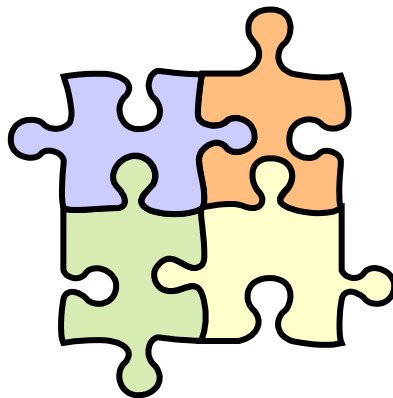


CFS/ME

Self Management

Workbook



South and West Devon CFS/ME Service

Team base: Castle Circus Health Centre,
Abbey Rd, Torquay TQ2 5YH

Tel: 01803 217721 email: swdevoncfsme.sdhc@nhs.net

How to use this Manual

Professional/Therapist Support – You may wish to consider working through this manual with the support and guidance of a community Occupational Therapist, Clinical Psychologist or a professional knowledgeable in CFS/ME. As discussed in the Self Management overview manual, it is challenging to make changes to your life.

Reading - This manual is designed to help you become aware of your habits and routines in your daily life. There are a lot of different concepts for you to think about so give yourself time to work through the manual slowly. It may look very large and unmanageable as a whole, but remember you are going to be working through it in small steps.

The manual has a star system to guide you. There is a line of stars to mark the end of each section. When you reach the stars it is a good idea to **stop at that point** and consider if you need time to reflect or stop completely for that day.



Taking Notes - There is a couple of blank notes pages at the back of the manual to write any of your own thoughts. This will act as a reminder when you revisit the manual and it can also be useful if seeing a therapist.

Contents

Tick the sections you have read and the exercises completed

1. Getting the balance right

Questions to ask yourself

Exercise – energy used in activity

Exercise – high, medium and low

2. Rest and relaxation

Exercise using the relaxation CD

Exercise – relaxation monitors

3. Activity Management

Exercise – completing an activity diary

Questions to ask yourself

Exercise - jug of life

4. Adapting activity

Exercise - stopping point

Exercise - getting the balance

Exercise - recovery kit

5. Managing flare-ups and setbacks

Exercise - reflective questions

1. Getting the balance right

Introduction

When asked 'what did you do today' most of us will respond with 'oh this and that' or 'pottered around' or 'can't really remember'. If we are to look at 'saving energy' or 'using it effectively' we must first be able to recall what we are doing. Within the real world, getting the balance right is very difficult as there are lots of aspects of life we can't predict or feel we can't control. With CFS or M.E, the aim is to manage the core aspects of daily life to allow extra energy for those unplanned events.

The most common symptom of CFS/ME is a limited supply of energy. It is recognised that the level of fatigue can be worsened by increased levels or complexity of physical, mental and emotional exertion or activity.

Every task we undertake, from getting out of bed each morning to undressing for bed at night requires energy. It is a pattern of 'supply and demand'. If our energy supply is low or disrupted and activity levels are high, the body cannot meet the demands of our life. In CFS/ME the severe drop in energy capacity means that even minimal activity can lead to exacerbation in fatigue levels.

However activity management is not necessarily about increasing or decreasing activity. It is often about adapting or replacing high level activities with those of less demand.



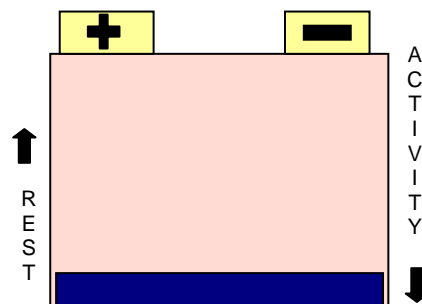
The Human Battery

People with CFS/ME often report not being able to recover fully after sleeping or resting and describe this as having a 'flat' battery.

Of course, the human body does not actually have a battery. Many of the body's systems have a role to play in creating energy. Our respiratory and circulatory system transport oxygen, the digestive system releases energy from food, hormones can regulate our energy supplies and the nervous system instructs the body parts to function and utilise energy. For most people with CFS/ME, on 'good days', energy levels are still significantly lower than before having the condition.

There is a tendency to be as active as possible when the energy is there, which can result in a flattening of 'the battery'. Then there is no choice but to rest or stop activity completely. This is known as the 'boom and bust' pattern of activity. Symptoms may begin to increase but they are ignored and 'pushed through'.

Alternatively some people try to avoid flattening the battery by staying within very small activity levels, but this means they can feel stuck, bored and frustrated, and they may be worried about doing more, for fear of exacerbating symptoms.



It is important to manage energy expenditure. The idea is to avoid flattening the battery and allow opportunities to build energy levels gradually over time. This is done by using smaller amounts of energy at any one time and spreading the total energy used over longer periods. This may mean prioritising the most important tasks or finding alternative ways to do things. By managing energy and leaving a small supply in your battery, the body has some reserves to put towards the recovery process.

‘Generating’ energy

It is important to explore how to generate energy as well as thinking about how we spend our energy. We will look at the activity itself and the periods between activity. People often believe that sitting or lying down is *rest* and it is important to understand the difference between not physically moving and actually *relaxing*. Relaxation strategies can be used to improve quality ‘rest’ which will help the production of energy. People often say that when they are sitting down resting, their minds are still very active, thinking about the things they should be doing. By learning how to relax both your mind and body you can help recharge your battery. There are also other ways to improve your supply of energy, which we will look at later in the manual.

Jump starting the battery

The body has an emergency energy system that can be used in a crisis or when we need to really push ourselves to do something important to us. In these situations we can use our body’s emergency response system to produce short-term supplies of energy. Some people describe this as ‘running on adrenalin’.

This may help us to get through the situation but will increase our fatigue levels afterwards as the body tries to recover. For example, if there was a fire in your house you would have a sudden boost of energy to help you to escape, but would suffer for this later.

Sometimes using this additional boost can be helpful, as it may enable you to do something you really want to do and so feel better in yourself, despite needing to increase your rest afterwards. But if you were doing this all the time it wouldn’t help your recovery. This is like eating some chocolate cake when you’re dieting. You can get away with it sometimes but not all of the time!



Questions to ask yourself

- **Do I flatten my battery or am I stopping before this happens?**
.....

- **Could I use my energy differently?**
.....

- **When I rest do I really relax or just sit/lie down?**
.....

How am I spending my energy?

Before starting to change our daily patterns of activity we first need to understand more about the things that we do each day. Usually in life we do things without thinking about them first. Our everyday life becomes automatic. However, with chronic fatigue, it's best to **think before you do**. This can be very difficult when we are so used to just getting on with life. Most of us do not realise the number of complicated processes and factors which all have to work together to enable us to do even a simple task, such as writing a letter.

Although it is not necessary to be able to understand all the changes that occur in your body to allow it to move and function, it is important to have an awareness of the variety of factors that can influence your ability to perform a given task. People who have CFS often say they have 'done nothing all day' because they are comparing themselves to their previous lifestyles, and don't think about the way small, everyday jobs can affect their fatigue.

They may also be unable to identify anything in their routine that has led to an increase in fatigue levels because they are focusing on physical activities and forgetting that energy is needed for all types of activity, including emotional, mental and social tasks. Therefore, the first step in managing fatigue is to become more aware of our everyday lifestyle and the energy that is needed for all the things we do.



