

## Activity management

This leaflet will help you work out what your limits are in some activities, this is your **baseline**. This should ensure that on good days **and** bad days you are able to keep your activity levels much the same.

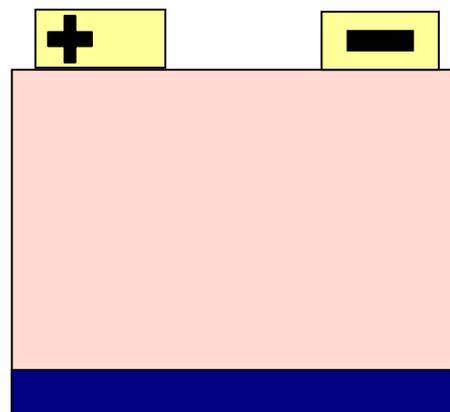
**Pacing** is keeping to a regular amount of activity each day. This can be done by making a plan. What you do each day should be based on that plan and **NOT** on how tired you are feeling. This should enable you to feel more in control of your daily activities rather than relying on how you feel.

**Grading activity** is looking at the things we do in every day life and breaking them down into achievable steps. Grading activity is important in relation to fatigue because:

- People with CFS/ME have a limited supply of energy to serve the body's needs
- The level of fatigue can vary and is worsened by high levels of physical and mental 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 simple question of '**supply and demand**'
- The severe drop in energy that CFS/ME causes means that even minimal activity can lead to prolonged periods of fatigue

### The Human Battery

People often associate the concept of energy with batteries and will describe that having fatigue makes them feel like they have an empty battery and that even on the 'good' days their energy levels are still significantly lower than prior to developing CFS/ME. This can be illustrated on the battery by a low level of charge.



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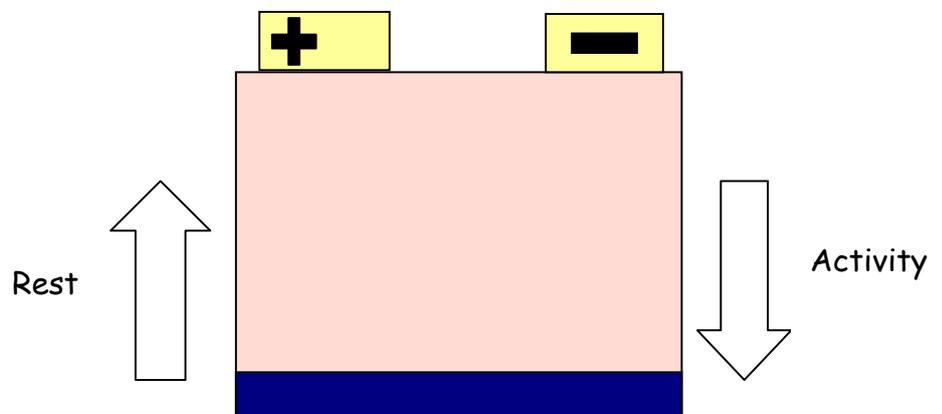
You may feel guilty when you are inactive; especially if those around you are working, and so on the days that you feel you have some energy you may try to do as much as you can while the energy is there. This can lead to a flattening of the battery and a need to rest in order to re-charge. This pattern is known as ‘**activity cycling**’.

**Pacing and grading activity** rations energy and uses it to best effect. The intention is to avoid flattening the battery and allow opportunities for energy levels to rise. **Pacing uses smaller amounts of energy at one time and spreads the total energy used out over longer periods.** This may mean **prioritising the most important tasks** or finding alternative ways to do things, which can conserve or reduce the energy required.

We all have back-up emergency supplies of energy that we use when we are in a crisis or when we want to do something really important to us. Sometimes this additional energy may enable you to do something you really want to do and so feel better in yourself. However, if you do this all the time it will not help your recovery – just like eating chocolate when dieting – you can get away with it sometimes but not all the time!

### Rest

People often use the word ‘rest’ to refer to when they are reading a book or watching TV, however both these activities require mental activity and are therefore not ‘rest’. It is important to take quality rest that allows your battery to re-charge; relaxation techniques can be useful in helping you do this. Learn to use rest as a pause within activity, by switching between short periods of activity and rest you can increase the total amount of activity you do, i.e. by pacing. **Avoid long periods of rest as this increases muscle weakness and deconditioning.**



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Useful Questions to ask yourself:

- Do I flatten my battery or do I stop before this happens?
- Could I use my energy differently?
- When I rest do I relax or just sit/lie still?

### Analysing Activity

Usually in life we do things without thinking about them first, our everyday life becomes automatic. Some of the things we are use to doing automatically are not helpful in managing fatigue. In order to make changes to daily activities to help manage fatigue, you need to learn to **THINK BEFORE YOU DO**. This can be very difficult when we are so used to getting on with life.

The first step in the process of helping you to grade your activities is to understand your own experience of activity and how it affects your fatigue, this will be different from someone else with the same condition.

