity.

- It determines which activities are chosen
- It determines the activities on which you spend your energy

Questions to ask yourself:

1. What needs to be done (necessary to lifestyle)?
2. What do I like to do?
3. What do others expect me to do?
4. How much energy do these different activities use up?
5. What can I eliminate?
6. What can I delegate?

Standards are the expectations you place on yourself for the performance of an activity, they include:

- Frequency of performance
  - Number of times per day or week the activity is performed
- Quality of outcome
  - The level to which the activity must be performed

Standards can affect the amount of energy spent on an activity.

Questions to ask yourself:

1. How do my standards affect my activities?
2. Are they forcing me to expend an excess of energy?
3. Can some of my standards be changed?

If you are able to change your standards for activities your energy expenditure may decrease.

Questions to ask yourself about Priorities:

What needs to be done (what is necessary to lifestyle)?

What do I like to do?

What do others expect me to do?

How much energy do these different activities use up?

What can I eliminate?

What can I delegate?

Questions to ask yourself about Standards:

- How do my standards affect my activities?

- Are they forcing me to expend an excess of energy?

- Can some of my standards be changed?

Adapted from Packer et al 1995 *Managing Fatigue*

Participant Handout

Priority Activities in my Week

- Think back to the past week, think of the activities you did and the activities you wanted to do.
- List them under the appropriate category below.
- Once the list is completed, select a number on the priority scale that reflects the priority level for each activity

Date:.....................................Name:..

	Priority Scale			
Self Care	Low High			
	1	2	3	4
	1	2	3	4
	1	2	3	4
	1	2	3	4
	1	2	3	4
	1	2	3	4
	1	2	3	4
	1	2	3	4
Productivity				
	1	2	3	4
	1	2	3	4
	1	2	3	4
	1	2	3	4
	1	2	3	4
	1	2	3	4
	1	2	3	4
	1	2	3	4
Leisure				
	1	2	3	4
	1	2	3	4
	1	2	3	4
	1	2	3	4
	1	2	3	4
	1	2	3	4
	1	2	3	4
	1	2	3	4

Adapted from Packer et al 1995 *Managing Fatigue*

Participant Handout

Priority Activities I did in my Week

- Think back to the past week, think of the activities you did.
- List them under the appropriate category below.
- Once the list is completed, select a number on the priority scale that reflects the priority level for each activity

Date:.......................................Name:...

Self Care	**Priority Scale** Low High			
	1	2	3	4
	1	2	3	4
	1	2	3	4
	1	2	3	4
	1	2	3	4
	1	2	3	4
	1	2	3	4
	1	2	3	4
Productivity				
	1	2	3	4
	1	2	3	4
	1	2	3	4
	1	2	3	4
	1	2	3	4
	1	2	3	4
	1	2	3	4
	1	2	3	4
Leisure				
	1	2	3	4
	1	2	3	4
	1	2	3	4
	1	2	3	4
	1	2	3	4
	1	2	3	4
	1	2	3	4
	1	2	3	4

Adapted from Packer et al 1995 *Managing Fatigue*

Participant Handout

Priority Activities I wanted to do in my Week

- Think back to the past week, think of the activities you wanted to do.
- List them under the appropriate category below.
- Once the list is completed, select a number on the priority scale that reflects the priority level for each activity

Date:......................................Name:..

Self Care	**Priority Scale** Low High			
	1	2	3	4
	1	2	3	4
	1	2	3	4
	1	2	3	4
	1	2	3	4
	1	2	3	4
	1	2	3	4
	1	2	3	4
Productivity				
	1	2	3	4
	1	2	3	4
	1	2	3	4
	1	2	3	4
	1	2	3	4
	1	2	3	4
	1	2	3	4
	1	2	3	4
Leisure				
	1	2	3	4
	1	2	3	4
	1	2	3	4
	1	2	3	4
	1	2	3	4
	1	2	3	4
	1	2	3	4
	1	2	3	4

Adapted from Packer et al 1995 *Managing Fatigue*

Participant Handout

Body Mechanics: An Overview

Spend less energy by using your body efficiently

Efficient use means:

- Use the larger and stronger muscle groups when you can
- Avoid straining the joints of your body because strain takes up extra energy
- When sitting or resting, be in a position that is actually restful for your body
- Sit when ever possible. A stool is a good alternative to sitting or standing.

