Manual for Participants

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 participants 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.

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) and 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. 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 may 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:

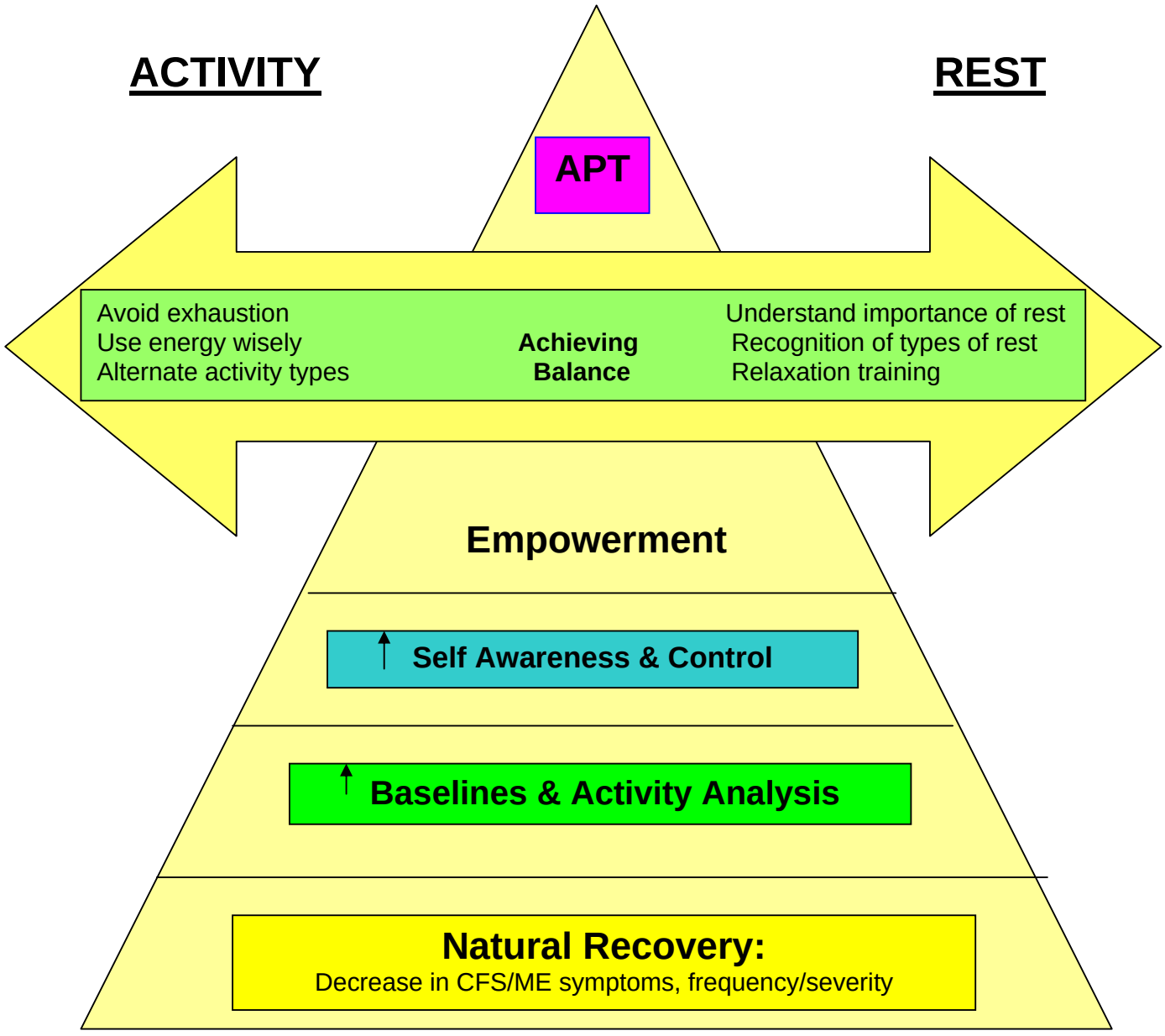
- Action for ME (2002) *Guidance on the management of CFS/ME* Wells: AfME
- Action for ME (2003) *Pacing data from members' survey: "your experiences" questionnaire.* London: AfME
- Birkholtz M, Aylwin L, Harman RM (2004) Activity Pacing in Chronic Pain Management: One aim, but which method? Part One: Introduction and Literature Review. *British Journal of Occupational Therapy* 67; 10: 447-452
- *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.
- Friedberg F, Krupp LB. (1994) A comparison of cognitive behavioural treatment for Chronic Fatigue Syndrome and primary depression. *Clinical Infectious Disease* 18 (supplement 1):s105-s109.
- Hanson RWGKE. (1990) *Coping with chronic pain*. New York: Guilford Press.
- Nielson WR, Jensen MP, Hill ML. (2001) An activity pacing scale for the chronic pain coping inventory: development in a sample of sufferers with fibromyalgia syndrome. *Pain* 89; 2-3:111-115.
- Pesek JR, Jason IA, Taylor RR. (2002) An empirical investigation of the envelope theory. *Journal of Human Behaviour in the Social Environment* 3;1:59-75.

