NHS
Torbay and South Devon
NHS Foundation Trust

PATIENT INFORMATION

Pacing

Neuropsychology Service Torbay &South Devon

Dear Patient

You have been given this booklet because you are experiencing fatigue due to a neurological condition. This booklet includes information on pacing, which is aimed at helping you to plan and use your current energy levels effectively and efficiently.

Fatigue is a normal response to activities and is a sign that we need to take a break. Fatigue becomes a problem when it is present most of the time and not improved by rest. This is commonly experienced by people with neurological conditions and you may find this has had an impact on activities you want to do. In this booklet, we aim to help you to learn to pace your activities.

Pacing is an important skill for us all; it is particularly useful for those with neurological conditions. You may find that your fatigue improves, however many people find this is a condition they must learn to manage over the long term. To begin managing your fatigue, it is useful to break down what you are doing day-to-day. Carefully planning these core aspects of your daily life will help maintain energy to respond to life's unplanned events.

You may come across problems that you find difficult to solve or change and so this guide is designed to work alongside sessions with a health professional; they can help you to look in more detail at how to overcome any obstacles and help you to make best use of your energy.

Your Fatigue

Typically, everyone feels tired after exertion or not getting enough sleep. However, pathological fatigue may not improve with rest. It's different from typical tiredness.

You might feel:

- unable to concentrate
- lacking in energy or motivation
- exhausted or weak
- frustrated, overwhelmed, irritable

You might find it makes other problems associated with your condition worse, like balance, vision, speech or changes in your thinking skills such as attention and memory.

It is hoped that this booklet will help you, and those around you, to recognise how you are feeling and support you to develop the best way to manage your symptoms.

Causes of your fatigue

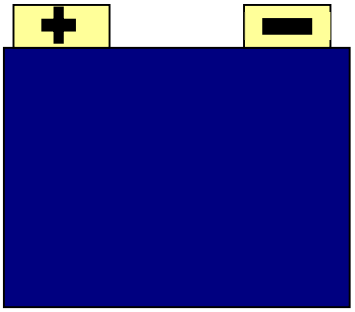
Your neurological condition is one cause of your fatigue. There may be other things contributing to it, which in turn influence how you deal with it. For example:

- your environment
- pain
- medication
- sleep

- thinking skills
- diet
- adjustment and coping styles
- identity and social roles
- expectations of others

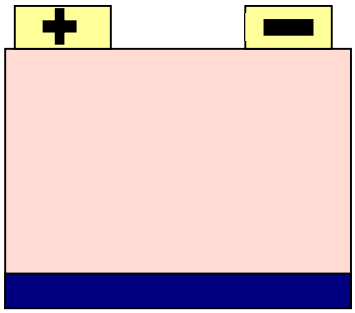
You might not have had to manage these things in the same way in the past. Thinking about these things now is a useful starting point as you begin to manage your fatigue. However, this can be difficult and you may wish to make a note of the things you are struggling with so you can discuss these with your psychologist. This booklet will provide some exercises to help you pin down some of these contributing factors.

The Human Battery



People often associate the concept of energy with ‘batteries’ and will describe that having fatigue makes them feel like they have a flat battery. However, in the human body this ‘battery’ isn’t in one organ nor does it involve just one biological process, as so many of the body’s systems have a role to play in producing or mobilising energy. For example: our respiratory and circulatory system get oxygen into and around the body providing energy, the digestive system releases energy from food, hormones can regulate our energy supplies and our nervous system instructs the body parts to function and use energy.

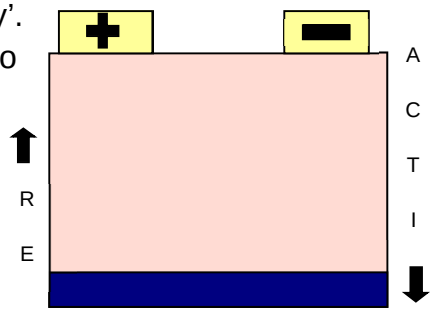
Many health problems that affect individual parts of the body can also give problems with fatigue. These are like specific faults in the battery, but if they are corrected the energy supply is returned. For example, if someone is diabetic they may feel more fatigued when this is not controlled but with the appropriate treatment the fatigue improves. People with neurological conditions often describe having fluctuating levels of energy and that even on the ‘good’ days energy levels are still significantly lower than before having the condition. This can be illustrated on the battery by a low level of charge.