You need to consider,

- Posture
  - Consider how you stand, is this the best posture that will not strain your joints

- Standing
  - Do you need to stand for the activity? Could you sit or perch instead?
  - If you do need to stand,
    - Wear comfortable shoes, balance weight evenly on both feet, relax arms close to body, hold up head, change position often
  - You can put one foot on a low stool to take the strain off your back when standing for long periods

- Sitting for Work
  - Sit rather than stand whenever possible

  - Use a chair that allows you to have feet flat on the floor and hip & knees at a 90 degree angle
  - You may need a small pillow in your lumbar region
  - Sit close to the desk or activity, elbows should be bent at a 90-degree angle

- Sitting for relaxation or rest
  - Keep legs supported
  - Do not fully recline

- Lying down
  - Lie on your side with upper leg flexed and supported by a pillow

  Or
  - Lie on your back with a pillow under slightly bent knees

- Lifting and carrying
  - The best height to lift from is between the knees and chest
  - Avoid lifting and carrying as much as possible
    - Use a wheelbarrow or cart
    - Use a rucksack or shoulder bag
    - Slide rather than lift
  - When carrying hold the object close to you

Ergonomics considers how tasks, tools, equipment, and materials should be designed and used for safe and healthy work. This includes how you use your body.

Adapted from Packer et al 1995 *Managing Fatigue*

Participant Handout

Ergonomics and Activity Stations

Definition:

Ergonomics considers how tasks, tools, equipment, and materials should be designed and used for safe and healthy work. This includes how you use your body.

- A work environment must be set up to allow for proper body mechanics
- This includes fixed structures as well as tools and technology

Examples of fixed structures include:

Countertops, table tops, chairs, filling cabinets, clothesline, shelves, cupboards, hooks etc.

Height of work surfaces (desks, countertops, workbenches)

- Elbows should be at 90 degrees when sitting at a desk
- Elbows should be bent at 90 degrees when standing at a counter
- If doing heavy work surfaces should be a little lower
- If doing fine work surfaces should be a little higher
- If working at a computer, keyboard should be lower than desk so elbows remain at 90 degrees
- Chairs should encourage proper positioning and provide lumbar support

Consider using tools and technology where appropriate

Some tools and technology can increase independence such as scooters, walking sticks and disabled parking permits.

Energy efficient tools are those that are,

- Used frequently
- Easy to clean
- In good working order

Such as

- Electric toothbrush
- Electric knife
- Electric can opener
- Powered lawn mower
- Perching stool
- Parking permits for people with disabilities (minimise unnecessary walking)
- Wheels
  - Trolleys
  - On furniture
  - Scooters, wheelchairs (for longer outings)

Points to Note

- Remember you are **BANKING ENERGY** through efficient use of your body
- Tools and technology can save energy when completing tasks
- Whenever possible store items at heights that are easy to reach (between knee and chest is best)

(Ergonomic diagram (Packer et al 1995 *Managing Fatigue*) Handouts 1-4 follow in actual handout pack)

Adapted from Packer et al 1995 *Managing Fatigue*

Participant Handout

Activity Analysis

Activity Analysis is taking an activity and breaking it down into its component parts. Activity analysis is useful because it can help you bank energy.

- You can determine which steps are the most energy demanding
- You can modify many different aspects of activity

You need to consider

1. The type of activity
2. The steps involved in completing the activity
3. The movements and postures used for the activity
4. Any tools or technology used during the activity
5. The amount of energy the activity uses (Low, Medium, High)

By modifying an activity you may be able to move it from a high energy activity to a medium or a medium to a low. The more energy an activity requires, the more that activity should be modified.

Wherever possible simplify the activity.

- Eliminate steps;
    - For example throw laundry downstairs in the bag or pillow case rather than carrying it
- Change the sequence of steps
    - For example, sort laundry into two baskets as it is collected, one for light colours, one for dark colours
- Combine steps
    - For example, put clothes directly onto hangers as they come out of washer and/ or dryer.
- Use tools to save energy
    - For example, use a clothes dryer rather than hanging items on a clothes line
- Rearrange the Activity Station to increase efficiency
    - Place washer and dryer next to or on top of one another

Overall try to reduce the amount of physical effort.