Participant Handout

The Adaptive Pacing Therapy Model of CFS/ME

The Energy Envelope

Successful Energy Management



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?

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

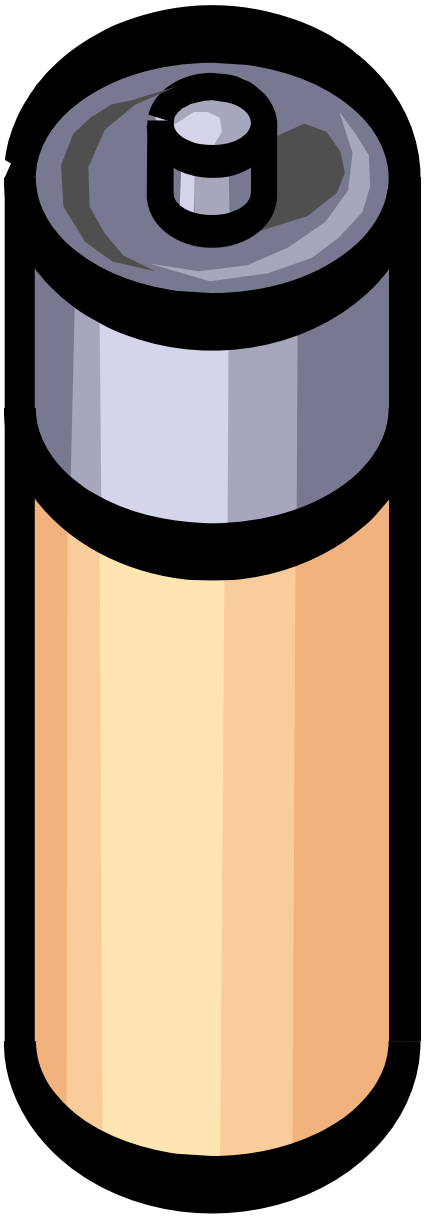
Plan energy expenditure by,

- 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

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

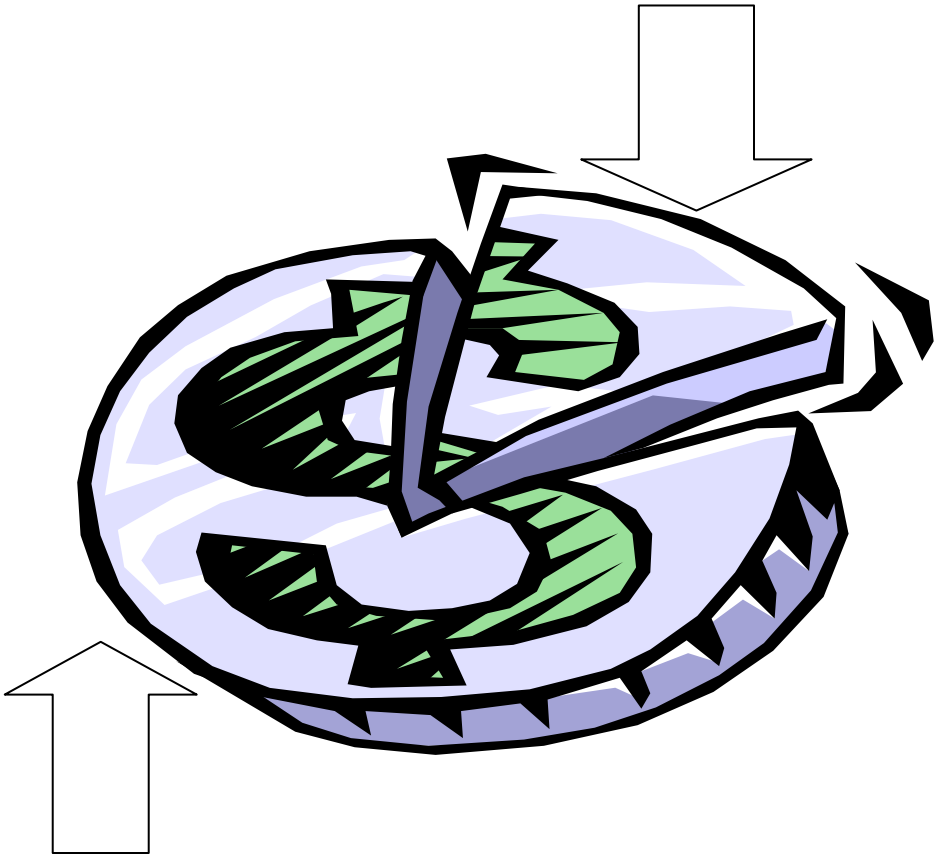
Participant Handout

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.