Exercise – Energy Used in Activity

Write a list of all the activities that you can think of, whether you are currently doing them or not. Think as broadly as you can. Then work through your list, and tick whether you think each activity would be **high, medium, or low**, in relation to its energy requirements for you. Remember energy used can be either mental, emotional or physical energy.

You can assign an activity to more than one category if you feel that other circumstances may determine how much energy the activity would require. For example, walking could be high, medium or low, depending on whether you were walking around the house, going to the shops, or doing a strenuous walk.

For example:

Activity	High	Medium	Low
Dressing	✓		
Washing up		✓	
Phone Call		✓	
Paying bills / organising money		✓	
TV			✓
Rest			✓

NB: Some days you may feel an activity takes more or less energy than before. You must make each decision on how much energy you felt you *used at the time of that activity*. e.g. A phone call from a friend in need may use up more energy than a phone call from a friend in good spirits. Notice how you feel doing one activity compared with others. For example, is watching television really **low** or is it **medium** compared with relaxing in the garden or on the bed?

Exercise – High, medium and low

Think about and record the things that influenced your decisions about whether to tick high, medium or low for each activity.

- Are there any aspects of the task itself that makes it harder, such as standing for a long time?.....

- Do you generally find particular types of tasks harder, such as physical or mental tasks?.....

- Did it **depend** on lots of other things, such as:
 - where you were doing the activity (quiet room, noisy, uncomfortable)
.....
 - whether other people were involved
.....
 - when you were doing the activity (time of day, in a rush, planned)
.....
 - whether it was a good day or a bad day?
.....

- Did whether you enjoyed the task make any difference?
.....

- Was it harder if emotions were involved, such as stress or conflict? Or when doing something to meet others' expectations?
.....

It is only by questioning yourself that you start to increase your awareness of the complicated nature of apparently simple things. This is why when you try to make changes to your daily routines; you find that there are no magic formulas or simple answers. You need to learn how to think about activity and how it affects you and your fatigue, as this will be different to someone else with the same condition.

The next section focuses on activity and how we think about it, in more depth. We consider ideas about changing how we live our daily lives, but you will need to experiment with activity to find the right balance for you.



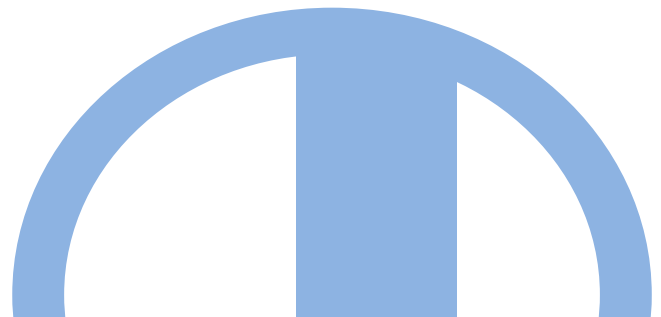


2. Rest and Relaxation

Rest is an essential part of activity management. When we are resting effectively there is minimal brain and body activity enabling the body to recharge. It is important to get the right amount of rest for you. Too much and you will start to become reconditioned and lethargic. Too much rest during the day may have an impact on night time sleep and upset your natural patterns of waking and sleeping hours. Too little rest can result in an increase in symptoms and a perpetuation of the boom and bust pattern of activity. If you think of all the activity you have to do in a day as a bridge (see diagram), several pillars of rest are needed to support that bridge. If you push on through, ignoring your symptoms, you may be forced to take a longer period of rest but this may not be effective in terms of supporting your 'bridge of activity'.



Regular pillars of rest
supporting bridge of activity



Large pillar of rest
ineffective in supporting bridge of activity

Effective rest is a challenge. People with CFS/ME can find it hard to relax. It can be difficult to turn down the sensory overload. It can also be difficult to relax if you are constantly thinking about what you feel you should be doing. Relaxation techniques may be helpful in learning to rest effectively.

Relaxation

Experiment with the techniques described in the relaxation CD provided, and find one that works for you. It may increase your awareness of how relaxed you could potentially feel. This, in turn, may help you recognise other activities in your lifestyle that have a similar effect. You may wish to continue exploring relaxation and look into other techniques or methods. New skills take time to learn. If this is a new skill for you, take time to become comfortable with the techniques and slowly incorporate into your daily routine.

Exercise – Using the relaxation CD

Dip in and out of the CD, trying one method at a time. This will help you assess which style of relaxation suits you most.

CD Content	Listened to \checkmark
Introduction	
Guidelines for Practice	
Breathing Technique	
Tense and Relax	
Passive Muscular	
Autogenic	
Special Place	
Visualisation	

Exercise – Relaxation Monitors

Note the level of tension you are experiencing prior to the relaxation and after.

Technique Used	Tension before (0 = no tension 10 = max tension)	Tension after (0 = no tension, 10 = max tension)
Breathing Technique		
Tense and Relax		
Passive Muscular		
Autogenic		
Special Place		
Visualisation		

Technique Used	Tension before (0 = no tension 10 = max tension)	Tension after (0 = no tension, 10 = max tension)
Breathing Technique		
Tense and Relax		
Passive Muscular		
Autogenic		
Special Place		
Visualisation		

Technique Used	Tension before (0 = no tension 10 = max tension)	Tension after (0 = no tension, 10 = max tension)
Breathing Technique		
Tense and Relax		
Passive Muscular		
Autogenic		
Special Place		
Visualisation		

3. Activity management

Once you start to understand all the different things in your everyday life that require your energy, you can start to think about how you could make changes to using the energy that you have in the most effective way. The way we did an activity in the past may have worked for us then but does it work for us now? Could you do some tasks differently to reduce the amount of energy used, for example sitting to do something rather than standing, or getting other people involved?

No two individuals are the same! This seems like an obvious statement but it is amazing how many of us compare ourselves to others or to our past achievements, and then question why we fall short. You may be feeling at the moment that you ‘can’t do anything’, because you are comparing yourself to the past. But the starting point for improvement is to first look at the here and now. If you do not have a clear picture of what is happening now, how do you know what to change, and how will you know if you have changed it?

In the next stage of the process you can start to look at your daily life and where your energy is going each day, to try to find areas that you could adapt or change. As people have different ways of looking at things we have included 2 different approaches to starting to understand your patterns of activity.

The first is taking the *microscope* view, which involves looking in detail at each day, each activity that you do and how this affects your fatigue.