#### Exercise

Example Activities:

- |                   |               |                    |
|-------------------|---------------|--------------------|
| * Getting dressed | * Washing up  | * Phoning a friend |
| * Paying bills    | * Watching TV | * Driving the car  |

For each of the example activities ask yourself these questions:

- Are there any aspects of the activity that make it harder, such as standing for a long time?
- Is the activity harder because it is a physical or a mental task?
- If I enjoy the activity does it make it easier?
- Does the time of day make the activity easier or more difficult?
- Is the activity more difficult or easier when another person is involved?
- Was the activity more difficult if emotions, such as stress or conflict were involved?

### Making Activity Work for You

Once you understand how the different activities in your life affect your energy levels you can start to think about changes that you could make to maximise the energy you have. Grading activity is often about 'common sense' solutions. The way you did an activity in the past may have worked then, but does it work now? Could you do some tasks differently to reduce the amount of energy it takes to do it? You may be aware of what is not working but feel stuck as to how to change it.

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- Try to see if there are patterns in each day, perhaps you are doing all your activity in the morning and resting all afternoon.
- Try shorter periods of activity with rest periods in between so that your energy lasts all day
- Try sitting instead of standing when doing activities such as preparing a meal or ironing
- Ask other people to help you with activities that you find difficult

Analysing activity like this might seem laborious at first but hopefully will help you to make changes that will become more automatic in time.

### Over-doing it

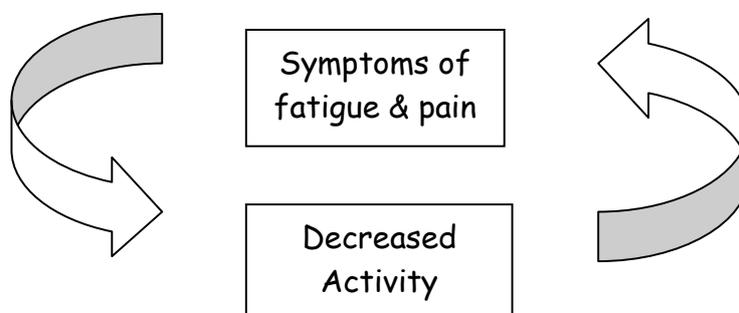
You may find that when you have a little more energy than usual you tend to 'over-do it' which then leads to an increase in your fatigue. Sometimes people know they are doing too much on their 'good days' but don't want to give in to their illness or find it hard to change how they have always been.

Useful questions to ask yourself:

- What have I found difficult this week?
- What might have triggered the worsening of my fatigue on that day?
- How could I have done things differently to prevent this happening?

### Under-doing it

Activity is needed to improve our mental skills and maintain our confidence, doing limited activity can make us feel exhausted and lethargic. This then becomes a vicious circle where we are fatigued if we do things but we are equally fatigued if we don't. The less we do the more fed up and frustrated we feel which may increase our risk of depression.



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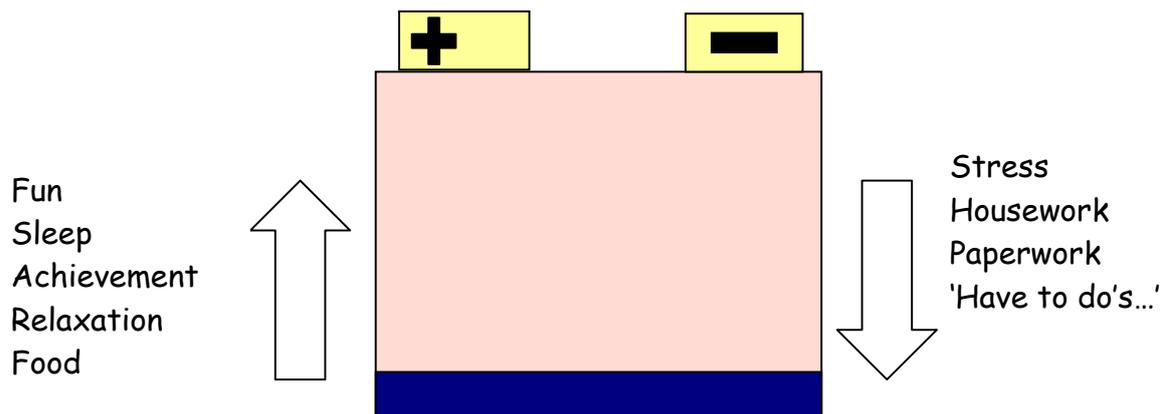
If this is the case for you, you may have to gently work through high levels of fatigue very slowly increasing your level of activity despite the fatigue. Try to avoid making big increases in your activity levels which will make your fatigue worse. This is very difficult to do and may feel like walking along a tightrope but sometimes it is the only way to cross to the other side.

#### Useful questions to ask yourself:

- Has doing nothing or very little improved my fatigue?
- What is likely to happen to my body and general health if I stay very inactive?
- Will doing a very small amount of activity make me worse?
- What are the benefits of doing a little more, physically and psychologically?
- If I am doing very little any way does it matter that I need to rest more so that I can do something that I really enjoy?

