



GRADED EXERCISE THERAPY

Information for Participants

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On behalf of the PACE trial management group

FINAL TRIAL VERSION: (MREC Version 1)

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

Name:

Hospital Address:

Telephone:

USING THIS MANUAL

This manual contains a combination of information, advice and practical worksheets you will be using throughout your GET programme.

It is useful to become as familiar as possible with the contents of this manual, so that you can really get the best from your programme.

However, do not feel that you need to read it all at once. Your physiotherapist will guide you to read certain sections at the right time in your programme.

You may also find it useful to show this information to friends and family, so that they can support you with your programme.

Please inform the physiotherapist if you do not understand any aspect of the manual, or any information or advice given to you. You can always ask any questions you feel unsure about, even if the question seems simple or the therapist has been through something before.

Please bring this manual with you to each session and feel free to write in it as you go along to help you remember important points.

UNDERSTANDING CHRONIC FATIGUE SYNDROME (CFS) AND MYALGIC ENCEPHALOMYELITIS / 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 people in whom characteristic fatigue and other symptoms cannot be explained by other diagnoses.

What is the cause?

No specific cause has been identified. We identify below some of the factors that may make CFS/ME more likely to happen in some people. It is possible that different factors apply to different people.

FACTORS THAT MAY CONTRIBUTE TO THE DEVELOPMENT OF CFS/ME

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

1. Infections

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

2. Lifestyle

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

3. Life Events

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

4. No apparent cause

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

FACTORS THAT MAY MAINTAIN CFS/ME

Just as there are many factors associated with the development of CFS/ME, there are also many factors that maintain it. Maintaining factors are so important in CFS/ME because they give us clues as to the current problems that are stopping you from getting better.

These may include the following:

1. *Resuming normal activities too soon after an initial infection*

It can be helpful to rest in the initial stages of an acute illness.

2. *Resting too much*

Although resting for a short time is the correct thing to do when you have an acute illness or infection, prolonged rest can impede recovery and cause its own set of problems. Evidence clearly suggests that the longer you rest when you have a viral illness, the more symptoms you will have six months later. Prolonged rest reduces activity tolerance and also impairs the way that the body works. It will affect the cardiovascular system, nervous system and muscles.

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

This inadvertently makes the problem worse in the longer term, as it is difficult to establish any type of routine.

4. *Receiving confusing messages about the illness and how to deal with it*

You may have sought help from a variety of people all of whom may have offered different treatment or advice. Receiving different messages may have resulted in you feeling baffled about what to do for the best and trying a variety of different treatments that have not been helpful.

5. *Disturbed sleep pattern*

An irregular bed-time or getting up time or resting too much in the day, may

contribute to disturbed and unrefreshing sleep at night. Not sleeping well at night is likely to increase feelings of fatigue and other symptoms such as muscle pain.

6. *Symptom focusing*

It is understandable that you would be concerned about symptoms that don't go away. Unfortunately a disadvantage of this is that the more you focus on the symptoms, the worse they sometimes get.

7. *Concerns about activity making the illness worse*

You may experience increased pain or fatigue after any activity and naturally read this as a sign that you are doing harm to your body. You may therefore have reduced your activities, and rested for long periods thinking that "resting" will help you to feel better.

8. *Life stress and low mood*

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

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

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

PHYSIOLOGICAL ASPECTS OF CFS/ME

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

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

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

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

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

1. Changes in muscle function

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

These changes may account for the feeling of a lack of power or energy in the muscles and stiffness after normal exercise and activity.

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

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

When muscles are not used regularly, they become weaker or deconditioned. One week of rest reduces strength in large muscles by 10%.

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

However in all individuals, muscle pain and stiffness are natural and normal responses to unaccustomed physical activity.

GET can help by building muscle strength, which in turn allows you to do more.

2. Changes in the cardiovascular system

The cardiovascular system (which incorporates the heart and blood vessels) becomes out of condition very quickly with rest. The longer you rest the more changes occur.

Physical changes that occur with cardiovascular deconditioning include:

- reduced blood volume after 1 or 2 days bed-rest
- reduced volume of red blood cells after 8 days bed-rest which reduces oxygen carrying capacity of the blood
- volume of the heart reduces by about 15% after 20 days of bed-rest therefore less blood is pumped to other organs
- When standing it is more difficult to maintain a normal blood pressure

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

Following a “lying down” rest there is a drop in blood pressure on standing up (postural hypotension) due to blood pooling in the legs. Consequently, less blood returns to the heart and therefore less blood goes to the brain causing these symptoms.

The reduced blood flow to the brain causes dizziness and sometimes fainting on standing up.

GET can help by improving fitness and the efficiency of your cardiovascular system.

3. Regulation of body temperature

Due to changes in metabolism and other adaptations to bodily rhythms following prolonged rest, changes in the perception of body temperature may occur.

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

4. Visual and hearing changes

Prolonged rest results in a change in the way the brain perceives external sensations, like noise and light, with consequent sensitivity.

This may result in visual problems and sensitivity to noise.

5. Reduced tolerance to activity or exercise

General weakening of the body occurs as a result of prolonged rest or reduced activity.

This results in being less able to tolerate activity as fitness and muscle strength reduces. Fatigue, pain and heaviness in the muscles can result, as can an overall sense of bodily fatigue.

GET can help by improving your ability to undertake physical activities.

6. Changes in the nervous system

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

Prolonged periods of inactivity therefore reduce our co-ordination.

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

GET can help by challenging your body physically, which can lead to improved co-ordination and balance.

7. Changes in the mental functioning

Prolonged rest deprives people of intellectual stimulation and has a dulling effect on intellectual activity. Excessive rest may even affect the way our brain cells make connections with each other.

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

GET has been shown to improve mental functioning.

8. Alteration of the biological clock

This “clock”, which is located in a part of the brain called the hypothalamus, regulates many body rhythms that run on an approximate 24 hour cycle. These rhythms are called circadian rhythms and they control vital functions such as:

- sleeping and waking
- feelings of tiredness and alertness
- intellectual performance
- memory
- appetite
- body temperature
- the production of hormones, for example, cortisol
- the activity of the immune system

Circadian rhythms are responsible for your body “feeling” things at certain times of the day, for example, hunger, alertness, tiredness, needing to go to the toilet. The biological clock is affected by the events of the day and is reset each day by cues such as getting up or going to bed times, meal times and performing daily routines. The biological clock’s time keeping can be disturbed if not reset by these cues, this can happen in situations such as:

- flying across different time zones (jet lag)
- working shifts

- experiencing illness

If regular cues are lost, disruption of the clock results in a slipping of body rhythms that can lead to:

- The “normal” intense feelings of tiredness at night shifting into the day making it difficult to cope with your usual routine.
- The “normal” daytime rhythm shifting to the night, making you more alert and causing difficulty in getting to sleep.
 - This can lead to:
 - poor quality sleep at night
 - increasing fatigue during the day
 - poor concentration and forgetfulness
 - low mood
 - feeling unwell
 - headaches
 - muscle aches loss of appetite
 - irregularities of bowel movement

As the symptoms of CFS/ME are so similar to those of jet lag, circadian rhythms of people with CFS/ME have been investigated. Evidence from some studies indicates that CFS/ME is associated with the biological clock losing control of the body rhythms.

It is thought that an infection, a very stressful life event or an accumulation of persistent stress may contribute to us breaking our usual daily routine and normal sleep-waking cycle needed to reset the biological clock. This is because a stressful life event or an accumulation of stress can cause worry and disturb our sleep at night, leading to irregular getting up and going to bed times and increased rests during the day.

The biological clock then loses control over body rhythms resulting in the above mentioned severe physical and mental symptoms of CFS/ME.

The GET programme will encourage you to take note of any irregular sleeping patterns and to address these.

9. Disturbance of cortisol production

Cortisol is a hormone whose production is controlled by a circadian rhythm. Cortisol switches on our metabolism in the morning to prepare us for the physical and mental challenges of the day. Short periods of physical activity and other factors can cause an increase in the level of cortisol in the bloodstream.

Research shows that some people with CFS/ME have a lower level of cortisol, but no disease has been discovered that would account for this finding. The low cortisol levels found in people with CFS/ME are probably caused by irregular and reduced activity and disrupted sleep.

Low cortisol levels have also been found in other people who have disrupted sleep such as a) healthy individuals who have rested in bed for more than 3 weeks b) healthy workers after working 5 nights of shift work c) people suffering from jet lag

Low cortisol may add to the feeling of tiredness, decreased alertness and poor performance seen in CFS/ME and night shift work. It has also been implicated in noise and light sensitivity.

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

Most people with CFS/ME complain of poor quality sleep. Common problems include difficulty in getting to sleep, restlessness, waking in the night and waking feeling unrefreshed and sleepy.

In a study where the sleep patterns of healthy volunteers were deliberately disrupted to be similar to those with CFS/ME, they developed symptoms similar to those of CFS/ME including feeling unrefreshed and physically weak, sleepiness, poor concentration and muscle aches. However, when they were allowed to sleep undisturbed, their symptoms subsided. This study indicates that a disturbed sleep pattern can cause some symptoms of CFS/ME but that these symptoms are reversible.

Disruption of sleep can affect the activity of the immune system, possibly increasing vulnerability to colds and infection.

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

AUTONOMIC AROUSAL IN CFS/ME

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

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

The physical effects of anxiety include the following:

1. *Increased heart rate*

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

2. *Increase in blood pressure*

A high blood pressure is noted in some people with anxiety. This is likely to be associated with an exaggerated response by the autonomic nervous system, to stress. There are usually no particular signs and symptoms of high blood pressure. High blood pressure is usually only detected in routine investigations by doctors or if another illness is present, e.g. heart or kidney problems.

3. *Breathlessness which can lead to hyperventilation*

This natural response to being anxious enables our lungs to be filled with oxygen to prepare us for action. However, if over-breathing (hyperventilation) continues for a while, an array of unpleasant symptoms may occur because it reduces the amount of carbon dioxide in the blood. This changes the balance of chemicals in the blood causing tightening of the blood vessels and reduced blood supply, especially in the brain.

This reduced blood supply to the brain causes sensations such as light-headedness, dizziness, faintness, feeling unsteady, clumsiness, blurred vision, pins and needles, tingling or numbness (sometimes one-sided) in the limbs or face.. Cramp-like muscle spasms may be experienced, particularly in the hands and feet. Increased sensitivity to light and noise may also occur. Other abnormal sensations such as feelings of being detached from oneself, feelings of unreality or being out of control may also occur.

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

The muscles of the chest wall can be over-used during hyperventilation which may lead to *chest pain or discomfort*.

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

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

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

4. Blood flow is altered

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

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

5. Muscle tension

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

6. Visual disturbance

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

7. Sweating

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

8. Sleep disturbance

As adrenaline increases at times of stress, sleep disturbance such as *difficulty getting*

to sleep or frequent waking is very common and can be accompanied by *nightmares and sweating*.

9. Mental functioning

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

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

Everyone experiences physical symptoms of anxiety in a different way and rarely experience all of the symptoms listed above. An increase in nerve activity and adrenaline production can *precipitate feelings of weakness and exhaustion and these can add to the fatigue and muscle aches* of CFS/ME.

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

How can GET help?

The autonomic response is your body's way of preparing you for action. However, if you don't take physical action, symptoms can result. You can therefore use GET as a way of dealing constructively with this response.

BENEFITS OF EXERCISE

Regular exercise has many known benefits to people of all ages and with many differing medical conditions.

Exercise of an appropriate duration, intensity, and regularity is known to affect the following in a positive way:

Cardiovascular System

Your heart, lungs, and circulation system work more efficiently, making your body more able to deal with the demands of daily activities. The improvements in the cardiovascular system can reduce your risks of certain diseases e.g. heart disease.

Strength

Exercises that challenge your muscles improve the strength of individual muscles and muscle groups, making some daily tasks easier, e.g. climbing stairs, hanging out the washing.

Endurance

Exercises that are prolonged enable you to do more than you could previously, e.g. walk further, swim further, and do the housework for longer.

Flexibility

Many exercises, especially those involving stretches (e.g. Yoga), can improve the flexibility of your joints, ligaments, and muscles helping you to move easier with less stiffness.

Balance

Certain exercises can improve your balance, e.g. dancing, standing on one foot.