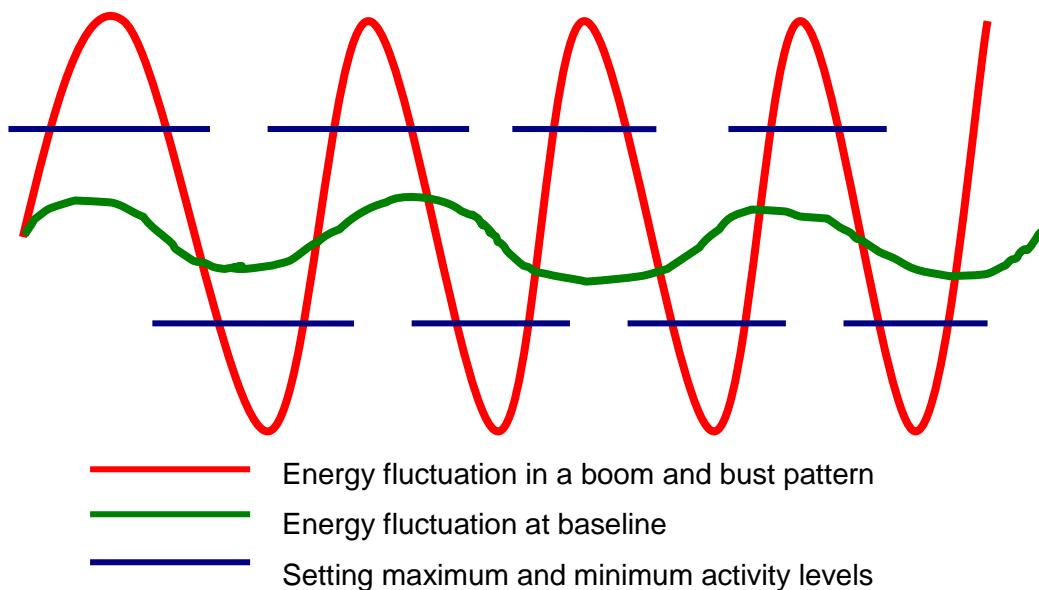
The second takes a *helicopter* view, which tries to look at the bigger picture of the different demands on your energy supply. These two approaches should begin to help you clarify what is happening in your life.



The Microscope Approach

Most people with CFS/ME find their fatigue levels will vary. At times you may feel that you have a little bit more energy and so try to do things while you can, but this leads to increased fatigue and longer periods of rest. This is the typical 'Boom and Bust' pattern associated with CFS (illustrated by the red line in the diagram below). The 'Boom and Bust' pattern can occur over the course of a day, a week, a month or even a 6 month cycle. Constant pushing through fatigue and ignoring symptoms will overload your system until it can no longer provide you with the energy needed to sustain this lifestyle.

Try to find a level of activity that you can manage that does not cause excessive levels of fatigue. Your fatigue level will still fluctuate (as illustrated by the green line) but by trying to avoid over-activity or excessive rest it stays in a more stable range. However each person is different so finding a manageable balance of activity and rest is a difficult process and it takes time to find what suits you.



Many people do not know where to start to find a balanced sustainable lifestyle. Some people try to do what they can manage on a good day, every day, which doesn't work. Others may follow what they feel their body is telling them to do, which can help to stabilise the symptoms but can be frustrating if they don't seem to be making progress. In order to find a starting point, it helps to gain an understanding of what you are currently doing. The next section focuses on this.



Activity Diary

An activity diary is a record of how time has been spent during the day. The important factors are to know the things that you did, for how long, and the effects on your fatigue or other prominent symptoms.

Warning - even healthy people struggle to remember all the things they have done in a day, If you also have memory problems, a common symptom of CFS/ME this can be doubly difficult. It will take energy to do a diary but if you can manage it, it will hopefully save energy overall.

The way that you record this information can be as simple or complex as you make it. Some people prefer to keep a detailed daily diary, and so require plenty of space to add descriptions, whilst others find this too time consuming and like to use general terms.

Use whichever approach suits you but to help a standard format has been included in this guide. It is useful to see the week as a whole as fatigue can often be delayed. Therefore it is important to be able to identify the things you did before the fatigue increased.

Exercise – Completing an Activity Diary

Use an activity diary to record your daily life over the period of a week. A version of a diary has been included on the next page. 3 weeks often provides a fair snap shot of your life.

- Make sure that you record rest periods through the day, and the times that you get up and go to bed.
- Colour code for the amount of energy you use on each activity.
- Use the fatigue scale to rate your fatigue as you go through the day. Try to think of 10 as the worst you have felt since experiencing fatigue and 0 as no fatigue. As you record each activity in your diary think about how far along the scale between 0 and 10 that you feel at that time.

This is not a scientific measure and can't be used to compare your fatigue to that of others, but will help you over time to assess if your fatigue levels are reducing.

Weekly Activity Diary - South and West Devon CFS/ME Service

Week 1 Beginning.....

Time	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
7-7.30							
7.30-8							
8-8.30							
8.30-9							
9-9.30							
9.30-10							
10-10.30							
10.30-11							
11-11.30							
11.30-12							
12-12.30							
12.30-1							
1-1.30							
1.30-2							
2-2.30							
2.30-3							
3-3.30							
3.30-4							
4-4.30							

4.30-5							
5-5.30							
5.30-6							
6-6.30							
6.30-7							
7-7.30							
7.30-8							
8-8.30							
8.30-9							
9-9.30							
9.30-10							
10-10.30							
10.30-11							

Rating of Fatigue When a Change Noticed 0 = No fatigue 10 = Worst Fatigue ever experienced
 Note the rating figure next to your activity NB: Group half hours together if doing the same activity

Key to amount of energy expended. This incorporates mind, body and emotional energy use.

Blue = Low

Green = Medium

Yellow = High

Pink = Very high

Clear = Resting/Relaxing

Reflecting on Your Activity Diary

The most important aspect of an activity diary is learning from it. They are only helpful if they help you to understand more about how you are using your energy.

Boom and Bust (fluctuating levels of fatigue)

This is the most common pattern where fatigue levels fluctuate. You may already be able to see the changes in your energy levels when you look at your diaries. Here are some different options for using your diaries when you have fluctuating levels of fatigue.

To start to identify patterns to your fatigue levels you can use the colour coding suggested. This will illustrate more dramatically any patterns of boom and bust.

Marking pleasurable activities in another colour can highlight any loss of these activities. You may be focusing on activities that you feel you should do and leaving out activities that you enjoy.

Another good starting point is to ask yourself what you noticed when filling in the diary. The main problems may be obvious, e.g. large time periods spent on one activity. Managing activity is often about common sense solutions. You may be already aware of what is not working but are stuck as to how to change this. People are often able to identify where they have pushed past their energy limits but find it difficult to stop doing this.

Try to see if there are any patterns in each day. For example, is all activity in the morning and all rest in the afternoon? To reduce the boom and crash cycle you will need to focus on balancing out activity through the day, as in the mix and match principle, to be discussed later in the manual.

Remember one of the commonest problems people with CFS/ME have is when energy levels rise they tend to over increase their levels of activity which leads to increases in rebound fatigue. Sometimes people know they are doing too much on their 'good days', but don't want to 'give into' the condition or find it hard to change how they have always been. But to achieve a balance, try first to reduce the fluctuations in fatigue to a more stable pattern, and then gradually build up the levels of activity.



Questions to ask yourself

Useful questions to ask yourself when reflecting on your diary:

- **Is there a good balance of activity, mixture of different colours?**

.....

- **Is there a pattern to your fatigue ? i.e. certain activities that increase the score?**

.....

- **Which day have you found to be most difficult this week?**

.....

- **What do you feel may have triggered the increase in your fatigue on that particular day?**

.....

- **How could you have done the activity differently?**

.....

.....



No Change???

Some people find that their fatigue levels are not changing. This may be because they have already limited any activity to avoid higher levels of fatigue. Or it could be the pattern has changed from a fluctuating to a more level pattern.

If your fatigue levels have improved overall but now seem stuck at around the same level (for example 6-7), this may indicate that you have found your baseline, and that you need to start applying the grading strategies in the next section. Alternatively you may have had some improvement by adapting and grading your activities and have now plateaued. In this case it would be useful to review your diaries and see where some small changes to increase your activity can be made. It may be useful to ask for a therapist for comment.