### Energy Demands

Some people with CFS focus on things that they feel they have to do, like personal care, paying bills or housework. These are things from which they probably don't get much enjoyment so they put nothing back in the battery. Activities that may seem like a waste of energy, such as seeing friends or doing hobbies, may be sacrificed even though these activities may help to recharge the battery.



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**Decreasing Demand**

Demands on our energy come from many different sources such as family and work. They can also come from the pressure of trying to meet our own expectations or standards. Try to identify whether any of the things that you do could be done by other people, or ask yourself do they need to be done at all?

<p><b>Exercise</b>  <i>Make a list of the things that help with the supply of energy and the main areas that demand your energy</i></p>	
<p><u>Demand</u></p>	<p><u>Supply</u></p>
<p>Look at the list of demands and ask yourself:</p> <ul style="list-style-type: none"> <li>• Is each one absolutely necessary?</li> <li>• What would happen if I didn't do it?</li> <li>• If I have to do them, can I do the most important things first and concentrate on one thing at a time?</li> <li>• Could anyone else help me with any of these demands?</li> <li>• Can I breakdown these tasks into smaller chunks?</li> </ul>	

## St. Helier & Sutton CFS Service Ways to Grade Activity

- **Time** - set a time limit for each activity based on how long you can do that activity without experiencing increased fatigue and then gradually increase the amount of time allocated to each task. For example, you might set a baseline of reading for 10 minutes, if you can sustain that every day for three weeks you might increase it to 11 minutes.
- **Distance** - is a useful measure for any activity that involves motion, for example, walking and driving. Try not to focus on the destination, such as getting to the local shop; instead identify markers, for instance, lamp posts or park benches, so that you can measure how far you have been and can see your improvement.
- **Speed** - is the combination of time and distance and it is often the case that 'more haste makes less speed'. Try to reduce the speed at which you do things.
- **Strength** - muscles become smaller through inactivity, this is called deconditioning. Strength can be regained through gradually increasing the muscle power used for a task. To increase your strength gradually increase the muscle power needed, for example, slowly increase the amount of shopping you carry or increase the number of stairs you climb.
- **Complexity** - the more complex an activity, the more energy it will require to complete it. People who are fatigued can lose the ability to concentrate on different activities at the same time, for example, talking on the phone and taking a message. To make tasks easier they need to be simplified. Try to focus on one task at a time and remove all distractions such as background noise.

### 'I've started so I'll finish'

Some people have a rule that when they start something they have to keep going until it's finished and they find it difficult to stop half way through. With CFS/ME the energy may run out before the task is completed, trying to finish the activity with no energy is like trying to drive a car with no petrol. This may prevent people from beginning a task in the first place.

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There is another way. You can achieve the task by taking small slow steps, it might be slower and perhaps even frustrating, but with a steady approach you can get to the end of the task. Take the example of trying to do an hours housework; if you tried to do this all in one go you might have to stop and give up after 30 minutes or keep putting off starting until you are having a 'good day'. However, if you did four 15 minute chunks of housework spread over the day you might complete it.

### **Setting the Stopping Point**

One problem you may have is recognising when to stop an activity. If you rely on your body and an increase in symptoms to tell you when to stop you will already have done too much.

You can experiment with your stopping point if you are measuring what you are doing in the first place. You may have to test out your stopping point a few times because fatigue is sometimes delayed after an activity.

### **Mixing and Matching Activity**

Mixing and matching activities throughout the day can help maintain energy levels as some parts of our bodies can relax whilst others are working. Try setting up a routine for yourself that involves short periods of different types of activity. Changing between physical, mental and social activities balanced with relaxation periods can be used to maximise your energy and prevent increasing fatigue.

### **Boosting energy**

Things that we enjoy or give us a sense of achievement can boost our energy levels. Even though you may feel fatigued by an activity it may give you satisfaction and help you to feel more positive about the future, this can then help to sustain you. Sometimes you might exceed your energy limits to do something you enjoy – just remember to adjust your programme to allow for some additional rest before and after the activity to compensate.

#### Useful questions to ask yourself:

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

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**Increasing Activity**

Every time you increase your activity it needs to be maintained before another increase is made, a bit like walking up a staircase not up a slope. Try to make small changes, small enough that your body will not react. It is better to take small steps than one big one that causes you to crash and give up. As you improve you may find that you can make bigger changes, but it is important to be realistic at the beginning.

Remember that if you are doing more physically you may get a slight reaction from your body. This is the same as when a healthy person starts to exercise for the first time, they may feel great at the time but be stiff and sore the following day. You will need to try and distinguish between the signals that your body is sending you about when you have over-done it and a true increase in your fatigue levels. This may not be easy to do!

**Making Changes**

Making changes is hard particularly if you have always done things in a certain way. However, it is something you can do to manage your fatigue. It might be helpful to communicate what you are doing and why to others to increase their understanding and support. It is also important to recognise all the little steps you make as achievements as it will encourage you to continue. Making changes takes time and perseverance and may require several attempts!

Much of the information in this leaflet was drawn from information produced by  
Leeds & West Yorkshire CFS / ME Service and is used with thanks