Immune system

The right amount of exercise maintains and improves your immune system, essential for fighting viruses and infections.

Sleep

A good night's sleep is essential in order to feel refreshed and wake up feeling better. Exercise improves slow wave sleep, during which hormones are released to repair your muscles.

Increase in bone density

Exercises that involve putting weight through your legs (known as *weight bearing exercises*)

help increase and maintain bone density, reducing your risk of broken bones and osteoporosis (*'brittle bones'*).

Thinking ability (cognition)

Graded Exercise Therapy for CFS/ME has been shown to improve thinking ability, or cognition.

Well-being and mood

Exercise releases your own natural hormones in your body that can make you feel more relaxed and happy. It can therefore, be of particular help to people affected by depression or anxiety.

Putting stress hormones to good use

Various natural substances are released into your bloodstream at times of stress, in order to prepare your body and muscles for physical action. Sometimes we are not physically active at times of stress, which can lead to certain symptoms, e.g. dizziness, muscle tension. Exercise can be an effective and positive way of utilising the physical preparation and helping to control certain physical symptoms.

Weight loss

If you are overweight, aerobic exercise is an essential component to successful weight loss.

Body Image

Exercise can make you feel better about your body.

Confidence

Participating in exercise can improve your confidence, especially if you are learning something new and challenging, or returning back to an activity you previously enjoyed. A sense of achievement is important to everyone.

Social Contact

Exercise can be a good way of establishing or re-establishing social contact.

WHAT IS GRADED EXERCISE THERAPY (GET) AND HOW WILL IT HELP?

Graded Exercise Therapy (GET) may seem a rather odd concept for someone who has CFS/ME. Joining a gym, riding a bike, or playing football may seem a bad idea if you are struggling to carry out simple tasks such as dressing yourself.

However, consider this: as well as feeling exhausted, does getting dressed also make you feel a bit breathless? How about having a shower, walking to a shop, or doing some housework? Have you considered this might actually be exercise, too?

What is Graded Exercise Therapy (GET)?

GET is the use of regular, physical exercise (and consider exercise in its broadest sense, including lifting a finger or rolling in bed) to aid recovery from CFS/ME.

GET works directly in partnership with your own individual level of current ability, and is directed by your own goals and objectives. In other words, the activity that you decide to work with is related to what you want to achieve. For example, if you would like to manage your home or garden better, GET helps to improve your strength and movement to allow you to do this. If you would love to be able to walk your children to school or get back to playing a sport you enjoy, GET helps you to gradually build up your strength and fitness to achieve this.

Your GET programme will be jointly negotiated between yourself and your physiotherapist, and will take into account current activity levels and other important factors such as sleep and setbacks.

RESEARCH INTO GET

In previous research studies, most people with CFS/ME felt either ‘much better’ or ‘very much better’ with GET.

Exercise has been considered a useful strategy for many years in the rehabilitation of fibromyalgia, Multiple Sclerosis, and many other neurological conditions. Research has now shown that carefully graded exercise (Graded Exercise Therapy) can also be a very helpful therapy for CFS/ME. You may be aware that the Chief Medical Officer’s Report of 2002 recommended GET as one of the most effective therapy strategies currently known.

Can exercise make me worse?

Any activity carried out to excess and beyond the capacity of that individual’s current physical level has the potential to increase symptoms and make someone feel worse. To ensure that this doesn’t happen, it is essential to start activities at a low level tailored to you and to build up very gradually. Because you are starting at a level you can easily manage (even on your worst days) and then building up slowly at a rate that is right for your body, symptoms are controlled and kept to a minimum.

People have reported that when they have tried exercising without appropriate supervision and careful monitoring, the starting point and progress can be hard to judge. Therefore, programmes that start too high, or progress too quickly, can cause difficulty.

However, you will be working with experienced physiotherapists who have been well trained in the application of exercise to CFS/ME.

What will my GET programme consist of?

Please be aware that you will not be expected to make progress by yourself or to follow this guidance independently, decisions will be made jointly with your physiotherapist, and you will decide together how and when to progress.

1. Setting goals jointly with your physiotherapist - goals that are important to you.
2. Stabilising your physical activity will provide the foundations for GET - this means helping you to work out a consistent pattern of physical activity before increasing exercise.
3. Gentle stretches are often a good start for exercise, as these can help your muscles to feel more comfortable and help prepare them for activity. You will work with your physiotherapist to plan a stretching programme to start with, even before you look at adding activity.
4. You will then negotiate an initial activity with your therapist, one that you really enjoy or one that is necessary in your life. This should be an additional activity to your normal, everyday activity. The purpose is to challenge your body slightly so that it strengthens.
5. This activity is started at a level that you know you can do manageably every day, even on your bad days, on at least 5 days out of 7.

If it can't be done every day, then the starting level is too high

6. Once this can be done consistently (of course, this should feel OK, because the level you choose is an easily manageable one), the time you do this activity for can be increased slightly. *The increases you consider are very small:* e.g. a 5-minute walk becomes 6 minutes. An increase from 5 to 10 minutes would not be advisable as this is an enormous 100% increase; our bodies tend only to be happy with increases of around 20%.
7. Getting started might seem difficult, possibly creating manageable feelings of stiffness or fatigue as a normal physiological response to activity. After a few days of maintaining the activity at this new level, these responses subside as the body adapts and strengthens. Gentle stretches can help minimise any stiffness and keep you supple.
8. Keep to this level of activity until you are used to it and it feels OK.
9. Once it feels OK (you're getting stronger!), another small increase in time can be

added.

10. When you can do an activity for a good length of time at a comfortable pace, e.g. 30 minutes, it is then helpful to start increasing the intensity of the activity. This increase is carefully planned with your physiotherapist. This might mean walking slightly faster for part of the time, for example.

This process may take anywhere from weeks to months – the process is slow and steady; patience and keeping your brakes on may be just as important as increasing activity.

Alongside this programme, you will be shown how to best deal with setbacks, improve your sleep and relax your muscles.

What activity should I choose?

The key to this decision is to choose a realistic, regular, and enjoyable activity. Many people start with walking because it is one of the main physical activities we undertake. Depending on how people are affected by CFS/ME and what they wish to achieve, someone might start by using physical activities around the home, while others may wish to go out for a daily walk. Those interested in sports may be more inclined to use cycling or swimming, for example.

Using a heart rate monitor or a 'perceived exertion scale'

Many people find that it can be difficult to increase the intensity of exercise, as some normal responses to exercise can feel worrying if they feel similar to CFS/ME symptoms. Your physiotherapist will use a heart rate monitor, which is an objective measure of how hard you are working, alongside a 'Rate of Perceived Exertion' Scale (the Borg Scale). These tools can help you to work out how to increase slowly and comfortably.

Your physiotherapist might also encourage you to strengthen your muscles, possibly

through a set of exercises – these tend to need the same caution: start low, progress slowly. Gradually getting used to more physical tasks in the home, e.g. hanging out washing, weeding, cleaning, or washing floors or windows can be one of the best ways of regaining strength as they are specific to the activities that are important to you.

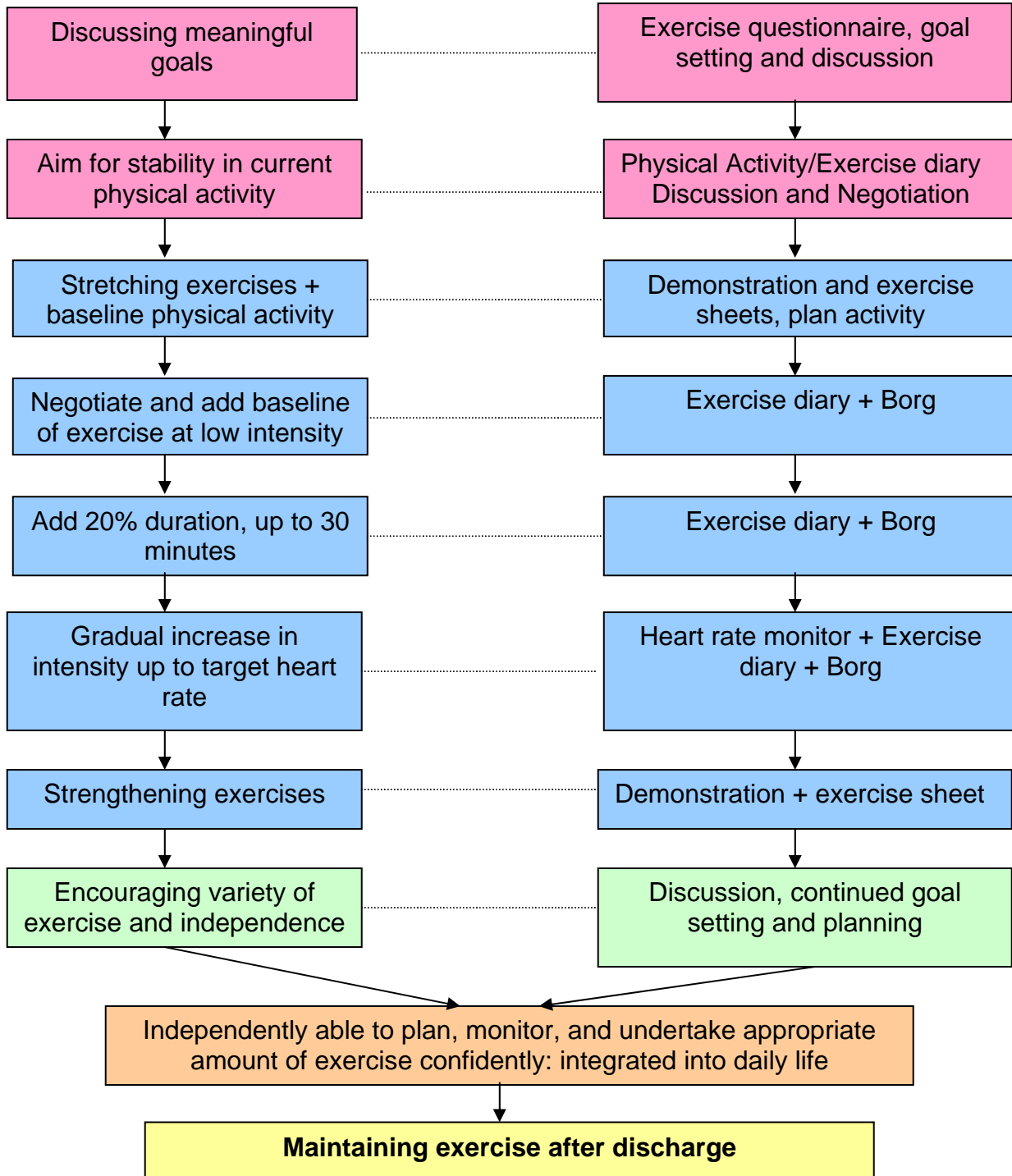
In summary

There is nothing to stop your body from gaining strength and fitness, as long as it is done in a carefully monitored way, relating directly with your own particular circumstances – started and progressed at the right rate for you. Good luck!