However, if you find your fatigue levels are high (for example always around 8-9) even though you have restricted yourself to very low levels of activity, this can sometimes need a different approach. If you haven't got any periods of over-activity to reduce, where do you start?


With this pattern it is important to remember that the human body needs activity in order to produce energy. Limiting activity too much can make us feel exhausted and lethargic. Activity is also needed to improve our mental skills, such as memory and concentration, and to maintain our confidence. If you consider people in situations where they have been forced to be more inactive, such as in some reality TV shows, their sleep cycle can be disturbed over time, increasing fatigue and lethargy, with sleep during the day. Our body is designed to be *doing*, so if there is nothing to do, it will not produce increased energy. Fatigue levels will increase, as will pain, as we become less mobile. Therefore this becomes a vicious circle. You are fatigued if you do things, but you are equally fatigued if you don't. Also the less we do the more fed up and frustrated we feel, and the risk of becoming depressed will increase.

It is very difficult when you are stuck between the 'frying pan and the fire' and the fatigue isn't reducing on its own. So you may have to very gently work through the high levels of fatigue, making very tiny steps forward (very slowly increasing levels of activity) despite the fatigue. In this case you are trying to remain around the same level of fatigue and avoiding making too big a step, which further increases fatigue levels. This is very difficult to do and can feel like walking along the edge of the cliff, but if nothing else is helping it is sometimes the only way to get to the other side.



Questions to ask yourself

Reflective questions to ask yourself:

- Has doing nothing or very little improved your fatigue or other symptoms?
.....
- What is likely to happen to your general health and your body if you stay inactive?
.....
- If you try to do too much activity this can make the fatigue worse, but will doing a very small amount of activity make any difference?
.....
- What are the benefits of doing a little bit more, physically and psychologically?
.....
- If you are doing very little anyway does it matter if you have to rest more so that you can do something you enjoy? 
.....

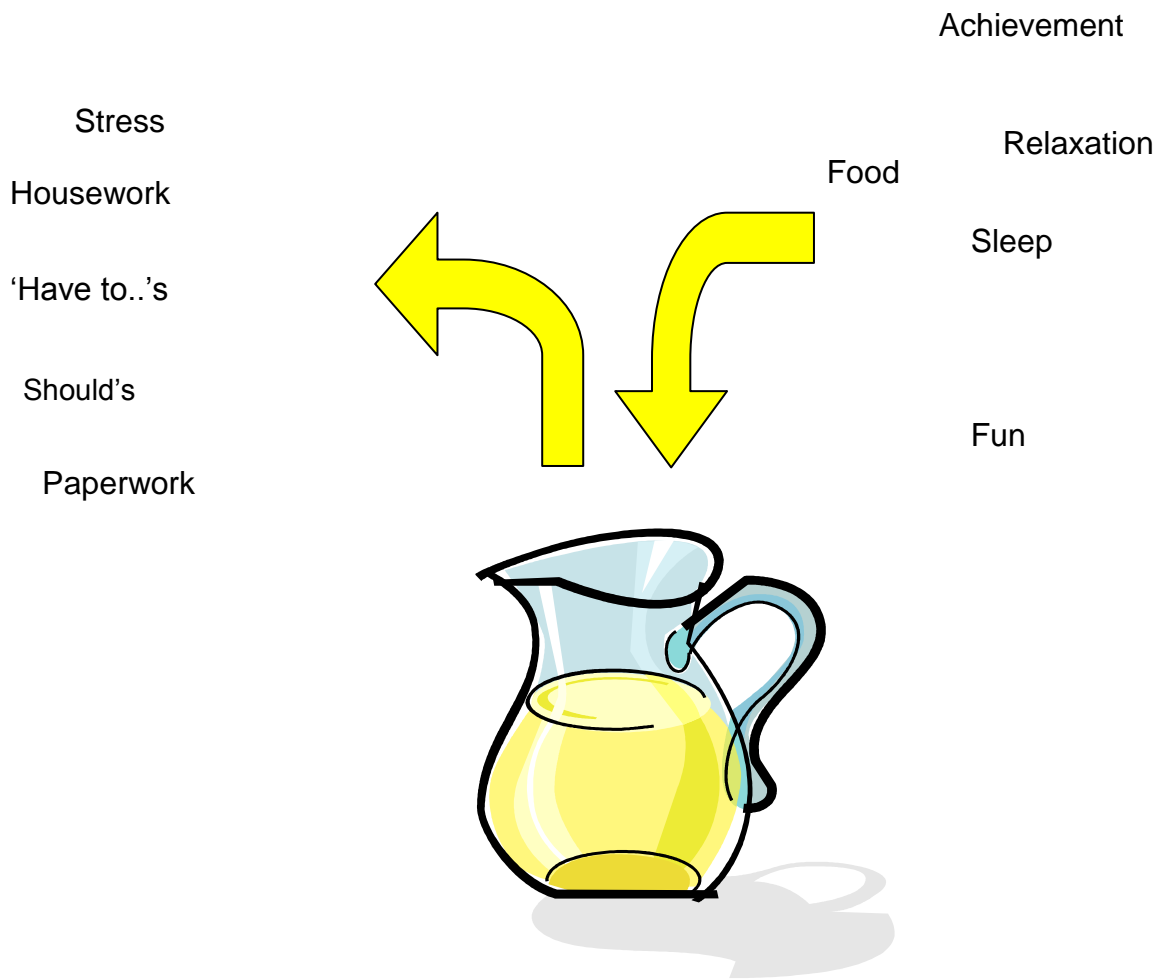


The Helicopter View – Seeing the bigger picture

Earlier we looked at the complexity of activity, and how many different things can influence the way in which we live our lives. Fatigue can be affected by a broad range of factors, not just how much energy we spend on each individual task.

For many people focusing in detail on how they are using their energy, by recording activities, helps them find a starting point before making changes.

The activity analysis approach does not suit everybody and for some people, there may be specific key factors impacting on their fatigue. There are many different approaches to change. One size doesn't fit all. In the next section, we will look at another model for understanding energy before looking at how to make changes to daily life.



Improving Supply

There may be things that we can do to help improve our supply of energy. For example, you may have looked at improving your diet or sleep (aspects of managing diet and sleep are included in other booklets).

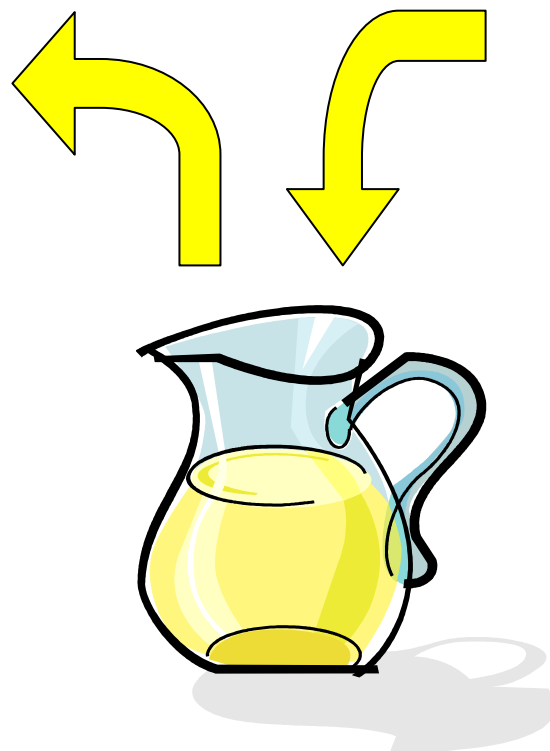
A helpful way to think about your energy supply is what we call the 'Jug of Life'. Inside your jug is your energy, which due to CFS/ME is now at a much lower level than before. Every day you give different amounts of your energy to all the things that your body and mind have to do. Some things will take more of your energy supply than others, like fighting an infection or dealing with stress.