Decrease the amount of,

- Standing
- Reaching
- Bending
- Crouching
- Lifting
- Carrying
- Pushing
- Pulling

Don’t forget to bank and budget for energy

Banking Energy:

- Activity Analysis
- Activity Modification
- Rest & Relaxation
- Balancing work, rest & play

Budgeting Energy:

- Evaluating priorities
- Evaluating Standards
- Planning your day

Remember mental tasks also demand energy. Although the examples given relate to physical activity, activity analysis can also be used to break down mental tasks.

In addition, the emotion involved in a physical activity can increase its energy demand, changing a low energy activity a medium or even a high energy activity.

Adapted from Packer et al 1995 *Managing Fatigue*

Participant Handout

Activity Analysis Sheet

Type of Activity		
Steps of Activity	Movements/ Postures/ or Mental/Emotional Demands	Tools and Technology
Energy Requirement	LOW MEDIUM HIGH	

Adapted from Packer et al 1995 *Managing Fatigue*

Participant Handout

Activity Station Analysis Sheet

Activity Station:

Major Task(s):

	Current Station	**Possible Changes**
Fixed Structures		
Tools and Technology		
Arrangement of Tools and Materials		

Adapted from Packer et al 1995 *Managing Fatigue*

Participant Handout

Activity Modification Worksheet

- Using less energy banks more energy for other activities
- The more energy an activity requires, the more that activity should be modified (refer to handout on Activity Analysis)

Eliminate, change sequence, or combine steps	
Reduce physical/ mental effort	Use new tools and/ or technology
Rearrange activity station	

Adapted from Packer et al 1995 *Managing Fatigue*

Participant Handout

Ergonomics II

Definition;

According to the Collins English Dictionary, (1995 edition)

'Ergonomics' is the study of "the relationship between workers and their environment"

Whereas

'Ergonomic' refers to something "designed to minimize physical effort and discomfort, hence maximize efficiency" i.e.: something designed specifically with the goal of reducing the amount of effort it takes to complete a task. (e.g.: built up handled cutlery, helping hands, etc).

Work, however, can mean many different things to different people.

In this case, 'work' equals any form of productive task performance

This could take place at a specified site: this could be inside the person's home or any formal setting.

What is the relationship between 'Ergonomics' and 'Body Mechanics'?

Ergonomics requires a good working knowledge of Body Mechanics.

Our bodies enable us to do so many things. Knowing how best to use our muscles can help save us energy. Improper use of our bodies causes pain, can damage muscles, tendons, joints and ligaments, and uses physical energy faster.

Recognising the natural curves of our spines, planes of movements of our joints and work capabilities of our muscles generally can help avoid overspending available energy.

Some examples as follows:

Stabilising the larger sections of the central trunk, the pelvic and/or shoulder girdle can free up more energy for head and neck control and/or the use of arms and legs. In the same way, providing support for your arm or forearm can free up more energy for efficient finger/hand use.

Sitting or standing with your hips tipped forwards helps ensure that you use both spinal muscles and stomach muscles to help support your back (this is why a lumbar support can help low back pain, and why standing with one foot on a low stool can reduce back strain).

Resting your feet on a small stool when sitting in a chair can decrease pressure behind your knees, as well as ensuring that your knees and hips are bent to slightly greater than 90' which will help tip your hips forwards.

<u>Torque, or the twisting and turning of one body part in relation to another, places more energy demands and stress on your body and can quickly result in painful joints. It may be good to avoid mixing heights and or planes of movement during an activity as much as possible.</u>

If possible avoid undue bending/ or stretching; in addition to requiring more power generally, this will affect your breathing and cause you to tire faster.

Static, straining movements will tend to make you hold your breath, raise your heart rate as well as require you to use more muscles simultaneously than other movements.

Every 'Work' Area has its own work surfaces, and conditions, however, the following will affect the energy demands of all tasks.