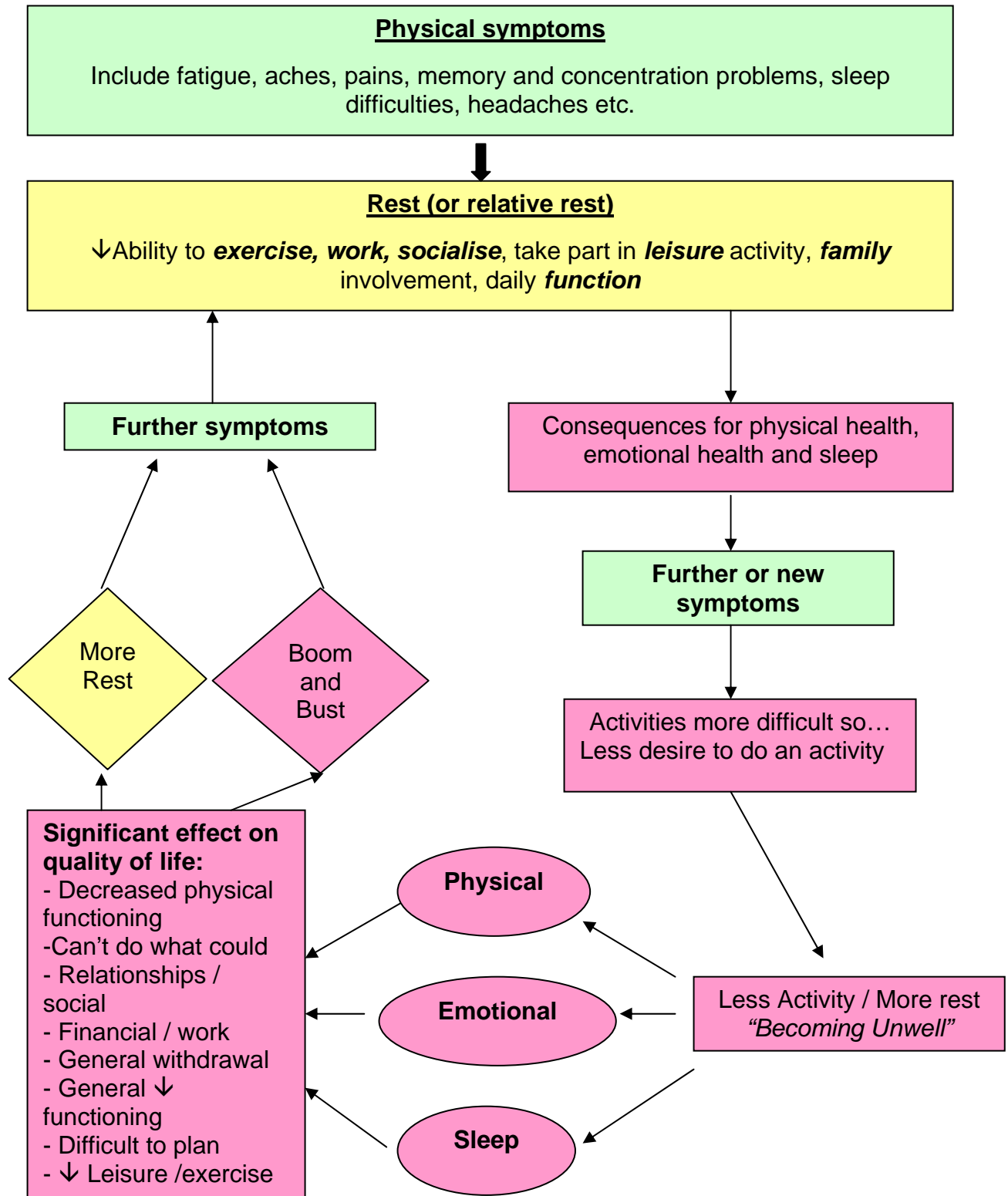
THE GET PROCESS

PROCESS:

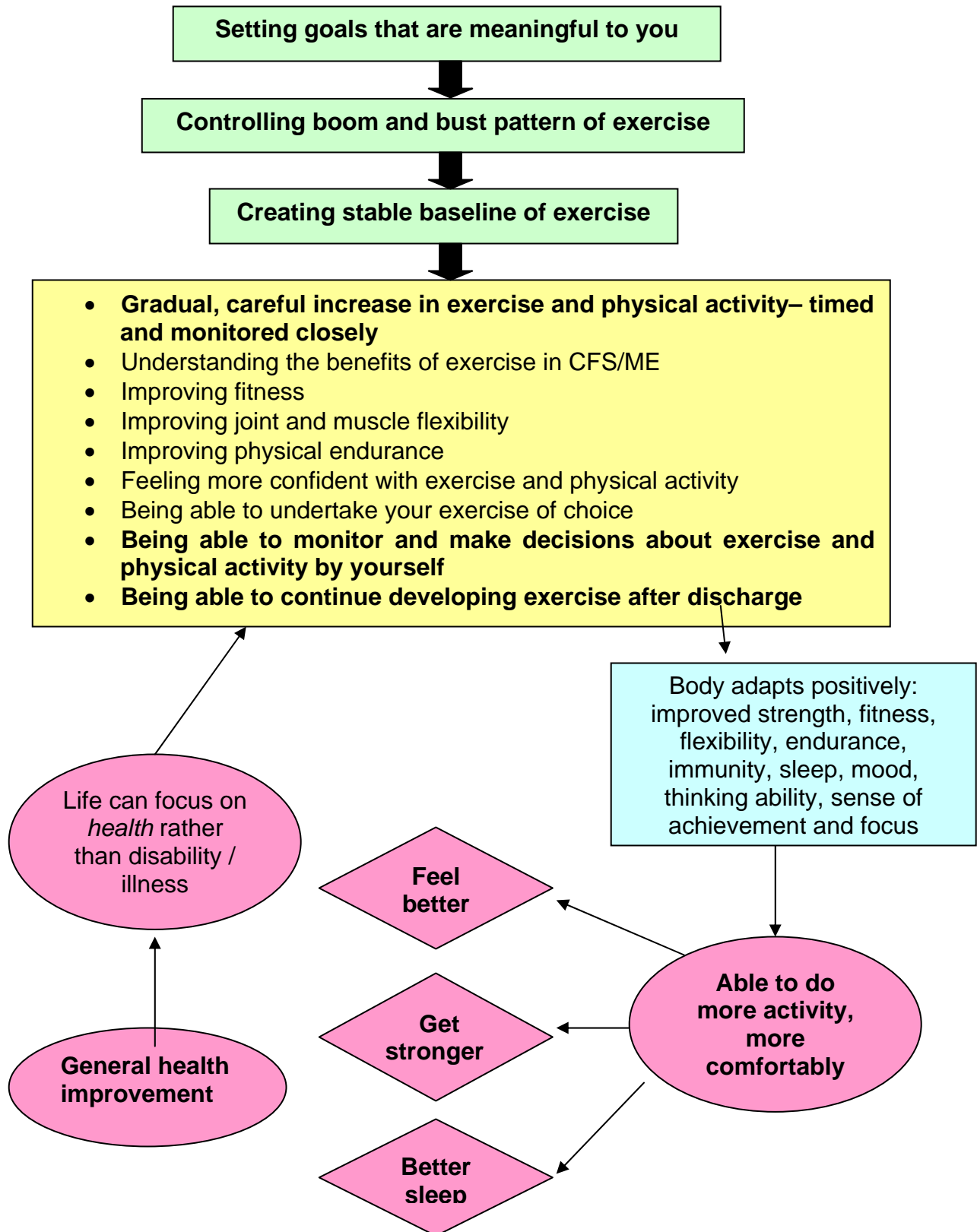
TOOLS:



UNDERSTANDING CFS/ME



FEELING BETTER WITH EXERCISE



SUMMARY OF GET SESSIONS

Please note: Due to various reasons, such as setbacks, illness, travel difficulties and holidays, it may be that 15 sessions are not completed. However, your therapist will work towards ensuring that all important aspects of the programme are covered.

Session Number	Week No	Time (mins)	Summary	Homework
1	1	90	- Assessment - The GET model - Start to investigate exercise goals	Activity diary + exercise questionnaire + goal setting
2	2	50	- Goal setting - Review physical activity diary - Negotiate physical activity - Stretches	Baseline physical activity + stretches
3	3	50	- Mutually agreed and prioritised goals - Talking about exercise	Start exercise baseline + activity baseline + stretches
4	4	50	GET - Active treatment - Using heart rate monitors - Sleep advice for exercise - Reviewing exercise record - Planning next session of exercise - Written setback plan - Reviewing goals - Preventing/managing setbacks - Maintaining changes - Adding strengthening exercises	Exercise
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	- Getting the intensity right	Exercise + variety + independence
14	24	50	- Encouraging variety / independence - Plan ongoing exercise	
15	36	50	Treatment booster session: - Maintenance of changes - Future goal setting and planning - Discharge	Ongoing exercise + goal setting

KEY:

- Phase 1: Assessment, engagement and treatment planning
- Phase 2: Active treatment
- Phase 3: Ending treatment and preparing for future
- Treatment booster session

THE ROLE OF YOUR PHYSIOTHERAPIST

The role of the physiotherapist is to support you with your graded exercise programme. The physiotherapist's job is to;

- Explain how Graded Exercise Therapy helps people with CFS/ME.
- Work with you to set your goals.
- Help you set a manageable level of physical activity.
- Demonstrate the stretches that are to be part of your programme.
- Plan with you what type of exercise you would like to be doing during the programme and set appropriate target heart rates for you.
- Explain and demonstrate how and when to use the heart rate monitors.
- Discuss with you appropriate increases in exercise duration or intensity.
- Monitor your progress.
- Give advice about sleep.
- Give advice about managing setbacks.
- Show you how to use muscle relaxation.
- Encourage you and support you throughout the programme.
- Encourage you to maintain your positive gains and changes after discharge.
- Answer any questions or listen to any concerns you may have with regards to your new graded exercise programme.

GETTING THE BEST OUT OF GET

It is important that you have a good understanding of how to get the best out of your therapy and appointments. It will be useful to:

- Complete all records and bring them to therapy session.
- Do as much of the homework as possible, whether this involves exercise or completing written sheets – to give you the best chance of making progress.
- Contact your physiotherapist as soon as possible if unable to attend an appointment - so that another appointment may be arranged as soon as possible.
- Keep your physiotherapist informed of any changes in medication, other treatments, changes in health etc.
- Participate in setting an agenda each session - so that all of your needs and requirements are met.
- Tell your physiotherapist if you are not clear on any aspect of the GET programme.
- Attend appointments on time (wherever possible) as your physiotherapist may have an appointment straight afterwards and would therefore be unable to offer extra time.
- Bring in this manual and all of the worksheets completed to sessions to get the best out of your appointment.
- Not start any other treatments while you are undertaking the GET programme, unless approved by your GP or PACE clinic doctor; this is a normal requirement of any therapy, which aims to ensure that we know what has caused the changes.

GETTING TO KNOW THE PAPERWORK

The physiotherapist will guide you as to what paperwork to complete at which time, so you do not need to know the following in detail. However, it can be useful to have a summary, and to explain the function of each sheet.

Exercise questionnaire

The first worksheet to complete is the exercise questionnaire (page 42), this will help you and the physiotherapist to work out what exercise you enjoy and what you would prefer not to do. It also explores how you feel about exercise and will help the physiotherapist to address any specific concerns. It will ensure that the exercise that you undertake is realistic and appropriate to you as an individual.

Goal sheets

You will then complete goal sheets together with your physiotherapist during your sessions. You can also use these sheets yourself in your own time if you want to break down your goals or clarify things further for yourself.

Physical activity and exercise diary

The *Physical activity/exercise diary* serves to get an idea of your daily routines and patterns. This can be helpful when working out your starting point or the timings of exercise sessions.

GET plans and progress sheets

This is a written plan of the next phase of treatment; you and the physiotherapist will write this in your sessions together. When you come back the next time, you will then complete the bottom section together, which serves as a review of how you got on.

Exercise records

This is the document you will fill out at home, keeping details of the type and duration of

exercise, Borg scale, and average heart rate achieved. This will also be used to plan your exercise with your physiotherapist, as well as functioning as a motivational tool for you. You will hand this into the physiotherapist at your next session, so always remember to bring it to your physiotherapy/GET appointments. If you would like a copy, please feel free to copy it yourself or ask the physiotherapist to do so when you see them next.

You are strongly advised to keep all of the sheets you work with, together in a file or safe place. These sheets can be a powerful reminder of your progress and can help you proceed if you get stuck.

Please remember to bring this manual and all worksheets to therapy sessions as they will provide the basis for discussion and planning.

GUIDELINES FOR CHOOSING EXERCISE AND PHYSICAL ACTIVITY

The activities you undertake should be

- Relevant:** Exercise should relate to an activity you enjoy (e.g. visiting museums / enjoying social outings) or an activity you need to do in your daily life e.g. housework, walking to the bus.
- Regular:** To make changes and maintain them, exercise needs to be done regularly and fit into your everyday life; it is a long-term lifestyle change – not a ‘quick fix’.
- Realistic:** Be sure that you are not aiming too high and attempting to do exercise that is beyond your current capacity. However, you may well be able to work up to your ‘goal exercise’ (e.g. joining a fitness class/playing football with friends) if you follow the concepts of Graded Exercise Therapy carefully.
- Enjoyable:** What do you really enjoy doing? Sometimes exercising in a group/ with your friends/ family can be more enjoyable.