Despite having low energy levels due to your neurological condition, on the days that you feel you have some energy, however small, you may try and do as much as you can while the energy is there or push past your limits. Often people can feel very guilty when they think they are not doing ’anything’, especially if their partner is working.

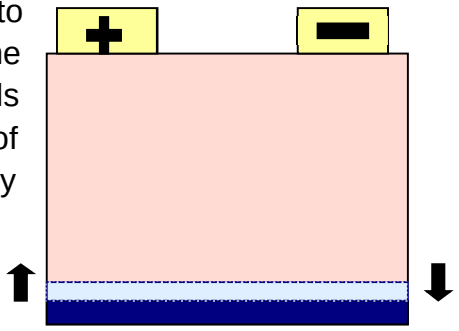
‘Using up’ energy

So the natural pattern of someone experiencing fatigue is to be as active as possible when the energy is there, which ‘flattens the battery’. When the battery has been flattened, then there is no choice but to rest or stop activity in order to ‘recharge’. This pattern is demonstrated through a ’boom and bust’ pattern of activity. Alternatively some people try to avoid flattening the battery by staying within very small activity levels. This helps to avoid the dead battery situation but means they can feel stuck at this level and are worried about how to do more, in case this starts to happen again.



‘Rationing’ energy

Grading activity rations energy and tries to use it to best effect. The intention is to avoid flattening the battery and allow opportunities to build energy levels over time. This is done by using smaller amounts of energy at any one time and spreading 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 / reduce the energy required. So if you do smaller amounts of activity, so that you don’t use up all the supply in your battery, this leaves some energy that the body can build on or use for other jobs, such as digesting food or fighting infection.



‘Generating’ energy

Grading activity also involves looking at ways to generate energy (recharging the battery) as well as thinking about how we spend our energy. For example, it is important to explore what happens in between periods of activity, in addition to what you are doing. 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* that their minds are still very active. They are thinking about the things they should be doing. By learning how to relax both your mind and body this can help with recharging your battery.

Jump starting the battery

We do also have back-up emergency supplies of energy that we use when we are 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, (which is described in more detail in the booklet on Stress and Relaxation) 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 from this. For example, if there was a fire in your house you would have a sudden boost of energy to help you to get out, 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. However, you know you will need to increase your rest afterwards. But if you were doing this all of the time it wouldn't help your recovery, just like eating some chocolate cake when you're dieting - you can get away with it sometimes but not all of the time!

Exercise

Useful questions to ask yourself:

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

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

- *Could I use my energy differently? How? Note your ideas below*

……

……

……

……

Effects of Fatigue

Fatigue can get in the way of doing the things you used to do. You may find it more difficult to participate in activities that are important to you and those around you. This can lead to; unhelpful thoughts ("*I SHOULD be able to do this"*), difficult feelings like irritability or despair, and lead to either avoidance of activities or over-exertion.

It is important to recognise this relationship between thoughts, feelings and behaviour. Noticing changes may provide you with indications that fatigue is getting on top of you. This is a useful first step in being able to manage your fatigue.

Tell-tale signs of fatigue

- Yawning
- Difficult to concentrate
- Blurred vision
- Frustration/irritation
- Head/stomach ache

However, signs of fatigue can be different for different people. Sometimes you may not notice that your behaviour changes first so it may be worth asking someone close to you what they think.

Exercise

Note down here what you notice as your signs of fatigue:

……
……
……
……
……

Note down here any observations from someone close to you:

……
……
……
……
……

Tasks that fatigue you

The following exercise asks you to start to think about the energy requirements of everyday tasks.

Using the sheet over the next page, write a list of all the activities that you can think of, whether you are currently able to do 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. This can be either mental 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, if you felt that walking could be high, medium or low, depending on whether you were walking around the house, going to the shops, or going a strenuous walk then you might tick all three. Social events may be both high and low energy because whilst they use energy they can also restore energy because it may be enjoyable to meet up with others.