Adequate lighting; ventilation; comfortable temperature; comfortable clothing; pleasant background noise; pleasant colours; safe, appropriate tools/equipment

Additionally, you will need more energy to complete tasks started straight after eating (when your body is already working on digesting), when you are upset, or surrounded by conditions you find unpleasant (e.g.: smells/sights/sounds etc), or generally finding it hard to concentrate.

General Tips to reduce the energy demands of simple tasks.

The heights of all surfaces are important. Look at the heights that you are getting up and down from each day. It takes so much less energy to get up/down or in/out from a bed or chair that is either at least 18” high or has arm rests—if necessary, riser-recliner chairs, mattress variators, bath lifts, stair lifts etc can help here.-

- Know the best ‘working heights’ for the tasks you want to perform.
- Often the best counter height to work in when standing is between 32” to 37” or about 2” below the height from the floor of your bent elbow
- When sitting down, your elbows should be able to clear the counter- top without winging out.
- Know your comfort zone for reaching with your arms, this will be different for you when you are standing, sitting, and/or lying.
- The distance you can comfortably work in is roughly the same as the distance from your armpit to your wrist (longer distances will involve combinations of bending, stretching and turning plus objects further away take more energy to move).

The postures you adopt when performing any task will contribute to the amount of energy you expend. Additionally, they will prevent you from getting the most out of your rest periods.

- Stooped, hunched postures will take more out of you in sitting, standing, lying down, and walking as well as compressing your rib cage and having an adverse effect on your circulation and breathing rates.
- Becoming aware of the energy demands of ‘incorrect’ postures and trying to change them will take more energy until the corrected postures become more automatic.

Examples to illustrate how Ergonomics is interlinked with Activity Analysis, Body Mechanics and Work Simplification.

Applying these principles to seating arrangements and its no surprise that executive seating involves:

- **Head rest (complete with side wings)**
- **Neck support**
- **Lumbar support**
- **Back of knee support**
- **Foot plate/support**
- **Additionally the seat is wide, well padded and supports the whole frame and can be reclined to obtain even greater comfort.**

The following chart illustrates these points slightly differently: It is adapted from an ergonomics website.

Tips for making your work more comfortable

Many aches and pains can be relieved by changing your working posture or work patterns. Here are some tips for people who work in offices:

Body part fatigued	**Common contributing factors**	**What you can try**
Back of neck	Looking down at documents or keyboard	Use document holder. Improve keyboard skills. Check monitor height.
Side of neck	Looking to one side	Locate documents and screen directly in front of you
Top of shoulders, outside or front of shoulders	Keyboard too high, arms unsupported	Raise chair, use footrest, rest palms on front of desk, reduce desk height (if adjustable)
Lower back	Inadequate lumbar support	Adjust back rest height and angle to give firm support, remove arms from chair, remove obstructions under desk (e.g. drawers)
Upper back	Twisted posture	Sit straight on, locate documents, screen and keyboard in front of you
Right arm or shoulder	Arm outstretched unsupported	Move mouse closer, use single surface desk
Left arm, shoulder or neck	Reaching for telephone or cradling telephone on shoulder	Bring phone closer. Use headset.
Leg discomfort, swollen feet	Underside of thighs compressed against chair seat	Use footrest or reduce desk and chair height
Headaches	Posture, visual problems, noise, stress, glare, high work load	Rearrange work area; re-direct traffic; screen filter; close blinds; shut door; vary tasks; take micro pauses; smooth out work flow; reduce time on computer; eye test.
Eye fatigue, temporary short sightedness	Visual problems, screen too close, poor image quality, glare, screen reflections	Rearrange work area; screen filter; close blinds; vary tasks; take micro pauses; eye test.

Participant Handout

Work Simplification

What does ‘Work Simplification’ Mean?

Work simplification is a term used to describe the alteration of any task of work to enable it to be done in a different manner. It is a process that is used, along with ‘Activity Analysis’ to help you find a new way to perform a task that is very important to you to be able to do.

What is ‘Work Simplification’?

There are three main components to every task –

1) Preparation - this is where we get ready for the task, perhaps by gathering the necessary tools/ equipment, organizing or clearing a work space, or getting ready to go from one area to another etc.

2) Performance of the task itself- usually this involves several components any or all of which could be analysed and altered as required.

3) Finishing up- this refers to the clean-up/ putting things away portion of any task.