Exercise can be about ‘sporting activities’

- Walking or cycling: for pleasure, to the bus stop, shops etc.
- Sporting activities e.g. football, swimming, cycling
- Home-based exercise programs or going to the gym

Exercise can also include

- Housework: e.g. Cleaning / vacuuming / putting on a duvet cover!
- Gardening, DIY; decorating and home maintenance
- Climbing stairs
- Playing with children/ grandchildren, e.g. playing ‘catch’ or football
- Yoga, Pilates, Tai Chi

The activities can be classified as ‘aerobic exercise’ if they make you feel breathless and are raising your heart rate.

SETTING GOALS FOR YOUR EXERCISE

At the beginning of your exercise programme your physiotherapist will help you establish goals to work towards. These goals involve physical activities that you would like to be doing again, by the end of your GET programme.

Long-term goals

These goals are the things you would like to be doing again in the future. For example, some people's goals are:

- Walking to the shops three times a week.
- Riding an exercise bike for twenty minutes every day.
- Weeding the garden for an hour at a time.
- Managing to vacuum the home all in one go.
- Swimming 20 lengths three times a week.

Short-term goals

It is helpful to break these long-term goals into smaller components –

For example, the goal above regarding walking to the shop could be broken down into walking half way to the shops in ten weeks time. This goal is then broken down further into weekly or fortnightly exercise goals.

Your goals should be **SMART**

Specific - exactly what do I want to do, where and with whom?

Measurable - how far, how long for and how often?

Achievable - are my goals within my reach? Not necessarily immediately, but gradually, as my capabilities and confidence grow

Relevant - to me, they need to be important to me.

Time related - by when?

After completing the exercise questionnaire, you will discuss and write goals down in your therapy session alongside your physiotherapist

EXERCISE AND PHYSICAL ACTIVITY QUESTIONNAIRE

There are different types of exercise: this worksheet aims to help work out what type of exercise is important to you, and which exercise you are not so keen on. The exercise questionnaire will help you to formulate goals that are important to you: these will be discussed at your next appointment, so please be sure to bring in your completed questionnaire.

1. 'Every-day changes' Exercise/Physical activity:

This category reflects exercise that you could add to your daily routine. It is not an extra 'sport' type exercise. For example, getting off the bus the stop before, making use of the stairs instead of a lift, taking a detour on the way back from shopping, walking to the shop daily for milk instead of having it delivered etc.

Could any of these, or other similar activities, be appropriate for you? (Please list)

a)

b)

c)

d)

e)

2. 'Sports-type' Exercise

Are you interested in any sports, or in attending exercise classes? Would you like to be able to join a local gym? Would you like to join a walking or cycling group near you? How about getting back into an exercise video or DVD you once enjoyed? Would you like to get back to playing football with friends or playing tennis with children?

Could any of these or other similar activities, be appropriate for you? (Please list)

a)

b)

c)

d)

e)

3. 'Around the home' Exercise

Do you have any physically demanding tasks around the home; tasks that might make you feel breathless when you do them? E.g. Gardening, Do-It-Yourself projects, housework? Do simple tasks like getting dressed or washed have this effect?

Would you like to work towards any of these activities? (Please list)

a)

b)

c)

d)

e)

4. Is there any exercise that you would prefer NOT to do? (Please state)

5. How confident do you feel about undertaking exercise? (Please mark on line)

Not at all confident 0----1-----2-----3-----4-----5-----6-----7-----8-----9-----10 Very confident

6. Do you have any concerns about undertaking exercise? (Please explain)

7. Apart from improving your chronic fatigue and symptoms, what other benefits of exercise interest you?

- a) Improved sleep
- b) Improved ability to do more activity
- c) Improved immune system
- d) Weight loss / control
- e) Prevention of osteoporosis
- f) A healthier heart
- g) Improved breathing / less breathlessness
- h) Improved body image and confidence
- i) Ability to exercise with children/ family
- j) Ability to exercise socially
- k) Feeling better in spirits
- l) Greater stamina
- m) Greater energy
- n) Greater strength

Please bring this completed sheet with you to your next physiotherapy appointment

NOTES FOR USING THE PHYSICAL ACTIVITY/EXERCISE DIARY

The information gathered in this activity diary will help the physiotherapist work out how much physical activity you are doing. This will help you and your physiotherapist plan your exercise, and you can use the information gathered to help stabilise your activity. The first step is to write down details of your activity on the Physical Activity and Exercise Diary.

 **Write down your daily activity for a week, including the following:**

Sleep: Time went to bed, woke up, got up, and any sleep during the day.

Activity: A log of your activity during the day (e.g. got dressed, walked 4 mins x 2 to shop, rest – sat down 10 mins, made lunch etc).

Symptoms: At relevant times, make a note of any important symptoms on a scale of 1-10 (10 being worst), e.g. fatigue 7/10 after going to shop, 2/10 when enjoying lunch with friend.

Rest: When, for how long, and how?

Exercise: Do you do any exercise? If so, how much, how often?

PHYSICAL ACTIVITY AND EXERCISE DIARY

Week Commencing _____

PIN _____

	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY	SUNDAY
07.00							
08.00							
09.00							
10.00							
11.00							
12.00							
13.00							
14.00							
15.00							
16.00							
17.00							
18.00							
19.00							
20.00							
21.00							
22.00							

EXAMPLE - PHYSICAL ACTIVITY AND EXERCISE DIARY

Week Commencing 25TH OCTOBER 2004

PIN _____

	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY	SUNDAY
07.00	Woke up, shower, breakfast	Woke up, shower	Woke up, shower	Woke up, shower	Woke up, shower, breakfast		
08.00	Dropped kids off at school	Breakfast, Walked dog 15 mins	Breakfast, Walked dog 15 mins	Breakfast, Walked dog 15 mins	Dropped kids off at school		
09.00	Breakfast, Walked dog 15 mins	Work	Work	Work	Breakfast, Walked dog 15 mins	Woke up, shower, breakfast	Woke up, shower, breakfast
10.00	On computer	Work	Work	Work	Household jobs	Kids to sport	
11.00	On computer	Work	Work	Work	Household jobs		Take kids to park
12.00	Lunch	Lunch	Lunch	Lunch	Household jobs		
13.00	Visit from friends	Work	Work	Work	Lunch	Lunch	Out for Lunch
14.00		Work	Work	Work	Rest	Sainsbury's	
15.00		Work	Work	Work	Visited parents		Walked dog with husband 20 mins
16.00	Pick up kids from School	Work	Work	Work	Pick up kids from School		
17.00	TV	Work	Work	Work	TV	Kids to movies	TV
18.00	TV	TV	TV	On computer	TV		TV
19.00	Dinner	Dinner	Dinner	Dinner	Dinner		Dinner
20.00	TV	TV	TV	TV	TV	Dinner	TV
21.00	TV	TV	Household jobs	Household jobs	TV	TV	Bed
22.00	Bed	Bed	Bed (2330)	Bed (2330)	Bed	Bed	

STABILISING PHYSICAL ACTIVITY

A very common factor that contributes to the maintenance of CFS/ME is reduced activity and increased rest. As we explained in the section “Explaining CFS/ME”, the less your body does, the less your body gets used to doing. As a result physical changes within your body occur. These changes cause an increase in unpleasant symptoms that can be very distressing and often lead people to an erratic pattern of rest and activity dependent on how they feel.

Your symptoms may be so severe that you spend much of your time confined to home and your days and nights run into each other. You may find that any activity is exhausting, e.g. brushing your hair, talking, walking to the shops, or doing the washing.

On the other hand, you may find that you can be reasonably active on some days, but as a result of “doing too much”, you become more fatigued and symptomatic resulting in being unable to do very much on other days. This is what we refer to as a “boom bust pattern”.

For these reasons it is crucial that the first step of your graded activity programme is stabilising your physical activity. This may mean even doing a little less activity but more consistently than you were doing before. Through this, your body is given time to adapt to the amount of activity it is doing and as a result you’re not constantly trying to recover from symptoms.

GENERAL ADVICE FOR STRETCHING

Why is stretching helpful?

Regular stretching will help to keep your muscles, ligaments and joints flexible and supple. They need to be supple in order to let you move freely, without pulling uncomfortably. They can 'stiffen up' if you have been in a position for a long period of time, or if you have been generally less active than normal. As muscles and ligaments can actually shrink in length, they may be uncomfortable or painful when they are pulled as part of normal every-day activity. However, the good news is, that with regular stretching, you can feel much more supple and this can make your muscles feel more comfortable. Many people with CFS/ME report how much better they feel when stretching regularly.

If you are used to doing particular stretches, e.g. Yoga, discuss this with your physiotherapist, as you might be able to do some of these as well/instead of those given.

When should I stretch?

You will see improvements only if you stretch regularly. You might start by stretching just once a day, but work up to stretching frequently. It is useful to stretch at the following times:

1. After a warm bath in the evenings: the warm water will soften your muscles and mean you can stretch a bit further and more comfortably.
2. If you are in one position for a long time, e.g. at a computer, lying down, or sitting. It is important to stretch every half an hour or so if you are in one position for a long time.
3. At regular opportunities during the day, e.g. waiting for the kettle to boil, watching TV etc.
4. Before and after any aerobic exercise or difficult physical activities, e.g. DIY, gardening.

What should stretches feel like?

Many people report that they feel more comfortable and flexible after they have stretched, and often people feel more relaxed. However, as you are stretching muscles that may be tightened, stretching may feel uncomfortable at the time of the exercise. Stretches should not lead to a pain that stays with you for a long time after the stretch. If you find this, please consult your physiotherapist who can help to alter the stretch for you.

Where should I start?

- When you first start to stretch, stretch gently, slowly and smoothly. As your body gets suppler you will find you will be able to stretch further.
- Start by holding your stretches for as long as feels comfortable (maybe 2-5 seconds), with the view of eventually working up towards 10 seconds. You might start by just doing one of each stretch, but will then work this up gradually.
- Over time you will find these stretches will become easier.

Your physiotherapist will advise you how to progress your stretching programme

Caution:

Never “bounce” when stretching. Stretches should be slow, smooth and sustained at all times.

If you are unsure how to perform a particular stretch, please don't hesitate to ask your physiotherapist. It is important to adopt the right position when stretching and do it correctly.

GENERAL ADVICE FOR EXERCISE

- ALWAYS do a warm-up and warm down: (a more gentle form of your exercise and stretches) *before* you start and *after* your exercise. Start your aerobic session gradually then build up the intensity, slowing down at the end.
- Take care not to 'over train' i.e. exercise for longer/harder than your body can deal with; this may seem like a step forward but is often two steps back. A manageable starting point and gradual progression is the key.
- Drink plenty of water or 'isotonic' drink (e.g. *Lucozade Sport, Gatorade, Isostar*) BEFORE, DURING AND AFTER exercise; don't wait to feel thirsty.
- Wear comfortable clothes, e.g. tracksuit, and wear trainers that will support your feet. Ask your physiotherapist for advice if you are not sure.
- If you use an inhaler, be sure to have it with you and use it appropriately.
- Avoid exercising after a large meal.
- If you have a temperature (tested using a thermometer), stop exercising **but be sure to seek advice from your physiotherapist regarding how and when to re-start.**
- Avoid exercising late in the evening as it has a tendency to 'stimulate' your body and therefore does not allow a 'wind down' before sleep; however, exercise early evening/afternoon can help prepare you for sleep later in the evening.
- Avoid exercising very first thing in the morning; your muscles/joints will usually need to 'get going' for a while. If this is the only time you can exercise, be sure to warm up and stretch sufficiently beforehand.

Your physiotherapist will be able to clarify any of the advice above; please feel free to ask questions if you have any queries or concerns.

THE NORMAL RESPONSE TO EXERCISE

The following signs and feelings are normal reactions during exercise; they show you that you are working at the right level to make real positive changes to your body. If you do not feel any of these when exercising, you will not be making any positive changes to your body.

Increased breathing rate

Your breathing will become faster than normal, to a rate that you are able to control. This is to supply your muscles with more oxygen because they are working harder than usual.

Increased heart rate

You may feel your heart rate increasing: Your heart will beat faster in order to pump the extra oxygen around your body to provide for your muscles.

Body parts turning red in colour

Your face, arms, legs, or other body parts may turn red in colour during and after exercise. This is because there is more blood being supplied to the muscles beneath the surface of your skin. It is also because your blood vessels move towards the surface when you are warm to help keep you cool.