But there are other things in life that give you energy. The first things we tend to think of are food and sleep, but many other things can give us energy. If we find something enjoyable or fun this can give us energy. If we feel we have really achieved something or feel proud about something this can give us energy. There are some activities that use energy, but we also get some energy back from them.

People with CFS/ME often focus on the things they feel they have to do, such as housework or sorting the bills. These are activities which probably give little enjoyment or satisfaction, so put nothing back into the jug. Whereas, activities that are seen as less important and therefore a waste of energy, such as interests or time with friends, are the first to be sacrificed. However these activities may be the things that help top up our energy supply.

Exercise – The jug of life

Can you identify what improves supply and what drains energy from your ‘jug of life’



Decreasing Demand

The demands on our energy can be positive and negative and come from lots of different sources, such as family, work, running a house, etc. They can also come from the pressure of trying to meet our own expectations or standards. It can therefore be helpful to identify whether any of these things could be done differently. Could anyone help with these demands, or do they need to be done at all!

Sometimes we have demands that we can do nothing to change. If it really is the case, that they can't be managed differently and if you don't have enough energy to do them all, then you might identify that your fatigue isn't going to change until something else on the balance

changes, such as your financial situation or support from others. This exercise will help you to look at areas of supply or demand that you could work on.

Incorporating Fun and Enjoyment

People who have CFS often feel guilty about not doing the jobs that they feel they should do, or are expected to do. So when they have any energy they push themselves to do activities that they feel they 'have to do' and sacrifice pleasurable and fun activities. But things that we enjoy or give us a sense of achievement can give us energy, and therefore are another source of supply for our energy balance.

To illustrate this point, think of a story of two men who run a race and both finish the race in two hours, using up the same amount of energy. For the first man this is the worst time he has ever run and he feels exhausted and frustrated at his performance. It might take him some time to recover from the effort of the race. For the second man this is the best he has ever done and although he feels fatigued he also feels elated and energised by his performance, and is more likely to recover quicker.

Therefore, sometimes even though you may feel fatigued by an activity it may give you satisfaction, enjoyment and help you feel more positive which can help to sustain you. This means that sometimes you might exceed your energy limits to do something you enjoy. Remember you will need to adjust your programme to allow for some additional rest, before and after a pleasurable activity, and reduce other activities to compensate for this.

Useful questions to ask yourself:

- What do I really enjoy or look forward to each week?
- Are there things I used to do but no longer do, because I would feel guilty about wasting energy?
- How did my fatigue feel the last time I did something I enjoyed?



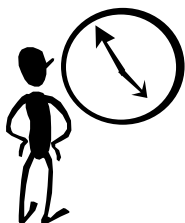
4. Adapting Activity

Once you have a more in-depth understanding of your current fatigue levels you can start to influence these, by changing your patterns of activity. All activities are made up of component parts and each of those components require energy. Therefore, some activities can be made easier by simply reducing the number of component parts involved. For example, if you do the ironing sitting down you are not using the additional energy required to stand. Activities can be made easier or harder depending on how we do them.

By understanding the different methods by which activity can be broken down, you can begin to understand the process of grading. The next section will describe the different ways in which activity can be broken into smaller parts, so that you can begin to grade what you are doing.

Breaking Down Activity - Ways to Grade

1. Time



The longer the period of time spent on an activity the more energy it will require. Time is the easiest way to measure what you are doing, and therefore used most often. You can set a baseline time limit for each activity, for example reading for 10 mins, and then gradually increase the time periods allocated to each task, so the next step might be 11 mins. The initial time period should be based on how long you can tolerate the activity for on a consistent basis without experiencing increased fatigue afterwards (in the next section we will look more at when to stop). Once this can be maintained the time period can be gradually increased for one activity at a time.

2. Distance



Distance is a more useful measure for any activity that involves motion, such as walking, swimming, driving etc. People can often be focused on reaching the end point, such as getting to the local shop, and find it difficult to stop before this point. So it may be hard for to see the point in only walking part way along the street, resting and returning.

The most important thing is to identify markers for each distance so that you know how far you have gone and can measure improvement, such as using lampposts on a street, or benches on a walk in the park.

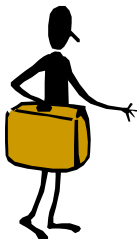
3. Speed



Speed is the combination of time and distance, the ability to perform the task faster. It is often the case with fatigue that 'more haste makes less speed'. When people try to hurry an activity they will make a higher number of mistakes and often experience an increase in rebound fatigue. Some people with CFS/ME would normally have done activity at a fast pace in the past (so they think fast, walk fast and talk fast).

Even though they now have fatigue, when they have the energy to do any mental or physical activity still tend to do it too fast. Therefore, the first step is to try to **reduce** the speed at which you do things. Increasing speed is not a useful focus for grading until the final stage of your recovery.

4. Strength



This relates to muscle power and stamina. Muscle bulk decreases through inactivity. People who have previously maintained high levels of physical activity may be frustrated by the effects of muscle de-conditioning.

Strength can only be regained in response to the demands of an activity, through gradually increasing the muscle power needed for the task. To grade any activity requiring strength, try to make the load as light as possible initially and then gradually increase. Some examples might be; for arms, gradually increasing the amount of weight carried in shopping bags, and for legs, this might involve increasing the number of stairs you are climbing.

5. Resistance



Resistance is tied to strength; the more resistance encountered the more strength is required to complete the motion. It is important when trying to make tasks easier that resistance is reduced wherever possible, for example walking along a level rather than up a hill.

6. Rest



People often use the word 'rest' to refer to when they are sitting or lying down. However you can still be using mental or physical energy in these positions, for example watching TV. This is therefore not 'rest'. It is important to think about 'quality' rest, when you really relax and let your battery recharge. How you rest is as important as the activity you do.

Prolonged periods of rest increase de-conditioning, and as the joints become stiff and the muscles weaken, it requires a greater amount of energy to start activity again.

Therefore, it is important to use rest as a pause within activity for the body to relax, but to try to avoid long periods of inactivity. If you currently chose to complete an activity all in one go before your 'energy runs out' you may find that by switching between short periods of activity and rest you can increase the total amount of activity you can complete.