Who benefits from Work Simplification?

Work simplification is a ‘tried and tested process used with any number of people suffering from a wide variety of special needs who want to return to doing things for themselves again.

Basic Principles of ‘Work Simplification’

1) Plan ahead. Being able to do the same task repeatedly at the same time, and, in the same manner, can help decrease the energy demands of the task.

2) Include all steps in a task within your plan as need dictates.

3) Stick to your plan.

4) Do not rush task components. Smooth, flowing breaths are as important as smooth flowing movements when doing any task in an energy efficient manner.

5) Delete portions of any task as appropriate/needed/able.

6) Be aware of the physical characteristics of the task- know whether it will be best for you to work:

    in standing
    in sitting
    when reclining

7) The amount of energy required by a task can be decreased if you provide support to the rest of your body whilst using only one or two parts.

8) Organize work areas in accordance with limits for reach, weight bearing, and posture.

  e.g.-arrange supplies within an easy to reach semi-circle
    Store items according to frequency of usage

9) Be aware that extremes of temperature will affect how much work you can do and will tire you out faster. Inadequate ventilation will also affect what you can achieve.

10) The type of movements required to complete a task will affect how much energy it demands: e.g. circular, rhythmic movements in your own natural speed are far less demanding than jerky back and forth motions.

11) Use gravity and momentum where possible to increase efficiency and decrease physical work loads.

12) Use work simplification principles, plus body mechanics after activity analysis to help do the tasks you want to

Participant Handout

Adapted Pacing Therapy Targets & Methods

Target	Methods
Establish a baseline.	• Identify "boom and bust" patterns by keeping diaries of both activity and fatigue levels. • Identify a manageable level of activity, which is anticipated to result in low-level symptoms, by reviewing activity-related fatigue (diaries) and trial and error. [Session 2 onwards]
Introduce proper rest and relaxation.	• Distinguish between real and perceived rest, by listing what you think of as restful and comparing to the APT philosophy. • Learn times when rest is advisable / essential, by developing an awareness of energy diminishing activities. • Learn and practice different relaxation techniques, and identify those most effective to you, by demonstration from the therapist, self-directed learning and trial and error. [Session 2 onwards]
Save and budget energy.	• Save energy by using rest and energy wisely. • Budget energy by prioritising, delegating and modifying energy. • Use the 70% rule. • Identify the energy requirement of an activity, by monitoring how fatigued you feel via daily diaries, and spread these activities equally over the week. [Session 3 onwards]
Improve sleep.	• Learn what helps and hinders your sleep pattern, by discussion with the therapist, self-knowledge, and the observations of family / friends. • Balance activity and rest – to ensure the body isn't over or under tired- by pre-planning your week into a schedule. [Session 3 onwards]
Live within your limits / balance activity.	• Identify the energy requirements of an activity, by using daily diaries / fatigue levels, then find ways to adapt the activity to decrease energy needed. • Prioritise what activities cannot be avoided, by completing a "must do would, like to do" form. As before, modify in order to expend less energy, and calculate what energy you have left for other activities. • Spread activities evenly, by planning your week in advance. • Save energy through rest and relaxation. [Session 4 onwards]
Use ergonomic techniques.	• Become aware of your postures and movements, by analysing your activities. • Identify unhelpful postures and movements, by relating to fatigue levels and comparison with ergonomic techniques. • Incorporate beneficial ergonomics into your weekly routine, by breaking down activity. [Session 6 onwards]
Devise a way to recognise energy expansion.	• Think of the last time that you had a "better" period of functioning. How did you know you had improved / what changed/ • How long would an improved period of function continue, before extended activity / energy was attempted? [To be constantly reviewed]