Sweating

Sweating is your way of helping to control your body temperature; as you become warmer on exercise, the sweat evaporates and it cools you down.

Increased temperature

You will feel warmer all over your body, as your muscles are working harder and giving off more heat.

‘Jelly feeling’, especially in arms and legs.

You may feel like your arms or legs are a little shaky or feel like jelly. When you stop

exercise and rest this feeling should gradually reduce and stop.

Normal response after exercise

A little known fact: A manageable stiffness and tiredness after exercise or activity is a positive sign that the body is adapting and strengthening. The body needs these mild to moderate 'stiff and/or tired' signals for muscle fibres to develop and for the body to adapt positively. So.... If there is no physical response at all, there is no strengthening – if there is no strengthening, then the body is likely only to maintain strength or sometimes even lose it.

After exercise, your heart and breathing rate will gradually slow down to their normal resting rates. You may also feel the following as part of a normal reaction after exercise:

Heaviness feeling

After your muscles have worked hard, they are likely to feel heavy.

Stiffness feelings in muscles

These come in varying degrees; a mild stiffness is normal and is associated with positive changes. Stiffness should gradually improve and should not last long. A good warm up and warm down will help reduce these feelings.

Stiffness feelings are associated with a build up of a normal by-product of exercise, known as lactic acid. Lactic acid gradually gets washed out of your muscles after exercise by your bloodstream. You can help this process and feel more comfortable by having a long, warm bath followed by gentle stretching exercises. Gentle movement, e.g. walking, can also help.

- Moderate or Intense stiffness – these feelings do not indicate harm to your body, but as they are uncomfortable, you may need to adjust your programme; ask your physiotherapist.

Natural tiredness

Exercise will make you feel a normal and natural tiredness and will help improve sleep: this tiredness may feel more intense than usual in somebody with CFS/ME.

RARE ADVERSE REACTIONS TO EXERCISE

IF YOU GET ANY OF THESE SIGNS DURING EXERCISE, STOP EXERCISING AND DISCUSS WITH YOUR PHYSIOTHERAPIST OR DOCTOR.

- Breathing becoming out of control
- Wheezing
- Chest pains
- Collapse or faintness
- Injuries

If you feel anything else that is making you feel uncomfortable during exercise be sure to discuss this with your physiotherapist or doctor.

NOTES FOR USING THE EXERCISE RECORD

Why keep an exercise record?

It is very useful for you to write down the exact details of the exercise you are doing. This acts in the following ways:

1. It can be very motivating for you to see how you progress: it can really help to see your achievements on paper to recognise how well you are doing.
2. To help you and your physiotherapist negotiate the next level of exercise.
3. To help you and your physiotherapist establish whether there are any difficulties with your exercise.



Using the Exercise Record, write down your exercise. Include the following:

Duration

- Record EXACTLY for how long you are exercising (the difference between 7 mins and 10 mins is important)

Heart Rate

- When asked to, record your average heart rate during the exercise, using your heart rate monitor.

Borg Scale of Perceived Exertion

- Using the Borg Scale to record the how hard you felt you were working during your exercise. Read the instructions carefully.

Comments

- Any further comments you may have? Feeling better during exercise? Different symptoms? Any changes noticed? Any problems to discuss?

It is essential that you record the length of time you are exercising precisely using a stopwatch or clock, and that you do not go over or under this time. e.g. For a 7-minute walk, this means walking 3.5 minutes then turning around and walking back.

THE BORG SCALE

Instructions for Borg Rating of Perceived Exertion (RPE) Scale

While doing physical activity, we want you to rate your perception of exertion. This feeling should reflect how heavy and strenuous the exercise feels to you, combining all sensations and feelings of physical stress, effort, and fatigue. Do not concern yourself with any one factor such as leg pain or shortness of breath, but try to focus on your total feeling of exertion.

Look at the rating scale below while you are engaging in an activity; it ranges from 6 to 20, where 6 means "no exertion at all" and 20 means "maximal exertion." Choose the number from below that best describes your level of exertion. This will give you a good idea of the intensity level of your activity, and you can use this information to speed up or slow down your movements to reach your desired range.

Try to appraise your feeling of exertion as honestly as possible, without thinking about what the actual physical load is. Your own feeling of effort and exertion is important, not how it compares to other people. Look at the scales and the expressions and then give a number.

THE BORG SCALE

Read the instructions on the previous the page and then rate the exertion you felt during exercise on the following scale:

Intensity	Please circle one number
	6
Very, Very Light	7
	8
Very Light	9
	10
Fairly Light	11
	12
Somewhat Hard	13
	14
Hard	15
	16
Very Hard	17
	18
Very, Very Hard	19
	20

USING YOUR HEART RATE MONITOR

Throughout the trial you will be lent a heart rate monitor so that you can measure the how hard you are working during your exercise. This involves a strap that fits under your shirt that picks up the beat of your heart, and transmits this signal to a receiver on a watch. The heart rate monitor will help you and your physiotherapist to measure the effects of physical activity, which will help to ensure that your programme is progressed at the rate that is right for you.

Instructions for using heart rate monitors

- It is essential that you wet the electrodes on the skin side of the monitor to ensure correct function.
- Place the heart rate monitor directly on your skin around your chest. For women, this is just underneath the bottom line of your bra.
- The heart rate monitor should be a snug but comfortable fit
- Make sure you start the heart rate monitor watch immediately before the aerobic component of your programme, in order to ensure that the heart rate recorded is an accurate measure of the exercise, and not the stretching period beforehand.
- Wear the heart rate monitor only for exercising, and not at any other times during the day.
- Be aware that the heart rate monitor can give incorrect readings if you are in close proximity to other people wearing heart rate monitors.
- Please let your physiotherapist know if your heart rate monitor isn't working.

GENERAL ADVICE FOR IMPROVING YOUR SLEEP AND SLEEPING WELL

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

The following is encouraged:

1. A wind-down routine and hot bath

A general slowing down of physical activities towards the end of the day aims to prepare the body for sleep. The last hour of the day can be dedicated to a warm bath (20 minutes) followed by a gentle muscle stretching routine. The bath is likely to relax muscles and increase blood flow: this may reduce stiffness feelings and help prepare muscles for a gentle stretching routine at night.

2. Establish an optimal sleep pattern

a) Efficient sleeping

Your sleep pattern is *optimal* when it is both *efficient* and *regular*. By efficient, we mean that the more time you are asleep when in bed, the more *efficient* your sleep is. To establish your optimal sleep pattern, you may need to reduce the amount of time you are in bed, in order to increase the amount of time that you are asleep.

Calculate your total time asleep on an “average” night.

Stay in bed for the time that you are usually asleep only.

For example, if you are usually in bed for 10 hours a night, but are only asleep for 6 hours in total, you should only stay in bed for 6 hours. This change should be made gradually.

You may feel more tired for a while, but the slight sleep deprivation you may experience will

in turn produce faster sleep onset, reduced broken sleep and a deeper sleep.

b) Daytime sleeping/napping

You may find that you sleep during the morning or day, or sometimes after work or early evening. Sleeping during the day has been found to affect the quality of the sleep at night, so it is important to gradually reduce and eliminate this e.g. a 4- hour sleep in the afternoon could be gradually reduced by 30 minutes each week, or as appropriate. You might relax in an upright chair instead of sleeping, for example.

c) Not sleeping enough

If you are not sleeping enough, you may have difficulties in the first part of sleep (initial insomnia) and/or in the middle of the night (middle insomnia). Your physiotherapist can show you relaxation techniques for both types of insomnia, which may help this. Exercise will also be helping you directly by increasing the depth of your sleep.

3. Sleeping too long

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

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

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

4. Sleep Hygiene

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

The following guidelines may help to promote an improved sleep pattern:

- *Exercise:* Avoid exercise within 1 hour of bed-time, as this may potentially waken you up. Exercise in the late afternoon may deepen sleep.
- *Diet:* A light snack before bed-time may be sleep inducing, but a heavy meal too close to bed-time will interfere with sleep. Fluid intake should be limited just before bed.
- *Caffeine* is a central nervous system stimulant and is associated with delaying sleep onset and it can cause wakefulness. Substances containing caffeine, e.g. coffee, tea, chocolate and coke should be avoided 4-6 hours before bed-time or during the night if you wake up. Coffee has approximately twice as much caffeine as the other drinks although this depends on its preparation. Some patients with CFS/ME find they need to give up caffeine completely to improve their sleep.
- *Nicotine:* is also a central nervous system stimulant and although many people say that cigarettes help them to relax, the overall effect is one of stimulation rather than relaxation. Smoking cigarettes should therefore be avoided near bed-time and during night time waking.
- *Alcohol:* is a central nervous system depressant, although it may speed up sleep onset, it often causes disrupted sleep later in the night as it is metabolised. A milky drink before bed can help you to feel sleepy and will not cause you to waken in the night. (We know that it is unusual for people with CFS/ME to drink much alcohol)
- *Environment:* Your bed and mattress should be comfortable. Minimise light, noise and excessive temperature during your sleep period. Your room temperature should be around 18° C. Use blinds if necessary or an eye mask; ear plugs if you live in a particularly noisy place and are unable to get used to it and use a fan/heating to control temperature.

5. Preparing for sleep

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

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

6. Using muscle relaxation techniques

Sometimes people with CFS/ME describe that it can be difficult to sleep as their muscles feel sore. Using the muscle relaxation technique regularly will help your muscles to feel more comfortable, as well as helping you to get to sleep.

MUSCLE RELAXATION TECHNIQUE

Muscle relaxation

CFS/ME can be associated with muscle soreness. Some people describe this as a pain, or as a heavy or stiff feeling, or a muscle tension. Some people notice that their muscles feel tighter or firmer, these symptoms can be very uncomfortable. Some people notice that these symptoms can be related to physical activity.

There has been interest into why people with CFS/ME have muscle soreness, and it appears to be related to either a hypersensitive response to physical activity or due to delayed muscle soreness after unaccustomed exercise. Athletes tell us that when they exercise hard, they also get muscle soreness as a result of challenging their muscles. We believe that this symptom of CFS/ME is a normal response to increased exercise or physical activity, and that it can even be seen as a positive sign that our body is being challenged and is strengthening.

However, there may be times when these muscle symptoms can be uncomfortable, making it more difficult to manage physical activity. The good news is that our muscles respond well to techniques that make them feel less tension and more relaxed, improving the body's ability to heal and feel more comfortable.

When to use the muscle relaxation technique

You can practice this technique anytime that works for you. Some people choose to use relaxation when their symptoms are particularly uncomfortable, while others enjoy the ability to feel more comfortable before bedtime. Others will use relaxation after a period of exercise or physical exertion, to give the body time to switch off and gain real benefit from the period of rest. Others choose to use this technique in a warm bath, whilst winding down before bedtime; sometimes followed by some gentle stretching exercises. Other people find they can use this technique whilst on a bus, or even whilst sitting on a park bench. You can try different places and work out what works best for you.

Relaxation is a skill, it does not come naturally for most people, and to gain real benefit you will need to practise it frequently. It is recommended that you build up to using this technique for 20 minutes each day.

Instructions:

Most people find that it can be useful to record this script onto a tape – talk to your physiotherapist about what is the best way to do this.

Find yourself a comfortable place to sit or lie: using pillows to support you if this makes you more comfortable.

If you have other people living with you, it can be useful to tell them that you are relaxing and not to interrupt you: some people even find taking the 'phone off the hook can also be useful to gain maximum benefit from not being disturbed.

Relaxation script

“Relaxation is used by wise people in many different cultures in different ways, and has been shown over thousands of years to have significant healing effects. This particular form of relaxation will focus upon helping your **muscles** to feel more relaxed.

We know that as you really take the time to feel more relaxed, muscle tension can reduce and make you feel much more comfortable.

The first part of this technique will focus upon your breathing. As you sit, or lie in the position that is comfortable for you, just take a moment to become aware of your breathing pattern. There is no need to try to breathe in a particular way, just become aware of your own pattern.

You may notice the air as it comes in through your nose, and maybe even the feelings in

your chest as you breathe that air in. Some people become aware of their abdomen rising and falling, or notice where exactly the air seems to end up in their chest. Just become aware of the sensations and feelings as you breathe in..... and out.... noticing the whole journey that the air takes from outside....to inside...to outside again.