Activity	High	Medium	Low
e.g. Getting dressed	✓		

Next, try to 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?*
- *If you enjoyed the task, did it make any difference?*
- *Was it harder if emotions were involved, such as stress or conflict? Or when doing it to meet other peoples' expectations?*

Note your observations below:

……
……
……
……
……

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 pace and grade what you do each day that 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.

Why are simple tasks so much harder?

It is only when you lose your energy that you really start to appreciate how much energy everyday activities take. If you stop to think about how many different things are involved in us doing an activity you can begin to realise how complicated daily life really is.

For us to complete an activity, such as making a cup of tea, lots of different processes have to work together, below is just an example of a few of these.

Senses

Muscles

Nervous System

Memory

Concentration

Cardiovascular response

Perceptual skills

Motivation

When it comes to performing an activity therefore it is important to be aware of the role of some of the systems within your body.

The different systems of our bodies:

- *Biomechanical*
  This refers to how our bodies move and the signals our brain sends through the nerves to the muscles and the joints. An apparently simple action like lifting a kettle requires some muscles to tense whilst others relax in a specific order. Feedback needs to go back to the brain through the senses and central nervous system to allow the brain to make adjustments to the movement.

- *Physiological*
  The body needs to adjust its internal systems in response to our activity. So, our heart rate may increase, the amount of oxygen in our blood may change, we may release endorphins or have other chemical responses.

- *Sensory*
  The brain gets a constant stream of information about what is happening both inside and outside of the body through our senses. Our senses, such as vision, hearing, touch, smell and taste help us to adjust our actions and keep us safe, for example making sure we are pouring the hot water into the cup.

  Our internal sensors, such as for identifying pain or pressure, alert the brain to any danger or change, whilst others help us to know where we are in relation to space and gravity.

- *Cognitive processing*
  The brain interprets the information it receives and uses our memory, perception and decision-making centres to co-ordinate the movement and determine our actions. The brain needs to sequence a series of different actions in order to complete the task based on what it has learnt from past experience.

- *Emotional*
  Our emotional state can affect our performance of an activity, for example if we are upset or anxious we might shake and spill our drink, or we may not want to do the activity at all.

As well as our internal processes there are also external factors, which can affect how we do a task.

- *Social*
  The context in which the activity occurs can change how we perform the activity, for example it may be easier to make a cup of tea for yourself than in front of a group of people at a meeting.

- *Environmental*
  Where we do the activity can also make a difference, for example whether it is too hot or cold, do we have to stand or sit down, is there enough light to see or is it too bright?

In addition, there are other factors around your individual relationship to that activity, for example:

- *History* – your past experience and skill in the activity
- *Self Esteem*– your thoughts and expectations of yourself in relation to the task
- *Reward and Purpose* – what is its meaning and purpose for you
- *Roles and relationships* – how does it define the person you are and how you relate to others
- *Spiritual* – how the activity itself or the way we carry it out relates to your belief system
- *Cultural* – the meaning of the activity within your social group.

Therefore, all of these things are involved in what you do and how you do it. Why you are having difficulty with an activity could relate to one or many of these factors. So, as we start to look at patterns of activity and using energy more effectively, remember it can take time to find the right solutions when doing even simple things can be so complicated!

So to summarise, activities can use cognitive energy, emotional energy and physical energy.

Making activity work for you

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 it takes to do it, for example sitting to do it 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.