Participant Handout

Pressure from Self and Others to deviate from Adapted Pacing

WHAT HELPS	ASSOCIATED STRATEGIES and TOOLS
KEEPING TO YOUR LIMITS	• Listen to your body and use the 70% Rule • Avoid the Boom and Bust pattern of activity • Re-visit your baseline • Is your current level of functioning within your energy envelope? • Say NO to demands/pressures from self and others
PLANNING YOUR TIME	• Use Daily Programme Schedule and Weekly Plan if found to be helpful • Plan ahead and incorporate periods of rest • Use time limits if necessary if you experience difficulty listening to your body • Communicate and negotiate with others • Utilise problem solving skills • Delegate as necessary, and be assertive when making requests of others • Prioritise must do/want to do activities
USE OF APPROPRIATE TARGETS AND PRIORITES	• Be realistic, remember the 70% Rule and stay within your energy envelope • Be flexible and regularly review your standards and priorities • Make use of time management skills • Utilise problem solving skills • Communicate and negotiate with others • Delegate tasks/activities as necessary • Congratulate any successes in maintaining baseline
ALTERNATE REST AND ACTIVITY	• Balance activity with periods of rest and relaxation • Balance physical and mental tasks, remembering each activities energy requirements • Balance work and leisure • Balance needs and wants
MODIFY YOUR ACTIVITY	• Use ergonomic techniques, modifying tasks and workstations on a daily basis • Utilise the skills of Activity Analysis • Communicate and negotiate with others, saying NO if necessary

Participant Handout

Some quotes to assist with explaining “pressures from self and others”

- **Plan your time**

“It is trying to be aware of when I am starting to overdo it e.g. too long a meeting, noisy social environment. Take steps to plan my time. If one day has been quite demanding, plan to have a quiet following day. Doesn’t always work due to external pressures” (AfME 2003, 281)

- **Keep to your limits**

“Pacing to me is the knowledge learnt through trial and error of how far I can go before putting myself in a relapse position. If I go out for the day on coach or car trip I need to have the next day free to recover, if I am doing any work around the house or in the garden and I suddenly feel any tiredness or muscular weakness I must stop and rest to carry on would mean I would be useless for the next day or two. I have experimented with pushing myself further but in my case this has caused a relapse. The key is to know your limits” (AfME 2003, 63)

- **Set appropriate targets**

“To know your limits. Set a small target for the day; if you complete it congratulate yourself. Don’t think I have done this so I can do more, there’s always tomorrow. Should be pleased with smallest of tasks, may be able to do more next day, keep positive” (AfME 2003, 123)

- **Alternate activity and rest**

“I find it helpful to alternate periods of activity with periods of rest, this pacing help maintains an even keel. Sometimes though life gets in the way or I try to meet someone else’s expectations and fall into “Boom & Bust” where I do too much then have a relapse. Pacing takes patience and planning and limits everything I do every day but it seems to be how I have to try to manage my life these days” (AfME 2003, 237)

- **Modify your activity**

“…resting at regular intervals in order to avoid relapse. Avoid the boom or bust cycle of over doing things on good days to catch up with bad days. You must conserve energy even on good days to avoid relapse” (AfME 2003, 352)

Participant Handout

Problem Solving in Adaptive Pacing Therapy

Many events occur in life which influence our decisions and our plans, and may provide obstacles in adhering to the principles of Adaptive Pacing Therapy. Pressure to engage in activities outside your current energy envelope, or which get in the way of rest periods, come from a variety of sources. Problem solving is one strategy which can be utilised in relation to this issue.

Problem solving will not be new to you; it is something we all do on a daily basis in relation to the tasks we need to perform. All that is being suggested here is a strategy that may generate alternative and more workable solutions. When involved in this process it is helpful to be as clear and concise as you possibly can as this in itself can provide an immediate solution to the problem as it avoids ambiguity, prevents misunderstandings and helps resolve any misconceptions. However problem solving and communicating the solutions to others is a skill that can be developed. It may prove useful to use time within sessions to practice these skills through rehearsal and role play.

Identify the problem

- What needs to be done?
- What are the steps involved?
- What are the energy requirements of each step and the task as a whole?
- Who and what else is involved? When thinking about the actual problem it is worth identifying anybody else involved. What part if any do they play in generating the problem? What help, practical or emotional, can/can't they provide? Do they know and understand the principles of APT, and if not is it important that they do so?

What are the available solutions?

- Brainstorm tried and tested solutions (what has previously worked). Revisit solutions you may have previously written off as unusable or impossible. Use your imagination and be creative, even the most outlandish possibilities are worth considering.
- Can any of these potential solutions be modified in any way? Use your knowledge of activity/task analysis. If you were to utilise the support of others or were to undertake only a smaller component of the task would this allow you to remain within your energy envelope?