7. Complexity



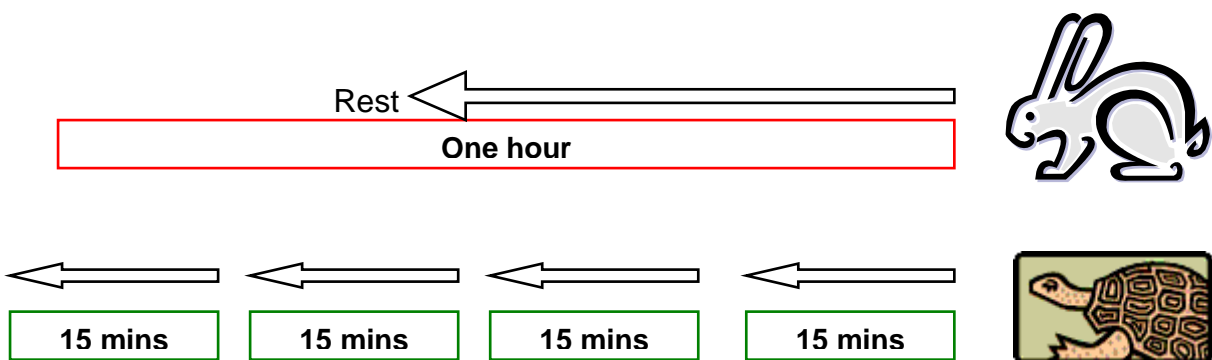
Complexity is an issue most associated with mental tasks. The more processes that are required to complete the task, the more energy it will require. People who are fatigued can lose the ability to concentrate on different activities at the same time, for example talking on the telephone and remembering a message. Therefore, to make tasks easier they need to be simplified. So it helps if you can **focus on one task at a time** and try to remove all distractions, such as background noise.



The Dangers of the ‘Starter-Finisher’

Some people live by the rule that when you start a job you have to keep going until it's finished. They find it very difficult to stop an activity in progress. This works well when you have sufficient energy to complete a task, but people with CFS often run out of energy part way and push their bodies to try to get to the end, like driving the car on the empty fuel light. This then reinforces the ‘boom and crash’ pattern. Often this also results in people not starting any activities they want to do because they know they won't be able to finish them.

But there is another way, which follows the story of the tortoise and the hare. Instead of racing to try to get to the end of the task and having to rest, like the hare, you can take the tortoise approach of taking small slow steps. It might be slower, which is frustrating, but by a steady approach you can get to the end of the job.

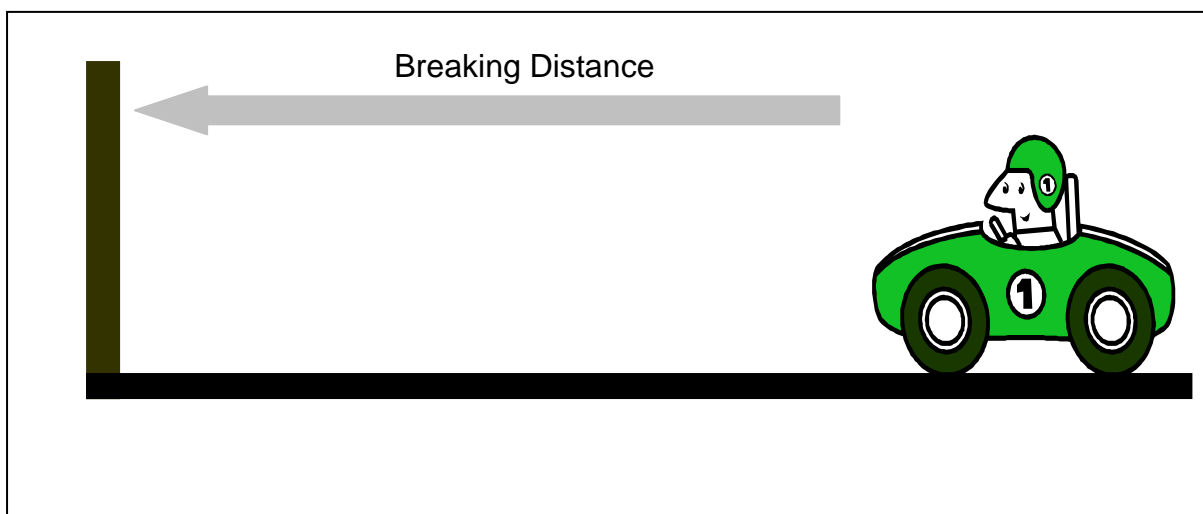


So take the example of trying to do some housework for an hour. If you tried to do this with CFS you might have to stop and give up after 30 mins or keep putting it off till you have a ‘good’ day and can face doing it. But if you did 15 mins at four times spread through the day you might manage it.

Setting the Stopping Point

One problem you may have is knowing when to stop an activity. Often people with CFS don't stop until they are beginning to experience significant increases in their symptoms. If we rely on our body to tell us when to stop we will already have done too much.

A helpful way to think about this is to think about the breaking distance for cars. If the car needs to stop to prevent it hitting a wall, the brakes need to be applied with enough time for the car to slow down, and avoid damage being done to the car. In the same way the body needs to stop before hitting the wall, not after starting to feel the effects.



Unfortunately the body has no indicators for when to stop so the breaking distance for each person can only be found through trial and error. You can only experiment with your stopping distance if you measure what you are doing currently and have an idea when you might hit the wall. With this information, you can set a time or distance, to allow you to stop prior to the crash. Test this out a few times to check if this is the right point for you to manage consistently, because you may have been having a good day or there may be a longer delay in your fatigue.

The next exercise will focus on how to start breaking down an activity and finding the point at which you should stop. If you can get this right with one activity you can then apply the same method to the other things that you do.

Exercise – Stopping Point

Select one activity that you would like to be able to undertake on a regular basis.

- *How could you break this down into manageable steps using one or more of the approaches that have been described?*
- *How are you going to measure each step?*

Write a plan for this week that includes the first step for your activity. Think about whether this needs to be done every day or at intervals through the week. Is there a best time of the day? Are you going to need any help?

Then try out your first step and record what happens. It may help to write down your fatigue level (using the scale of 1-10) before, during and after the activity to know more about its impact. If there is a significant increase in your fatigue levels, reduce your planned stopping point the next time you do it.

Keep repeating the process each time you do the activity until you find a level that does not significantly increase your fatigue levels afterwards.



In life we do not undertake activities in isolation; our day contains a varied combination of tasks, each with its own physical, mental and social demands. Therefore, how each activity interacts with the others within our day is vitally important. It is important to try to maintain a balanced day so that activities with a high level of similar demand are not grouped together in one time period, increasing fatigue.

Mix and Match

Trying to mix and match different types of activities within your day can help to maintain energy levels, as some parts of your body can relax and recover whilst others are working. A general rule is to try and set up a routine for yourself that involves short periods of different types of activity. For example changing between physical, mental and social activities and relaxation periods can be used to maximise the energy that you have or to prevent increasing fatigue levels.

Try not to do two things in a row that are similar, like reading and then filling in a form. Remember you may have different tolerances for different activities, such as for mental or physical tasks, so think about the stopping point for each one separately, based on what suits you.

An example from a programme may be:

Time	Activity	Type of activity
10.00	Washing Up	<i>Physical</i>
10.10	Rest / Relaxation	<i>Rest</i>
10.30	Read paper	<i>Mental</i>
10.45	Phone a friend	<i>Social</i>
11.00	Rest / relaxation	<i>Rest</i>
11.20	Watched TV	<i>Mental</i>



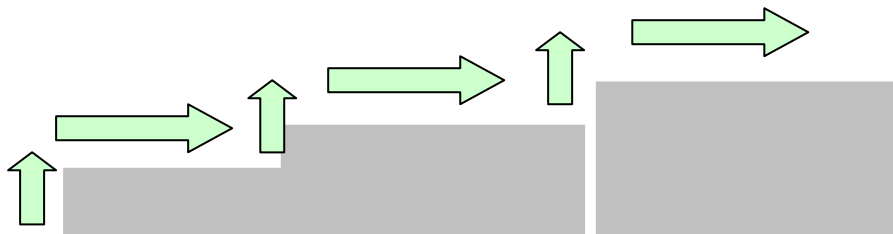
Making the Grade

The word 'grading' means to arrange in degrees and to reduce to easy gradients (Oxford English Dictionary, 1998). Grading implies movement or progression in moving through levels of activity.