The Energy Overdraft

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"



The Energy Account

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.

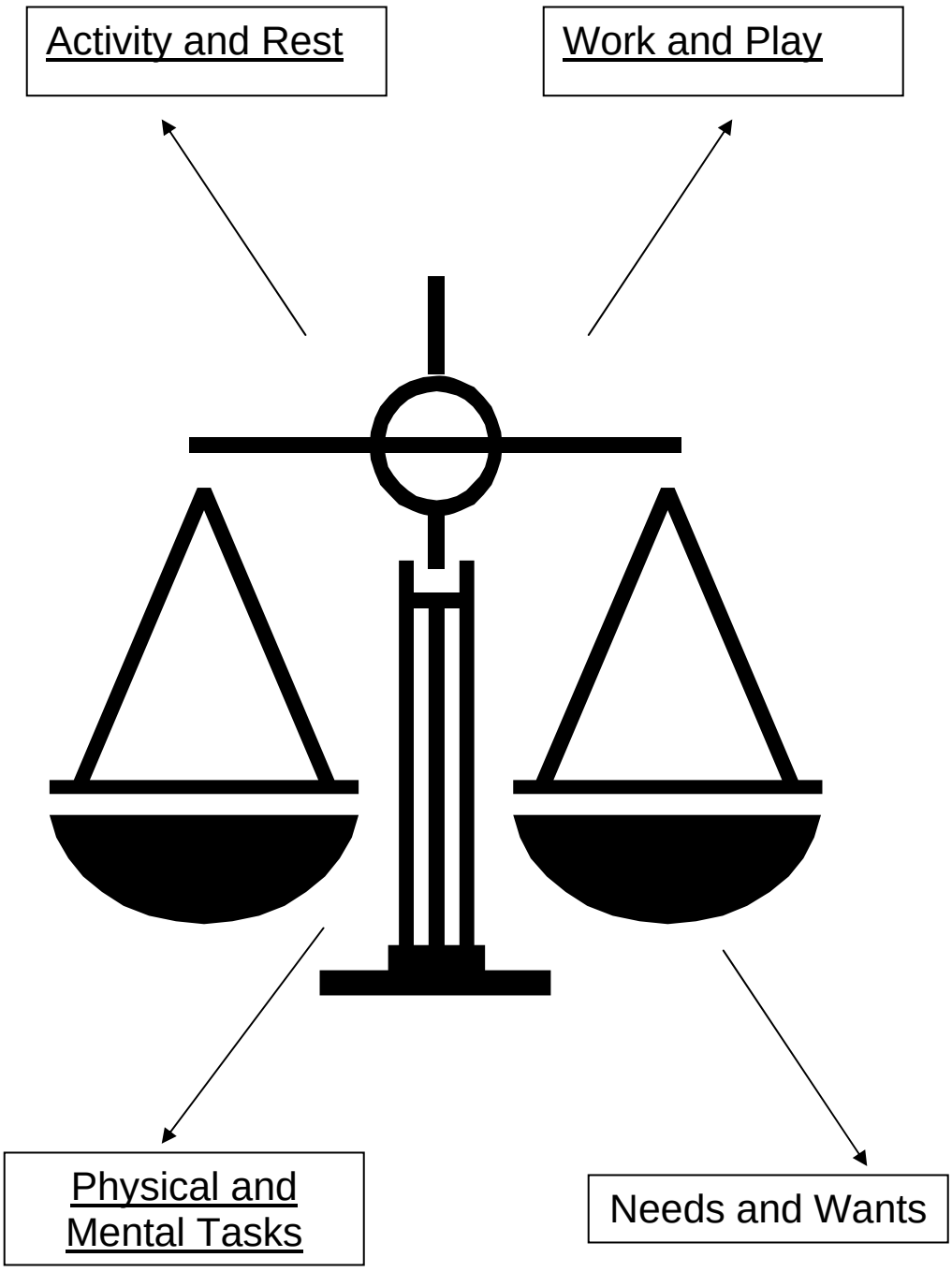
So **Balance** is the watchword throughout the management of CFS/ME:

- 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:.....