Prioritise

- Prioritise solutions according to the help and resources available.
- Discuss possible solutions with others involved informing them of your needs and what can/can't be done within your current level of available energy. Saying NO and/or delegating are okay as this recognises your own needs as well as the needs of others.

Select the most acceptable and workable solution

- Try it out. Does it allow you to adhere to the 70% Rule? Are there any signs of symptom exacerbation?
- Review and re-select as necessary. The right solution on one occasion may be the wrong solution at another time.

Practice the strategy

- Use of role play
- Summary & feedback

Evaluate the effective strategy and re-visit the problem cycle

Remember tackle one problem at a time

Participant Handout

A number of quotes to assist with explanation of "increasing as able".

Balancing activity

"About managing illness – gaining level of management/ balance where can have maximum quality of life with minimum output energy – regaining normal activity on graduated levels over period of time hopefully (or at least optimum). It's mainly about warning balance!! Not too much, not too little" (AfME 2003, 96).

Breaking down large tasks into small chunks

"Pacing to me is the measuring of energy. I look ahead for events that will use a lot of energy and plan the surrounding days so that I can conserve energy before and after. Also if I have a large task I will break it down into small chunks that can be spread over a number of days. I try to stick by the 70% rule doing only 70% of what I feel I am capable of each day. I don't drain my energy banks; I am able to increase the amount I do gradually over the months" (AfME 2003, 278).

Importance of monitoring

"Basically it means listening to your body. Adapting activities and lifestyle so that symptoms are not exacerbated and recede & gradual improvement takes place. These may mean a very drastic reduction in activities and some having to be abandoned completely initially. Both mental and physical activities must be monitored. The amount of rest and activity have to be varied slightly according to how the illness is at any given time – because it fluctuates in severity e.g. an infection exacerbates so more rests needed at such times. Use only 70% of energy in activities to allow for healing & minimise exacerbations. Keep brief notes to work out what you can and can't do to maintain progress" (AfME 2003, 354)

Participant Handout

Energy Requirements

What category does the ACTIVITY fall in to? How much does the ACTIVITY cost you in terms of energy needed?

Low	
Medium	
High	

A landscape version of this handout is provided in separate participant handouts landscape appendices

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Participant Handout

DATE: **NAME:**

Baseline Sheet

A *baseline of activity* is a comfortable level of activity that you can manage on a regular basis, without experiencing an increase in symptoms.

What would be your own baseline at present?