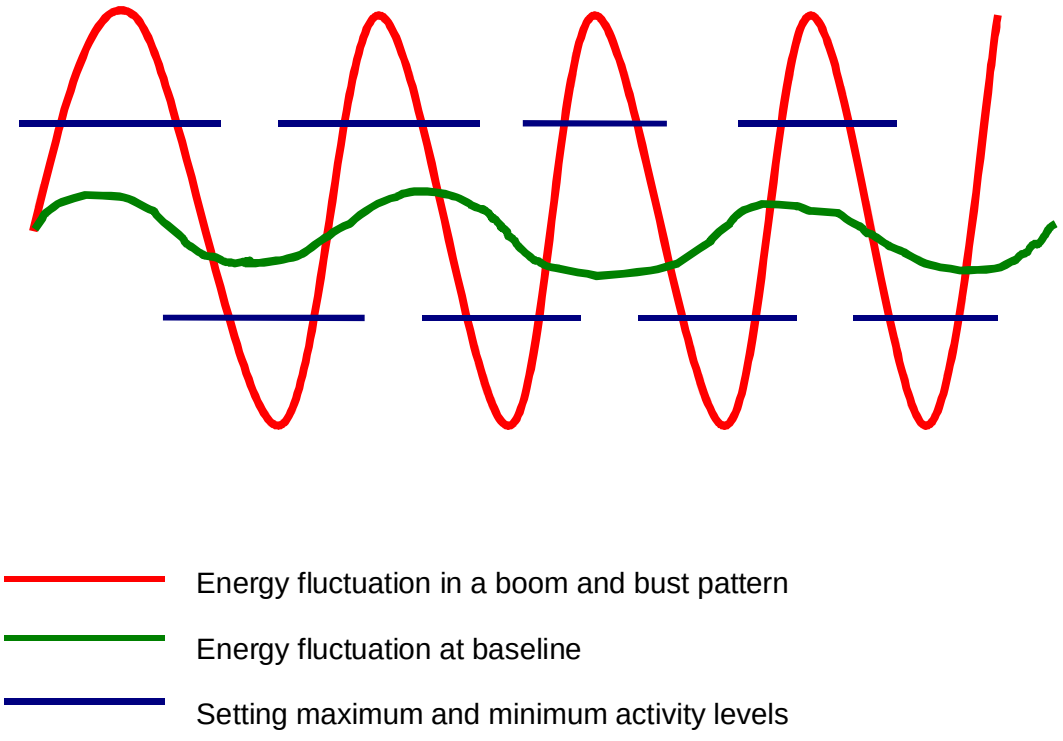
The first is taking the *microscope* view, which involves looking in detail at each day, each activity that you do and how this affects your fatigue.

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.

Setting a Baseline

If you think of this in terms of a journey, the baseline is the departure point or like building the foundations for a house. The problem is finding the right place to start. This is because your fatigue levels will vary, so on some days you may be able to do more than others. This is the typical 'Boom and Bust' pattern often experienced by people with neurological conditions (illustrated by the red line in the diagram below). 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 periods of increased fatigue, meaning you then have to rest. For some the 'Boom and Bust' pattern can occur in a day, a week, a month or even in a 6 month cycle it is still the same problem, pushing through fatigue and symptoms until your system can no longer provide you with the energy needed to sustain this lifestyle.

With the baseline you are trying 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 what is 'over activity' or 'excessive rest' will be different for each person so finding your baseline is a difficult process and you have to find what suits you.



So many people do not know where to start in finding their baseline. Some people try to do what they can manage on a good day, every day, and this doesn't work. Others may follow what they feel their body is telling them to do, which can help to stabilise the symptoms but they don't seem to be making progress. So to know where to start it helps to know what you are currently doing and the next section focuses on how to really

Using an 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 what happened to your fatigue or other prominent symptoms.

Warning - even healthy people struggle to remember all the things they have done in a day, so when you add in the memory problems with fatigue, if you don't write it down you are likely to misjudge. It will take energy to do a diary but if you can manage it, it will hopefully save energy overall.

The way that you get 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, and therefore it is important to be able to identify the things that you did before the fatigue increased.

Exercise

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 100 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 100 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 reduc

Weekly Activity Diary -

Week Sample

Time	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
7-7.30	Sleep	Sleep	Sleep	Sleep	Sleep	Sleep	Sleep
7.30-8	↓	↓	↓	↓	↓	↓	↓
8-8.30	↓	↓	↓	↓	↓		↓
8.30-9	Get Up	Get Up	Get Up	Get Up	Get Up	Get Up	Get Up
9-9.30	Dressed	Dressed	Dressed	Dressed	Dressed	Dressed	Dressed
9.30-10	Breakfast	Breakfast	Breakfast	Breakfast	Breakfast	Breakfast	Breakfast
10-10.30	Rest	Rest	Rest	Rest	Rest	Rest	Out with Friends
10.30-11	Walk (5 min)	Walk (5 min)	Walk (5min)	Walk (Increasing to 10 min)	Walk (Increasing to 10 min)	Meet Friend	Rest ↓
11-11.30	Fun	Fun	Fun	Fun	Fun	Fun	
11.30-12							
12-12.30	Lunch	Lunch	Lunch	Lunch	Lunch	Lunch	Lunch
12.30-1	↓	↓	↓	↓	↓	↓	↓
1-1.30	Sleep	Sleep	Sleep	Sleep	Sleep	Sleep	Sleep
1.30-2	↓	↓	↓	↓	↓	↓	↓
2-2.30	Snack	Snack	Snack	Snack	Snack	Snack	Snack