Now some people notice that they breathe slightly higher in their chest, whilst their abdomen does not move as much, whilst others notice perhaps that their shoulders rise as they breathe. Others notice that their breath travels further down into their chest towards their abdomen – just notice what it feels like to breathe for you.

Now think about the rhythm of your breathing: it might be that your out- breath is longer than your in-breath, or maybe that your in- breath is longer than your out- breath, or maybe even that your in-breath and out -breath are about the same length. It really doesn't matter right now.

As you become aware of what is normal for you, you can now become more aware of a particular breathing pattern that will help you to feel better. It might be that you are breathing like this anyway, or it could be something new to you, but just take a moment to notice how the location of the breath and the timing of your breathing can have impact upon your health as we work through a technique known as 'diaphragmatic breathing'. This breathing really makes use of our diaphragm – a large, flat muscle located at the bottom of our lungs: but sometimes we are not very good at using it to its maximum benefit.

Sometimes we breathe more towards the upper part of our chest, or even use our shoulder or neck muscles in the process: muscles that are not well designed for this task.

Diaphragmatic breathing is much more efficient than other types of breathing, and uses less energy to do. So it is well worth finding a way to practise it regularly.

When we really use our diaphragm to breathe, the breath is taken to a lower place in the chest... just notice that now as you start to feel that bit more comfortable... Try to direct the breath towards your abdomen allowing it to gently lift and fall.... Being aware that this is a

comfortable breath that is more efficient and calming. Some people like to place a hand on their abdomen, just below the rib cage so they can feel the action of the diaphragm really working. You can either use your hand yourself, or simply be aware of your abdomen rising and falling...maybe you can feel your clothes against your skin as you breathe in and out. You might like to imagine a little balloon just under your ribcage filling and letting go gently as they do this. You can try this for a while, being aware that this type of breathing really helps your whole body system to relax.... (pause).

As one part of your mind concentrates on breathing to that lower place, another part of your mind can think about the timing of your breathing. We know that breathing longer on your out breath can be very relaxing ... just now direct your attention to the rhythm of your breath now and see whether you can make breathing out last a little longer. Some people find this difficult at first, and if so, don't worry, just try this for a while and gradually you can find it becomes easier and easier with time.

Some people like to count their in and out-breath, to help them get into a pattern: for you, it could be breathing in for 2 and out for 3 for 4, or perhaps counting a little faster you may find that the right pattern for you could be in for 7 and out for 11. Everyone is different, and you can now think about finding what works for you as you practise now.

As you feel more comfortably relaxed with each breath you take, you can become more aware of your body and the way it feels right now. It could be that your muscles are feeling relaxed already, or maybe that they feel a little uncomfortable. Either way, just find a way to accept how they feel right now, knowing that in the next few minutes and every time you do this technique, that they can feel more and more comfortable, and more and more relaxed.

You may notice that there are muscles that feel a little tighter: this could be around your jaw, neck or shoulders. Or it could be your tummy muscles or your scalp that feels slightly tighter. Wherever it might be for you, just notice how you can slowly let go of the tension within them: this might mean becoming aware of more space between your teeth, or

perhaps just dropping your shoulders a little. Let go of the tension in these muscles, if you feel it wants to go.

It might be that you enjoy imagining your muscles melting slightly, or else softening gently in their place. An image that can be particularly helpful in muscle relaxation is imagining a cloud floating gently across your muscles, gradually absorbing tension from them, changing to a deeper colour as it goes: when you have finished, this cloud, full of the muscle tension from the day, can float away and disintegrate in the distance. Or you might like to think about your muscles feeling heavier or lighter, warmer, or floating or sinking comfortably. You can even create your own techniques...this is about working out what works for you, and as we work through your different muscles, you can choose and practise different things as you go along.

As we now take a journey around the muscles in your body, you may wish to concentrate for longer on some muscles than others: it may be that spending a shorter time on some may be appropriate: it's up to you.

It can be useful to concentrate first on your feet, and now just becoming aware of how they feel... it might be that you can feel your feet in your shoes, or maybe you are not wearing shoes and you can feel your heels on the floor or another surface. Whatever it is for you, just become aware of the position your feet are in, and allow them to be comfortable. You can now think about your cloud, absorbing tension from the day's physical activity, or perhaps concentrate on a light or sinking feeling in your muscles: whatever feels good.

Then you can take your attention further up your legs to below your knees, where you can allow your calf muscles at the back of your legs to relax more comfortably....(pause)... And now you can focus on your thigh muscles at the front of your legs... use whatever images or thoughts help you to feel more relaxed, as you allow your muscles to release their tension and instead be filled with a sense of comfort and warmth.

You can now take your attention to your buttocks and then your tummy, where you can allow yourself to soften into the chair or bed and let go of tension you might find.

As you let go, you can think about the muscles a little higher up in your tummy, and you may even find that you can become more aware of the muscles around your diaphragm, again focusing upon the rising and falling as you breathe in and out gently.

Now you've covered nearly half of your body, you can notice that feeling of relaxation travelling further up towards your chest - again feeling the rising and falling of your breathing. You can notice that as you feel more relaxed, your shoulders may have dropped, making the muscles around your neck and upper arms feel heavier, softer, warmer or even lighter.

You can then allow this feeling to float now towards the muscles of your arms... and towards the muscles in your hands. Your hands can open now as they lie gently on your lap, or wherever they are comfortable. You may notice how much better they can feel in this opened position, where the muscles have chance to really rest.

You can take this feeling with you up your arms again and now direct it towards your neck – it might be that you enjoy the thought of gentle kneading at your neck muscles, or a feeling that the deeper muscles in your neck can gently unwind as you focus upon them.

You may find that there is more space now between your teeth as your jaw muscles relax and allow your face to feel more comfortable. This release can now be linked to smoothing out your forehead and allowing any tension to dissolve away.

Your head also has some tiny muscles that can do with some attention, and just focus upon these now, letting the top and back of your head feel warm and rested.

Now that you have given attention to every part of your body, just notice how simple it can

be for your muscles to feel better. As your muscles feel better, they can get the rest they need to restore themselves and allow you to feel more comfortable during the night and day.

If you are using this session to help your muscles feel more comfortable for sleep, then you can go through the process again, noticing how more relaxed you feel as you go through a second, or maybe third time... allowing yourself to drift comfortably into a good night's sleep.

If you are using this during the day, then you might like to now just become slowly more aware of the room that you are in and when you are ready you can open your eyes and gently start to move your arms and legs, knowing that what you have just done will help you to be more comfortable and active during the day.”

PROBLEM SOLVING TECHNIQUE

Sometimes things happen in life which will get in the way of your GET programme. There may be unexpected happenings, which distract you, affect your energy levels, or leave you with insufficient time to do your GET. 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 activities we need to do. 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.

Identify the problem

What is your problem? Try to define it as clearly and objectively as possible. In what way is it interfering with your GET?

What are the available solutions?

- Brainstorm possible solutions (what has previously worked). Revisit solutions you may have previously written off as impossible. Use your imagination and be creative. For example, if you have been asked to travel to attend something, can this be broken down into easier steps, as you would do with your exercise programme? Can it be incorporated into your GET programme?
- Can any of these potential solutions be modified in any way? Use your knowledge of your graded approach to activity to think about possible solutions.

Prioritise

- Prioritise solutions according to the time, resources and help available.
- Discuss possible solutions with others so they know what you can and cannot do,

within the limits of your GET programme and illness. Sometimes saying “no” can be the best solution, to prevent this affecting your GET programme.

Select the most acceptable and workable solution

- Try it out. Does it allow you to adhere to your graded approach to activity?
- Review and re-select as necessary. The right solution on one occasion may be the wrong solution at another time.
- Summarise the problem and solution you have chosen.

Evaluate the effective strategy and re-visit the problem cycle

Remember to tackle one problem at a time

GENERAL ADVICE FOR STRENGTHENING

Why do strengthening exercises?

As well as your body being generally physically fitter, muscles also need to be strong to enable you to do physical activities during the day. It takes muscle strength to climb the stairs, for example, or to wash your hair or do gardening tasks at home. It is also important to strengthen muscles if you are re-starting to exercise or trying a new physical activity or sport, so that you are strong enough to be able to do it. In essence: a stronger muscle will let you do more of the things you want to do.

How often should I do strengthening exercises?

It is best to try to work up to doing strengthening exercises daily if you can. However, you might start by doing them every second day to start with. It is better to do fewer repetitions more regularly than to do a long session all at once.

Where should I start?

Your physiotherapist will advise you where to start and how to progress. You will probably start with a low number of repetitions and then build up slowly, in the same way as you have increased your aerobic exercise.

When should I do strengthening exercises?

You can choose whether you would like to do them either all in one session, with maybe some rest breaks in between, or spread out throughout the day. Discuss this with your physiotherapist.

Recording your exercise

It can be very useful and motivating to keep a good record of the number of repetitions you are doing for each exercise, and how often you are doing them. This record will also be useful for your physiotherapist to see when you attend. As you get stronger, you can notice how much you have progressed.

What should muscle strengthening feel like?

At the time, a strengthening exercise is likely to feel quite hard, and you may feel a burning sensation, a “heaviness” or a “jelly feeling” in the muscle. It is at this stage that the muscle can get a message to the brain to build more muscle fibres and make you stronger. As with stretches, although strengthening exercises may feel uncomfortable at the time, they should not give you sharp pain, or pain that gets worse over time. If you are not sure about whether your reaction is normal, speak to your physiotherapist.

USING EXERCISE EQUIPMENT AT HOME

If part of your graded exercise programme includes the use of personal exercise equipment (e.g. treadmill, cross trainer at home), it is important to note that it is the responsibility of each participant to fully familiarise themselves with the equipment user's manual before use.

It is each individual participant's responsibility to maintain the equipment in a safe and fully working state, to pay for any repairs required and to discontinue use if the equipment is deemed unsafe or faulty.

The PACE team is not able to accept responsibility for any accident or subsequent harm that occurs to any patients whilst using home based equipment as part of the graded exercise therapy programme

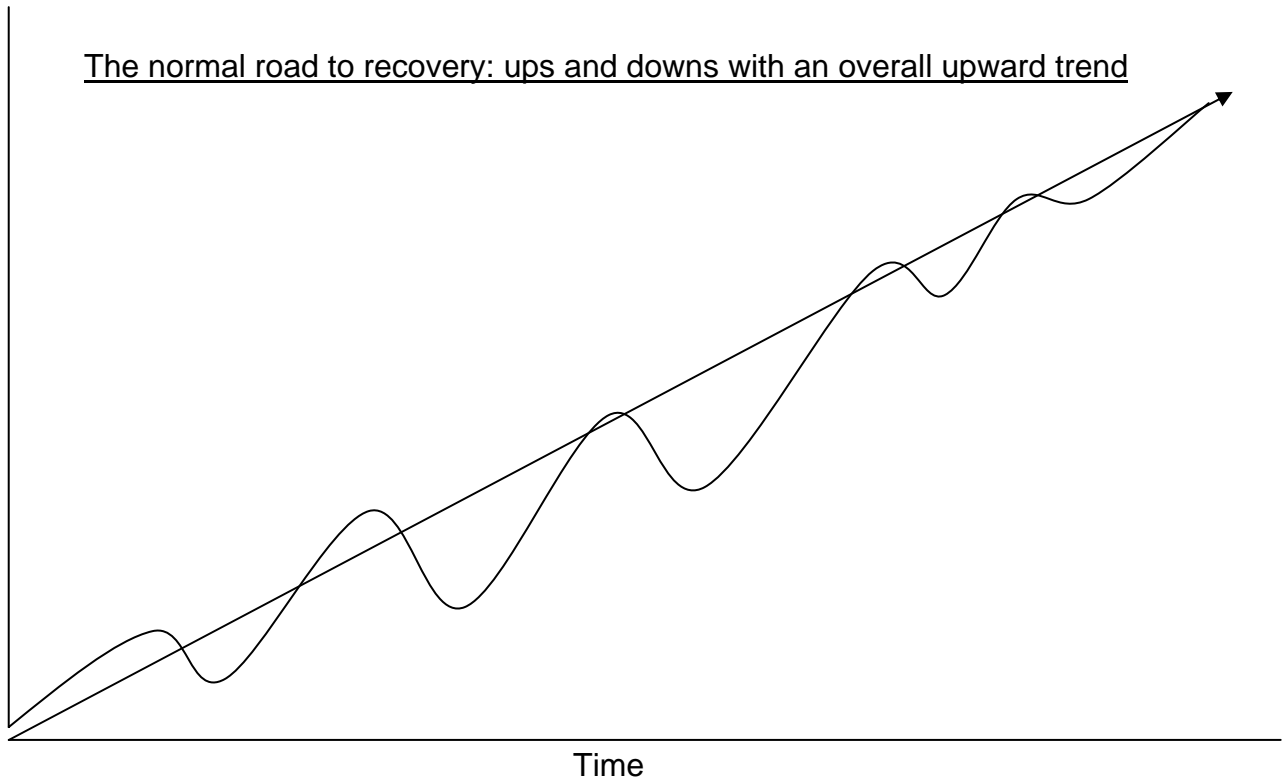
MOTIVATING YOURSELF

Different things motivate different people. For some, the most satisfaction comes from seeing themselves achieve their goals; for others, they may enjoy telling others about their progress. Here are some ideas that may help you to keep to your programme:

1. Keep a written plan at all times
2. Write down details of your exercise or physical activity achievements
3. Keep lists of plans and tick them off once you have done them
4. Keep a diary outlining all the things you learn from your GET programme
5. Tell friends and family about your plans and progress
6. Reward yourself when you have stuck to your plans, e.g. putting some money aside every time you undertake your plan and save for something special
7. Frequently go over your written plans and old exercise sheets and see the progress you have made
8. Become familiar with the GET theory
9. Draw a graph of the progress you are making so that you can see your exercise time going up
10. Do your activity or exercise with other people: walking at lunchtime with a colleague can be more motivating than going out alone
11. Become involved in a club or gym, if so advised, so that you can become committed to your plans and enjoy them with others, e.g. sports club or team, gardening group, walking group.

DEALING WITH SETBACKS

Setbacks are a normal part of getting better. Learning from setbacks and making changes to avoid them or cope with them better is an essential component to your feeling better. Therapy usually follows an 'up and down' pattern, but with an overall upwards trend:



The good news: it is normal for setbacks to become less severe, more manageable and last for less time as you get better.

It is important to remember that despite a setback, creating a 'dip' (as seen above in the graph), the overall trend is usually upwards. It can be useful to remind yourself of the progress you have made at this time to ensure you can see the overall upward trend during a difficult time.

What is a setback?

You may be familiar with setbacks: in this context, we are referring to an increase in symptoms that occurs, usually after an increase in activity or for some other reason, that significantly affects your ability to undertake activity for as time-limited period. The cause, severity and duration of setbacks can be variable.

How can I tell the difference between a setback and other illnesses?

A setback usually involves a worsening of your normal CFS/ME symptoms, or sometimes can involve additional symptoms that you may already be familiar with. However, sometimes it can be difficult to tell the difference between these symptoms and something else, like a cold or 'flu, as the symptoms can be very similar, e.g. sore throat, aching muscles, headaches. It is important to try to tell the difference between these as you may do different things in different cases to get better.

To help work out the difference, it can be helpful to think about the symptoms you are getting: are the symptoms your normal CFS/ME symptoms in a more intense form, or are there different symptoms common to illnesses such as a cold? Do you have a runny nose, for instance – or are you sneezing after visiting children who have had a cold? Do you have a cough that involves phlegm in your chest? Do you have a high temperature after measuring it with a thermometer? (sometimes we can feel hot, but not objectively have a raised temperature).

If you have a cold/cough then it is useful to reduce what you are doing for a short while and not exercise at a high intensity: try to go out for a short walk every day and maintain as much physical activity as you can without making you feel worse. Then, build up your activity as soon as you can, in a gradual way, as soon as you can – usually after a few days.

However, if you are not feeling well due to a CFS/ME setback, then the advice is different:

Dealing with a CFS/ME setback: what should I do?

During a CFE/ME setback, it is understandable that you might wish to rest and reduce the amount of activity you do, because you don't feel well and activity feels much harder than usual. This may even be a time in which you become concerned that the increase in symptoms may be causing you damage.

The evidence we have is in fact the opposite: there is no evidence to suggest that an increase in symptoms is causing you harm. It is certainly uncomfortable and unpleasant, but not harmful. In fact, there is much evidence to support the alternate view: if you rest too much, it is the resting that can cause negative changes in the body. Resting and withdrawing from activity can also make us feel fed up or worried, and this can also make it harder to continue being active.

The periods of excessive rest can be a time when the body adjusts to the lower level of activity and weakens: if the body weakens further, it can become more sensitive to activity and make overall symptoms worse.

Therefore, during a setback it is useful to maintain as much physical activity as you can. This is to avoid the weakening and tightening of muscles, and the reduction in fitness, which can occur surprisingly quickly (we can lose 10 % of our muscle strength in just one week of bed-rest, or even 1% per day).

Therefore, if at all possible, try to keep to your exercise and activity plan, knowing that in time your body will adjust.

Of course, if you are having a very severe setback, in which your previous level of activity is leading to distressing or unmanageable symptoms, then reducing activity slightly and increasing rest might be a temporary solution, as long as you build up again as soon as you can to your previous level. Building up again should ideally occur within a few days to avoid the detrimental effects of rest. Reducing activity should be avoided if at all possible.

It can be helpful to use other strategies during a setback, such as muscle relaxation, or gentle stretches that can relieve discomfort. Warm baths can also help your muscles feel more comfortable. It is also useful to try to avoid extra sleeping where possible, as this can make it harder for you to get back into physical activity.

WRITING A SETBACK PLAN

Because setbacks are a normal part of CFS/ME recovery, and it can be difficult at times to work out how to best deal with them, you are encouraged to think about how you might cope with physical activity and exercise in advance, so that you are prepared and feel confident that you know what to do: you can do this by writing yourself a 'setback plan'.

A setback plan is a written document that you have written that outlines what to do if you have a setback. It is kept in a safe place that is easy to find, so that you can read through advice you have written to yourself if you need some extra support or direction at that time.

You can imagine that it is a bit like offering good advice to yourself, or perhaps thinking about what you might like to tell a friend in a similar situation.

A setback plan can therefore include some practical advice, as well as describing the rationale behind your plan.

Example of a setback plan: (your plan might have some differences)

1. Setbacks are a normal part of recovery: it is the overall trend that is important
2. Setbacks are likely to become less severe and last for less time than previously as I get stronger
3. I should try to maintain as much physical activity as I can, even though this may feel more difficult than normal
4. I need to remember that there is no evidence to suggest that my symptoms are causing me any harm, even though they feel very uncomfortable
5. I should try to keep to my physical activity or exercise plan as much as possible, in order to maintain my physical health during this time
6. Resting too much may feel like the right thing to do now, but in the long run

is likely to worsen my condition

7. Resting for a week could lead to my muscles weakening by 10% - this will make it much harder to get back to the activity I was doing
8. I can reduce activity if I absolutely have to, but should try to avoid this where possible and build up again as soon as I can
9. I should try to get back into any activity I have avoided as soon as I can

THINKING ABOUT THE FUTURE: MAINTAINING POSITIVE CHANGES

This GET programme will equip you with a great deal of knowledge about your condition and how to manage it by taking notice of your physical activity and exercise. It is useful to think about how you will maintain the changes you have made and how you may continue to get stronger from discharge onwards.

Taking on the programme yourself

You will notice that as you progress, your physiotherapist will be keen for you to make decisions regarding physical activity and exercise for yourself. This is so that you can feel confident in working without a therapist to support you after you have been discharged. Try to be aware of the reasons behind making certain decisions about exercise, and become familiar with the process of increasing physical activity.

Involving friends and family

It can be very helpful to tell friends and family your plans and the goals that you are heading towards, and to share your progress with others. If you think it would be useful to include a good friend, partner or family member in your GET sessions, you are welcome to involve them and invite them to attend. Some people find this a helpful way of ensuring that they take in important information, as well as helping to support them.

Keeping written records for yourself

You are encouraged to keep a book to write in, so that you can summarise your GET sessions and keep a log of what you are learning at each stage. You are welcome to take notes in your GET sessions, and are encouraged to keep recording and monitoring your exercise.

Thinking about your onward plans and goals

It can be useful to keep setting yourself goals and challenges to focus your ongoing recovery after you have been discharged. You can use the goal sheets and exercise

questionnaire again to help you work out where to go from here. You might decide that you wish to join a sports club or gym for example, now that you are stronger, or perhaps you have decided that the goal you first decided upon is no longer appropriate or relevant. Continuing to challenge yourself can give you the focus and motivation to continue to improve from here.

Maintaining your physical capacity

Your improvements will continue as long as you maintain your level of activity and exercise. It is crucially important not to stop exercising after discharge, but rather to continue maintaining or building upon the changes you have made. Establishing a routine of physical activity and exercise is essential to keep your good health and to prevent symptoms in future.

Preventing disease and keeping good general health

Physical activity and exercise has been shown to be a major factor in preventing various diseases and cancers, and has a direct link to good physical and mental health. Therefore, maintaining your exercise serves not only to keep you well with regards to CFS/ME, but has a wider role in keeping you healthy in the long term.

FUTURE GOALS

Where do I go from here?

By the end of the GET programme you will have learnt how to manage and increase your tolerance to exercise in order to increase your fitness and general well being. You will have had experience at setting realistic goals and how to break them down into manageable achievable steps. You may have experienced setbacks and barriers to achieving the goals you had chosen, and will have worked through solutions to these with your therapist.

All of these skills will help you to approach new challenges in a realistic and graduated way and allow you to know how far you can push yourself and how your body will respond. Your physiotherapist may have acted as an initial facilitator but by the end of the programme the emphasis of helping yourself will have been put to you, making you now ready to face new challenges with many tools in your possession!

Where to start

By now you are likely to have improved your fitness and physical strength, and are likely to find that you will be able to do many daily tasks more easily. Activities that were initially part of your programme may now be normal daily tasks and it is very important to maintain these changes and current physical capacity level, whilst potentially working towards new things.

The goals that you originally set may be completed or close to being completed by now. In order to maintain this progress and aim towards new achievements certain aspects need to be considered.

Current goals

Can the goals that you originally chose be expanded or increased to challenge you further?

For example if you had chosen walking as your activity but have always wanted to try hill walking, why not think about expanding your current goal to being able to walk on an undulating terrain and then continue to build up your tolerance to walking up hill in preparation?

New activities

The goals that you had set initially may have been a start point and background towards developing a different activity – is there anything that you want to progress onto?

For example, if you had always wanted to start playing a team sport and had achieved walking or jogging as your activity, why not think about breaking the new sport down into manageable sections until you are able to play a full game as part of a team – team sports are also a great way of meeting new people.

Lifestyle changes and diversification

Having built up your tolerance to exercise will have had a subsequent effect on your ability to do normal every day tasks. Your new goals do not necessarily have to be about physical gains. It may be more important to you to now use your ability level to become more involved with friends and family. It is important to make sure that your lifestyle has a balanced mix of different kinds of physical and restful activities.

If you had a goal of being able to walk a certain distance, perhaps now convert that into a functional task which requires the same ability that you could do with friends and family. For example, going for a countryside walk to a restaurant at a weekend, going trick or treating with your children, meeting friends for a day trip, or doing some voluntary work.

Maintaining motivation and direction

If you still have outstanding goals, and targets that you are working towards, it may be useful to use the paperwork to monitor your progress. This will keep a record of your achievement and act as a motivator to future challenges.

Motivation during the programme was partly maintained by your therapist and by the objective tests and measurements that you recorded (e.g. the walking or sit to stand test and heart rate and Borg scale record). Even though the programme is ended there is no reason why you can't use certain measures to keep a record of how you are progressing.

You could use the exercise record to show how frequently you are carrying out a task and at what intensity. The objective measures of the Borg scale and heart rate can give a measure your general fitness and fatigue when carrying out certain tasks. By keeping a note of how you feel and what other symptoms you have could show trends and improvements in your general health.

Keep a 0-10 score of how realistic it might be to complete a task – if you score higher than 7 it is likely that you will be able to achieve that task!