Self Care
Productivity
Leisure

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

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:.....

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 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)

<table>
<tr><td colspan="2">Eliminate, change sequence, or combine steps</td></tr>
<tr><td>Reduce physical/mental effort</td><td>Use new tools and/or technology</td></tr>
<tr><td colspan="2">Rearrange activity station</td></tr>
</table>

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.

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.

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.

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 Aims & Methods

Aim	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.

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.

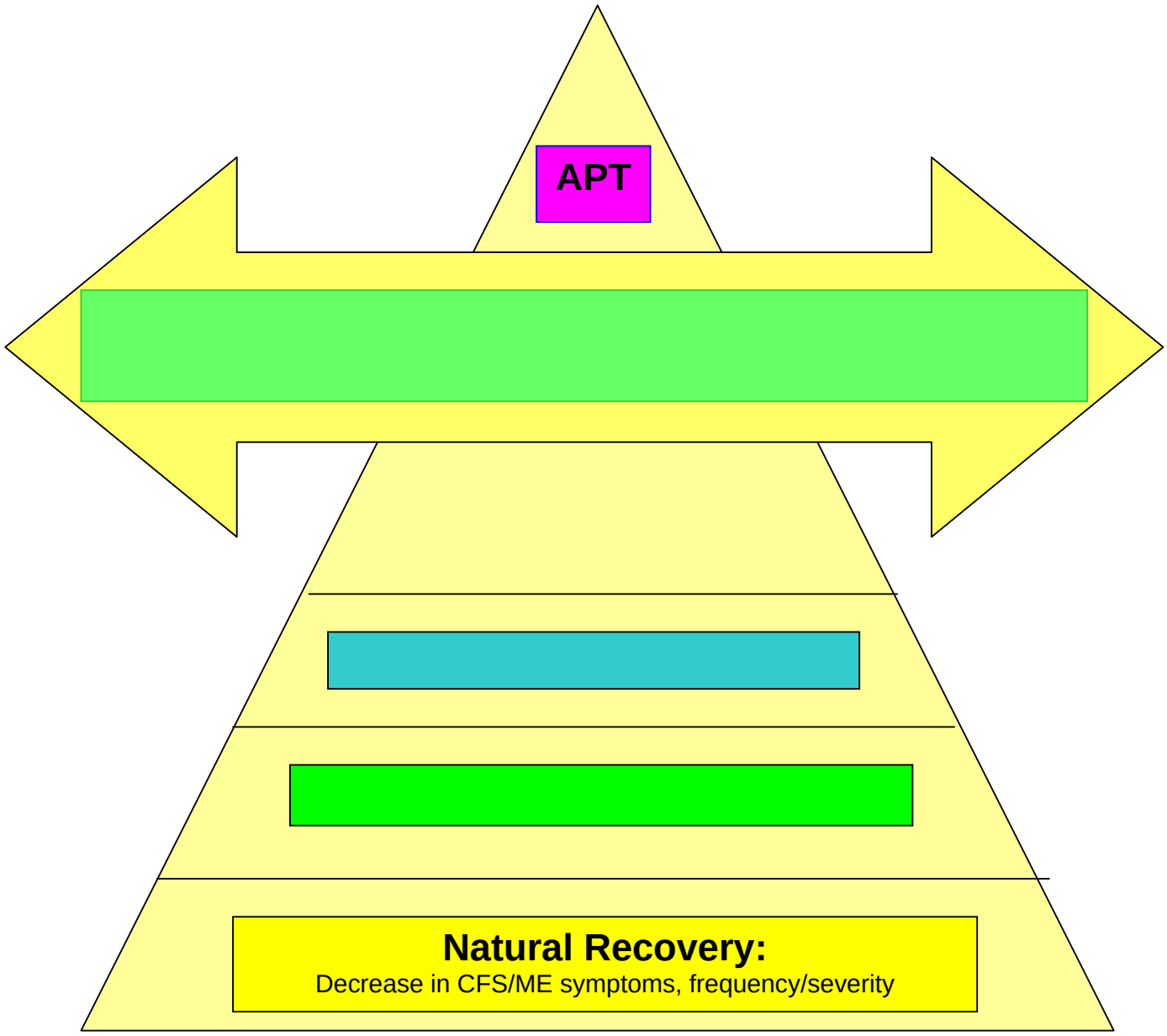
What would be your own baseline at present?

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