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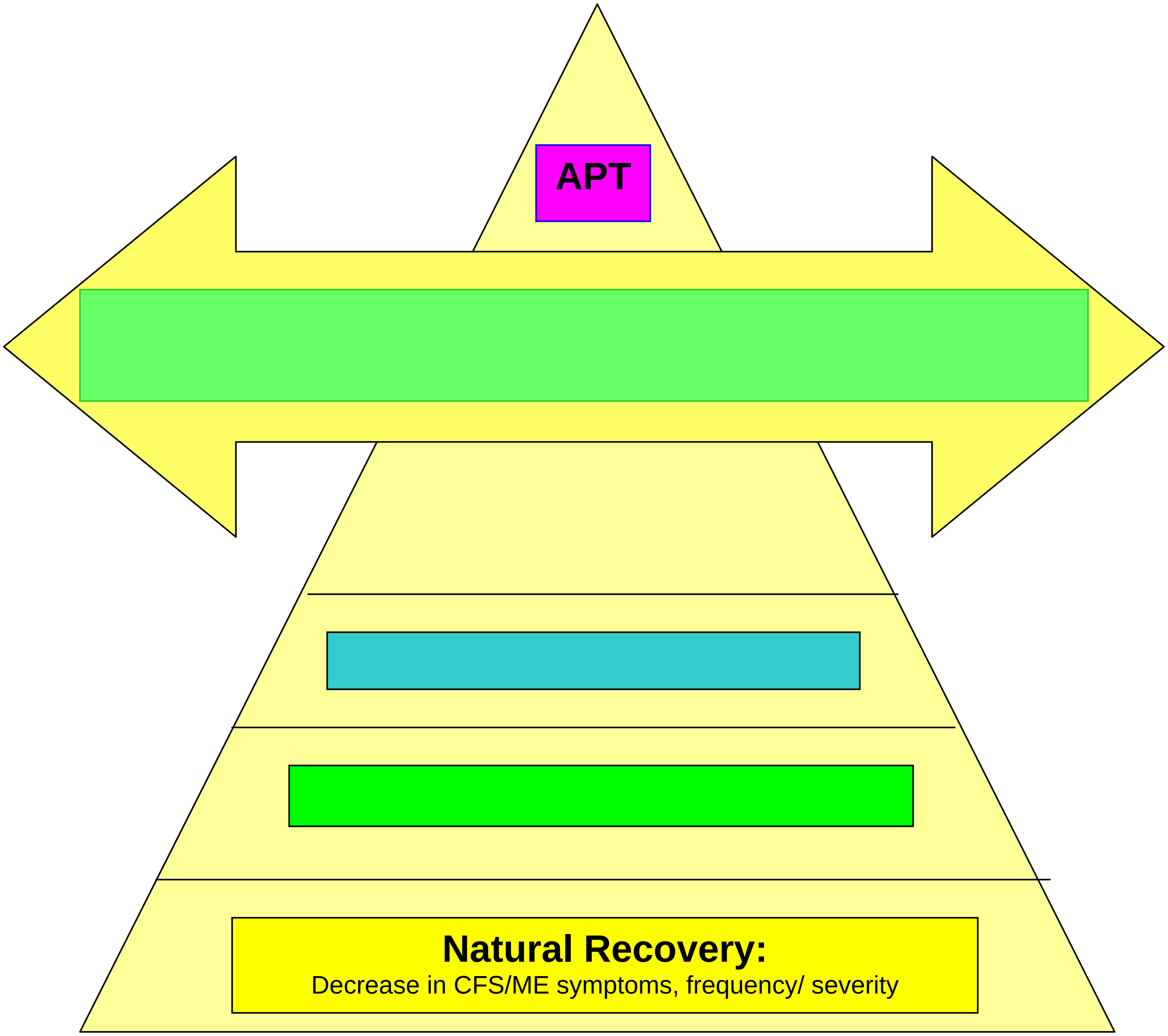
Participant Handout

The Adaptive Pacing Therapy Model of CFS/ME

The Energy Envelope

Successful Energy Management



Participant Handout

APT Review

Aim	Review
Establish a baseline.	Is it accurate, up to date? (look at diaries)
Introduce proper rest and relaxation Identify pertinent rest activities.	Has this been incorporated into daily life? (look at diaries)
Devise strategies to save/bank energy.	Are these strategies being used? (review activity analysis diary).
Employ techniques to improve sleep	Are these techniques effective / useful? (review daily diaries)
• Identify ways to incorporate a balance of self care, productivity and leisure activities within your energy limit. • Modify activities by identifying "real" priorities / responsibilities and "red herrings".	Is this being maintained long-term? (review daily diaries)
Incorporate energy saving ergonomics into daily routine	a - Are these ergonomic techniques achievable in daily life? b – Are the techniques being used? (review activity analysis sheets and daily diaries).
Use activity analysis (AA) to modify daily activities	Are these AA techniques being generalised to new activities? (review activity analysis sheets)
Devise a way to "understand" your body, and know when you have extended the energy envelope.	Are you living within your limits and finding them too easy, adequate, or too hard? (review baseline and daily diary / fatigue levels).

Partners, Relatives & Friends Information

If you are close to someone with CFS/ME who is participating in an APT programme, your understanding and support can be extremely helpful.

There are a number of ways in which you may be able to give this support.

You could;

- 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.
- Take time to read the information in this booklet/ manual, so that you understand what APT is all about.
- Offer time to prioritise activity together, by helping them break down activities into smaller achievable components
- Make time to discuss APT with the person, they may find talking through the model and ideas with someone else between sessions with the therapist useful.
- Discuss how family activities might impact on their daily programme.
- Discuss the importance of the energy envelope; rest and relaxation, and establishing rest periods.
- Consider how roles and responsibilities could be shard to assist in activity analysis, scheduling and modification.
- Help them identify their warning signs