FUTURE GOALS RECORD SHEET

Goal number	Goal	How to record progress	Time scale	How realistic is the goal (0-10 scale)

NOTES ON USING THE FUTURE GOALS SHEET

- Goal number
This is the number of the goal and indicates which goal has highest priority
- Goal
A brief description of the goal including the activity, duration (e.g. the time the activity should be carried out for), frequency (e.g. how often it is to be achieved) and intensity (e.g. how effortful the task is, for example waking on flat or an incline) if relevant.
- How to record progress
What markers will you use to show how close you are to achieving that goal (e.g. the duration or frequency of the task, physical markers in the landscape or physical effort markers)
- Time scale
This is an idea of how long you may give yourself to achieve a certain goal – it can be days, weeks or months
- How realistic is the goal
This is a score from 0-10 as to how realistic you feel it is to be able to achieve the goal. On the scale a score of 0 would indicate that you felt the goal was highly unrealistic, whereas 10 would indicate that you felt the goal would definitely be achievable with no problems. Generally a score of 7 or above indicates a realistic likelihood of completing the task

Future goals

Breaking down goals into manageable sections

Goal 1: _____

<u>Step number</u>	<u>Description of step</u>	<u>Timescale</u>	<u>How realistic (0-10)</u>
<u>Step 1</u>			
<u>Step 2</u>			
<u>Step 3</u>			
<u>Step 4</u>			
<u>Step 5</u>			
<u>Step 6</u>			
<u>Step 7</u>			
<u>Step 8</u>			
<u>Step 9</u>			
<u>End goal</u>			

Future goals

Breaking down goals into manageable sections

Goal 2: _____

<u>Step number</u>	<u>Description of step</u>	<u>Timescale</u>	<u>How realistic (0-10)</u>
<u>Step 1</u>			
<u>Step 2</u>			
<u>Step 3</u>			
<u>Step 4</u>			
<u>Step 5</u>			
<u>Step 6</u>			
<u>Step 7</u>			
<u>Step 8</u>			
<u>Step 9</u>			
<u>End goal</u>			

Future goals

Breaking down goals into manageable sections

Goal 3: _____

<u>Step number</u>	<u>Description of step</u>	<u>Timescale</u>	<u>How realistic (0-10)</u>
<u>Step 1</u>			
<u>Step 2</u>			
<u>Step 3</u>			
<u>Step 4</u>			
<u>Step 5</u>			
<u>Step 6</u>			
<u>Step 7</u>			
<u>Step 8</u>			
<u>Step 9</u>			
<u>End goal</u>			

Future goals

Breaking down goals into manageable sections

Goal 4: _____

<u>Step number</u>	<u>Description of step</u>	<u>Timescale</u>	<u>How realistic (0-10)</u>
<u>Step 1</u>			
<u>Step 2</u>			
<u>Step 3</u>			
<u>Step 4</u>			
<u>Step 5</u>			
<u>Step 6</u>			
<u>Step 7</u>			
<u>Step 8</u>			
<u>Step 9</u>			
<u>End goal</u>			

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, summarises 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 organisation, 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 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 therapies as a way of helping people to return to work. Some employers will offer retirement or redundancy packages on health grounds.

EMPLOYMENT AND EDUCATIONAL SCHEMES

Below, is a list of organisations 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 Help line 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 Help line 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.

Link line

Link line is a free telephone help line service for adults. It provides information and advice on training, learning and work.

Link line 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 organisations 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 Organisations) (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 organisation 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.citizensadvicebureau

Please note: This section was correct and up to date in March 2004.

FREQUENTLY ASKED QUESTIONS

Below are a number of frequently asked questions regarding Graded Exercise Therapy. If you have any further queries, please do not hesitate to ask your physiotherapist.

What happens if I don't like exercise?

No problem. The important thing to know is that you can choose any form of activity – for example DIY, household jobs, craft work or gardening.

What type of activity or exercise do I have to do?

You decide. Your physiotherapist will ask you what sort of activity you would like to focus on. This may include any hobbies such as gardening, household chores such as hanging clothes on the line, or any form of exercise from tai chi to swimming.

Your GET program will then be jointly negotiated between yourself and your physiotherapist and will take into account activity levels and important factors such as sleep and setbacks.

Do I have to do it by myself?

No. If you would like to do your particular activity with others e.g. go for a walk with your partner or go swimming with your friends you are more than welcome to do so. In fact, doing your activity may be more enjoyable for you and can often help with motivation.

What happens if I don't have time?

We understand life can get very busy with work, family commitments, household jobs and friends. This is why your physiotherapist will work with you to individualise your Graded Exercise program to fit your particular lifestyle. We do not expect you to spend hours everyday at a gym! Remember that GET may include every day activities as your exercise such as hanging washing on the line, cleaning the house, DIY or gardening. Between yourself and your physiotherapist you can negotiate what activity/ies you can do and exactly how long it might take.

How do I keep myself motivated?

There are a number of ways to ensure you keep yourself motivated and achieve the goals you will have set for yourself. Exercise or activity with friends can be very motivating & enjoyable as mentioned above, even walking the dog can be an incentive! Sticking to a routine each day can also help you to remember to do your activity.

INFORMATION FOR RELATIVES, PARTNERS AND FRIENDS

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

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

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

FACTS ABOUT CFS/ME

What is CFS/ME?

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

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

What causes CFS/ME?

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

- An initial illness or a series of infections is often reported as the start of CFS/ME. Fatigue can develop in association with a "busy" or "stressful" lifestyle, whether at work or at home
- Stressful Life events such as bereavements, moving house, changing jobs, getting married, pregnancy, ending a long-term relationship may lead to increased vulnerability to infections and/or fatigue.
- Having high personal expectations and driving to do things "perfectly" can be frustrating, cause despondency and fatigue
- There is evidence to suggest that excessive training/exercising can deplete the immune system, making a person more vulnerable to infection.

What keeps CFS/ME going?

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

- Resuming normal activities too soon after an initial infection may sometimes delay recovery.
- Resting too much once an initial infection has subsided can cause its own set of problems. The body becomes out of condition quite quickly; the muscles, immune system and nervous system being particularly adversely affected. The problems which may ensue include: muscle weakness, being more prone to illness, feeling sluggish with poor memory and poor concentration.
- Alternating over-vigorous exercise with resting for long periods can inadvertently make

the problem worse in the longer term, as the body does not get used to a consistent pattern of activity or rest.

- An irregular bed-time or getting up time or resting too much in the day, may contribute to disturbed and unrefreshing sleep at night. Not sleeping well at night is likely to increase feelings of fatigue and other symptoms.
- Worries about activity making the illness worse may lead people to stop or reduce certain activities. This may lead people to feel frustrated and demoralised due to a changed lifestyle.
- Receiving advice from a variety of sources can lead to confusion, particularly if the advice given differs.

The debilitating effects of CFS/ME can lead to other problems e.g. financial difficulties, reduced social contacts or changing roles within the family. These difficulties can understandably trigger feelings such as frustration, and helplessness. These feelings which are a natural human response to stress, can lead to low` mood for some people and depression in others. Low mood can lead to a variety of problems including tiredness, which can further reduce the desire to be active.

GRADED EXERCISE THERAPY FOR CFS/ME

What is Graded Exercise Therapy (GET)?

GET is the use of regular, physical exercise to aid recovery from CFS/ME. With regular exposure to a low level activity, the body begins to adapt physiologically and gradually increase an individuals tolerance to carrying out that activity.

GET works directly with an individuals level of current ability, and is directed by that persons own goals and objectives. In other words, the activity that an individual decides to work with is related to what they want to achieve. For example, If a person would like to manage their home or garden better, GET helps to improve strength and movement to allow them to do this. If an individual would love to be able to walk their children to school or get back to playing an enjoyable sport, GET helps to gradually build up strength and fitness to achieve this.

What does the GET programme involve?

The GET programme consists of up to 15 sessions based over a 9 month period. During this programme individuals will learn about the physiological processes that occur in CFS /ME and how exercise can help to counteract and reverse these. They will be encouraged to choose a realistic physical activity based goal and work in conjunction with the physiotherapist to achieve this. They will be given information and equipment to help keep them on track.

Stabilising Physical Activity

A very common factor that contributes to the maintenance of CFS/ME is reduced activity and increased rest. As we explained in other sections of the manual ,the less the body does, the less the body gets used to doing. As a result physical changes within the body occur. These changes cause an increase in unpleasant symptoms that can be very distressing and often lead people to an erratic pattern of rest and activity dependent on how they feel.

People with CFS/ME can experience symptoms that may be so severe that they spend much of their time confined to home and days and nights then begin to run into each other. People may find that any activity is exhausting, e.g. normal daily tasks such as brushing hair, talking, walking to the shops, or doing the washing.

On the other hand, people may find that they can be reasonably active on some days, but as a result of “doing too much”, become more fatigued and symptomatic resulting in being unable to do very much on other days. This is what we refer to as a “boom bust pattern”.

For these reasons it is crucial that the first step of the graded activity program is stabilising physical activity. This may mean even doing a little less activity but more consistently than they were doing before. Through this, the body is given time to adapt to the amount of activity it is doing and as a result the person is not constantly trying to recover from symptoms.

How can I get involved?

Because the treatment is specifically designed for one person, you will have to discuss whether your friend or relative wants to share the information and the programme with you. If your partner, friend, or family member is happy to share the programme with you, there are many ways in which you can act as a motivator and a resource for them. If you want to read the manual and get an idea of what the programme aims to do and what is required in order to do that. Some patients find it useful to bring someone to a few of their sessions to act either as a memory jogger or a partner in planning the activity involved in the programme. If the person has chosen a certain activity, you may also want to carry out that activity with them. In this way the patient has a mini coaching system and you have the opportunity to increase your own activity and fitness (please be aware that you will be responsible for ensuring that you are medically able yourself to undertake exercise, and should ask your GP for further advice if you are not sure).

It is however vital that you do not encourage people to push themselves past their limits.

Despite being tempted to increase what you are doing by a small amount, it can prove severely detrimental in patients with CFS/ME. Therefore it is important to act as a motivator but to take into account what the physiotherapist is advising in terms of progressing activity. Most people who start graded exercise therapy and do not progress well do so for this reason. The balance of stabilising and gradually increasing activity depending on the physical symptoms experienced is essential in the GET process.

If the person wants you to be actively involved in their programme, it may be helpful for you both to set aside a regular time each week in which to discuss how they are getting on. This will give you the opportunity to reinforce their achievements, give encouragement when they are having difficulties and discuss any worries that you have in relation to their programme. It is important that you approach any concerns about their programme, whether you think they are doing too much or too little in a “non-judgemental “ manner and refer back to the physiotherapist with any unresolved concerns.

Setbacks can occur at any time. They are a “blip” in the recovery phase and certainly do not mean that GET has failed. Setbacks are more likely to occur in certain situations, for example if the person has another illness, moves house, has a bereavement, or has a number of deadlines to meet. These “stressful” situations may give rise to increased symptoms and an inability to maintain their programme. At these times, it is important to remind the person that setbacks are only temporary. Encourage them to read the appropriate sections of the manual in order to get back on track again. Setbacks should be viewed as a challenge to be overcome and not a disaster. If a setback occurs after the person’s GET sessions have ended, then encourage the person to devise a small programme for a few weeks, or until they feel they are managing better.

By the time that people are discharged from graded exercise therapy, they will hopefully be able to do more and need less rest. It is important to encourage them to continue with a balance between different kinds of activities and rest. Breaking this routine or stopping certain activities or resting at irregular times may lead to a risk of sliding back. As long as a

good balance of activity and rest is maintained, then recovery will be sustained. They may gradually make quite substantial changes to their lives, e.g. returning to work, starting college, and taking over household responsibilities. Although a sign of progress, making these changes can sometimes be frightening, particularly if the person has been ill for some time. Your support and understanding is likely to be highly appreciated.

Finally, once one activity has been achieved, it is important to encourage diversification of activities. This may allow the person to meet new people and transfer the skills obtained into different settings.

If you would like further information on how to support your friend, family member or partner, please feel free to discuss this with the physiotherapist.

GET PLANS AND PROGRESS

Date:

Session Number:

Review of previous session plans: *(To be completed at the next appointment)*

GET Plans and Progress

Date:

Session Number:

Review of previous session plans: *(To be completed at the next appointment)*

GET Plans and Progress

Date:

Session Number:

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