Stabilising your fatigue levels is only the first step in managing fatigue. This can take a long time but once achieved, you can start to focus on increasing what you can do.

There is no set formula for each increase. We can't say, for example, increase each activity by 5 minutes per week, as this doesn't take account of how you respond to each increase and whether this is too big a step for you.

It is important to understand that the pattern of grading activity is like a staircase, not a slope. **Whenever an increase in activity is made this level needs to be maintained before another increase is made.** This is important as the condition can have a fluctuating pattern. If you make increases during periods of improved energy, which you can't sustain when energy levels reduce, this can increase the 'boom and crash' effect.



So try to make each increase small enough for your body to cope with. Try increasing by around 10% of what you currently can manage. It is better to start by making very small steps rather than making a big change followed by a crash which can be demoralising and de-motivating. As you improve the steps often become bigger but it is important to be realistic at the beginning.

Exercise - Getting the Balance

Make a list of things that you are currently able to do that you enjoy or help you to feel relaxed. Add any activities that you think you could manage but haven't been doing for other reasons.

Think about how you could incorporate these within your routine.



Exercise – Recovery Kit

We have mentioned fun, enjoyable activities that will put energy/resources back into your 'jug of life' or system. When having to manage a complex condition we can lose sight of what these are.

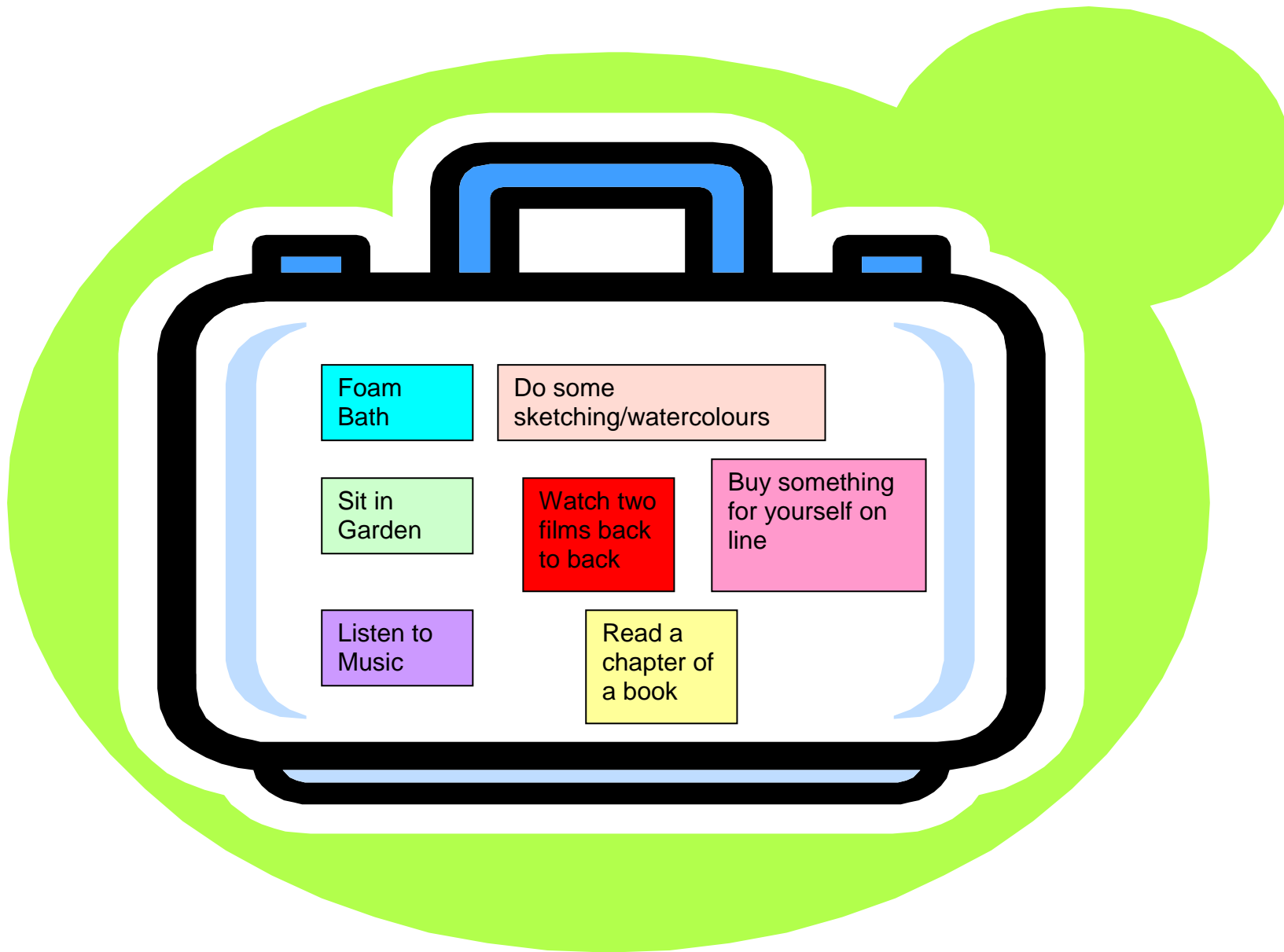
Take a look at the example and then take a moment to complete your own. You may wish to do this over a period of days and keep adding to it when you think of something else.

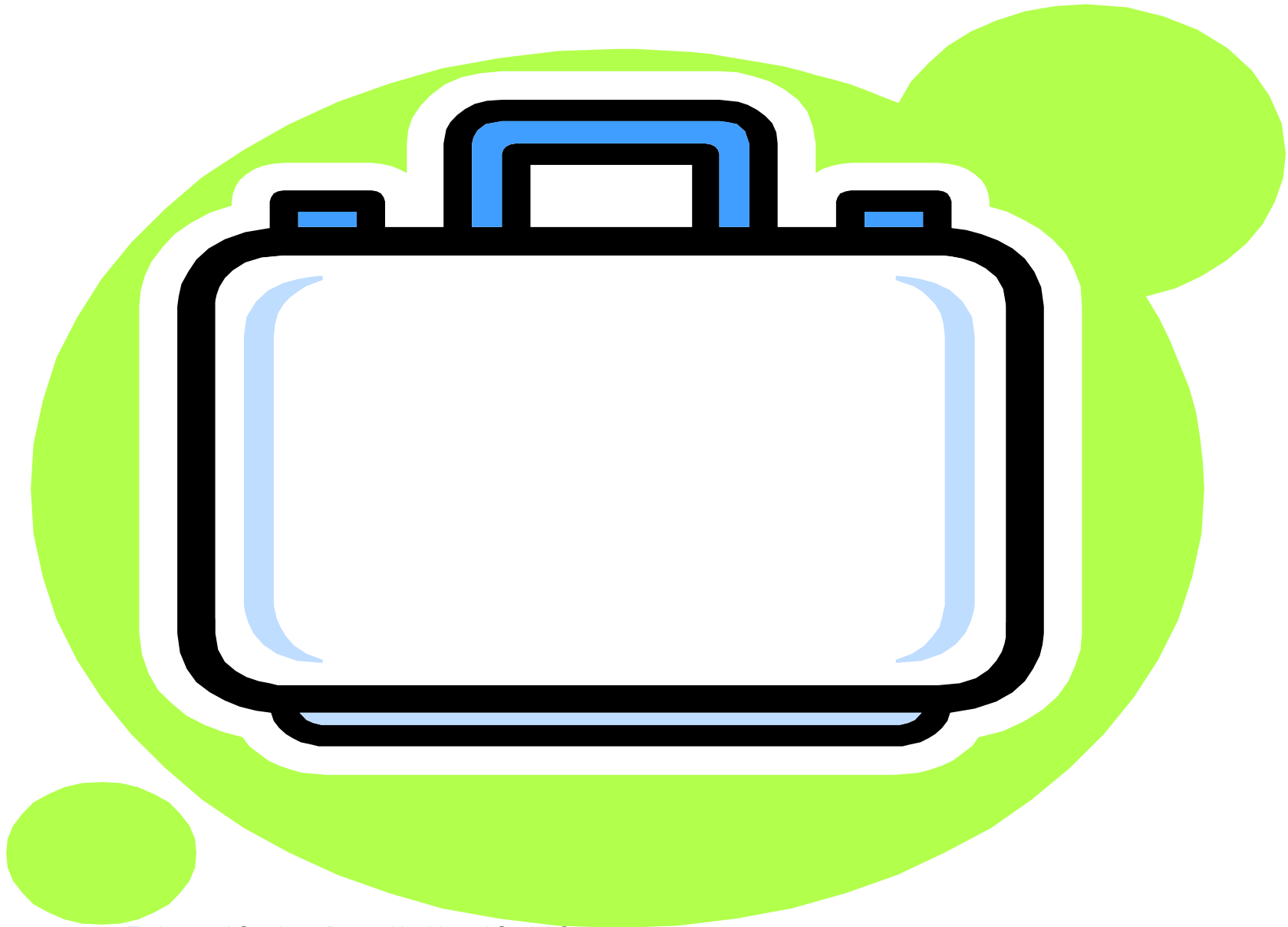
In our culture we are not good at looking after ourselves. We see being 'selfish' as a negative thing. Selfishness can be defined as looking after one's own desires, concerned with one's own interests, needs and wishes while ignoring those of others.

As a culture we tend to be uncomfortable with this, but surely if we do not practice this at times, we would always be emptying our jug and never filling? During a period of illness it is vital to give some importance to one's own needs.

Giving can also be positive but we must remember the balance and supply and demand. Will you have anything to give to others if you put nothing in?

All we ask is that you give yourself at least one activity a day from your first aid kit to improve your wellbeing and health. Of course the more the merrier!





5. Managing Flare-ups and Setbacks

Recovery from CFS/ME is rarely smooth. Many people will experience episodes of increased symptoms that may persist for several days or weeks. It is disheartening and worrying when this happens and you may feel that you are sliding backwards again. At these times it can be difficult to decide what to do for the best, and it is easy to return to old patterns and habits.

Accepting that flare-ups are to be expected can be a positive step. It will help you to develop an advance plan or blueprint so that setbacks can be kept to a minimum.

It is always helpful if you can recognise when a problem exists, as then you are more likely to be able to deal with it before it becomes any bigger.

Sometimes symptoms seem to flare up 'out of the blue', but often there will be triggers that make an increase more likely. For example,

- If you get another illness
- If there are new stresses or tensions – a disagreement or a particular worry
- Major life events like moving house or changing jobs; sometimes they may be pleasant events such as a wedding or holiday
- Changes in your routine such as holidays, changes in weather or clocks
- Increase in activity levels such as returning to work
- Increased pressures such as exams or work deadlines
- Not pacing effectively over a period of days or weeks; letting your symptoms dictate rather than your plan

All these triggers can lead to an increase in fatigue and other symptoms. This can make it much more difficult to follow your plan of activities and relaxation.

How to Tackle Flare Ups

- The first step is to keep calm and don't panic. A flare- up does not mean that you are back at square one and you will never get over it. Instead, try to see setbacks as an opportunity to understand and manage you CFS/ME. It is likely that you will have experienced setbacks before. Remind yourself that you were gradually able to recover.
- As with any difficulty, it is best if you can follow strategies that will limit rather than increase the problem. For example:
- If you are ill/have a raised temperature, scale things back considerably and rest for a day or two. Try to avoid complete rest for any longer than this. It may seem a good short term solution, but it does not help in the long term.
- If you are resting more, continue to keep up with gentle movement and stretching. This helps to improve circulation and encourages muscles to relax. It also will help to maintain mobility.
- Don't wait for symptoms to improve before returning to your plan. Begin again as soon as possible, but at a lower level. This will help you get back 'on track' again.
- Go back to basics – review what you have learned from you sessions. If necessary, begin to keep a rest and activity diary again to help you plan a new schedule. Set some small targets to help you move forward again.
- Reflect on possible triggers for this flare up:
Are you remembering to balance your activity and rest?
Are you expecting too much of yourself?
Has anything changed at home or at work?

If you continue to experience difficulties, please contact us for advice and reassurance. It can be hard to remember to follow the most helpful strategies when the going get tough. So that you can help yourself deal with these difficult times, it is a good idea to have put together your own blueprint for recovery.

Exercise - Reflective Questions

Individual Management Plan

1. What factors may have lead to a relapse in my condition?
2. What factors may have lead to my symptoms increasing?
3. What works to help with reducing my symptoms?
4. What things do I need to continue working on?
5. What am I like when I am well, when setbacks last no longer than half a day? (this is my baseline)

This is what I need to do for myself every day to keep myself feeling as well as possible. E.g. have regular rest periods, stop before fatigue increases.

-
-
-
-

This is what I need to do at least once or twice a week, to keep my overall wellness and sense of wellbeing. E.g. speak with friends even if only for a short period.

-
-
-
-

What prevents me from doing the above? (Barriers)

-
-
-
-

Recognising the warning signs before the start of relapse.

**What are the symptoms / warning signs that I need to be aware of?
E.g. Forgetfulness, ache legs, dizziness**

-
-
-
-

**What can I do to reduce my exposure to things that cause me to relapse?
E.g. pacing, relaxation**

-
-
-
-

**How can I best cope with things that may cause me to relapse when they do occur?
E.g. tell some one, take time out.**

-
-
-
-

**What steps do I need to take if I find myself in difficulties?
E.g. saying No. be assertive, honest**

-
-
-
-

Supporters.

List the people who can provide you with additional support and need to be contacted when things go wrong. They can be family members, friends, healthcare professionals or your care coordinator. You may want to name some people for certain tasks.

These are my supporters:

E.g. Name John Smith Phone No. 01777 7654321	Connection Neighbour, has spare key, will feed cat and water plants
--	--

Name Connection
Phone No.

Name Connection
Phone No.

25262 V1/Community/TSDFT/07.16/Review Date 12.14

44

Torbay and Southern Devon Health and Social Care Trust.
South and West Devon CFS/ME Service.
Created by Kirsty Penman and Katherine Woolnough July 2012
With thanks and recognition to Leeds and West Yorkshire CFS/ME Service