2-2.30	Snack	Snack	Snack	Snack	Snack	Snack	Snack
2.30-3	Fun	Fun	Fun	Fun	Fun	Fun	Fun
3-3.30	Rest	Rest	Rest	Rest	Rest	Rest	Rest
3.30-4							
4-4.30							
4.30-5							
5-5.30	Rest	Rest	Rest	Rest	Rest	Rest	Rest
5.30-6	Meal prep	Meal prep	Meal prep	Meal prep	Meal prep	Meal prep	Meal prep
6-6.30	Dinner	Dinner	Dinner	Dinner	Dinner	Dinner	Dinner
6.30-7							
7-7.30	Wash up	Wash up	Wash up	Wash up	Wash up	Wash up	Wash up
7.30-8	Rest	Rest	Rest	Rest	Rest	Rest	Rest
8-8.30	Music Crafts	Music Crafts	Music Crafts	Music Crafts	Music Crafts	Music Crafts	Music Crafts
8.30-9							
9-9.30							
9.30-10							
10-10.30	Up to bed	Up to bed	Up to bed	Up to bed	Up to bed	Up to bed	Up to bed
10.30-11	Sleep	Sleep	Sleep	Sleep	Sleep	Sleep	Sleep

KEY

Rating of Fatigue When a Change Noticed 0 = No fatigue 100 = Worst Fatigue ever experienced

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

NB: Group half hours together if doing the same activity

Weekly Activity Diary -

Week 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 100 = Worst Fatigue ever experienced

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
NB: Group half hours together if doing the same activity

Weekly Activity Diary - South and West Devon Neuropsychology Service

Week 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 100 = Worst Fatigue ever experienced

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
NB: Group half hours together if doing the same activity

Reviewing Activity Diaries

Your Activity Diary will only be useful if it helps you to understand more about how you are using your energy.

A common pattern where fatigue levels are fluctuating, which we have already looked at, is the boom and bust cycle. You may already be able to see the changes in your energy levels when you look at your diary.

If you want to start to understand any patterns in your fatigue levels you can use your fatigue scale scores, this will help show any patterns of boom and bust.

Another good starting point is to ask yourself what struck you when filling in the diary. The main problems may be obvious, e.g. large time periods spent on one activity. Grading 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, like all the activity is in the morning and resting all 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; a common problem is that when energy levels rise people 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 get the baseline we are trying to first reduce the fluctuations in fatigue to a more stable pattern.

Exercise

Useful questions to ask yourself when reflecting on your diary:

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 day?

How could you have done the activity differently?

……
……
……

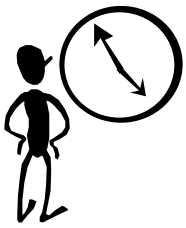
Making Changes - The Principles of Grading Activity

Once you have a more in-depth understanding of your current fatigue levels the next stage is to look at how you can balance these, through changing your patterns of activity. All activities are made up of component parts and each of those components requires 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. So 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. So 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 is the one 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). But once this can be maintained then 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 them 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

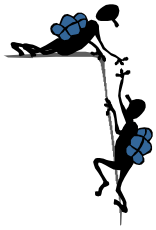
Speed is the combination of time and distance, the ability to perform the task faster. It is often the case with fatigue that 'more haste makes less speed'. When people try to hurry an activity they will make a higher number of mistakes and often experience an increase in rebound fatigue. Before their neurological condition, some people might normally have done activity at a fast pace (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.

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. So to grade any activity requiring strength try to make the load involved as light as possible to start with 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.

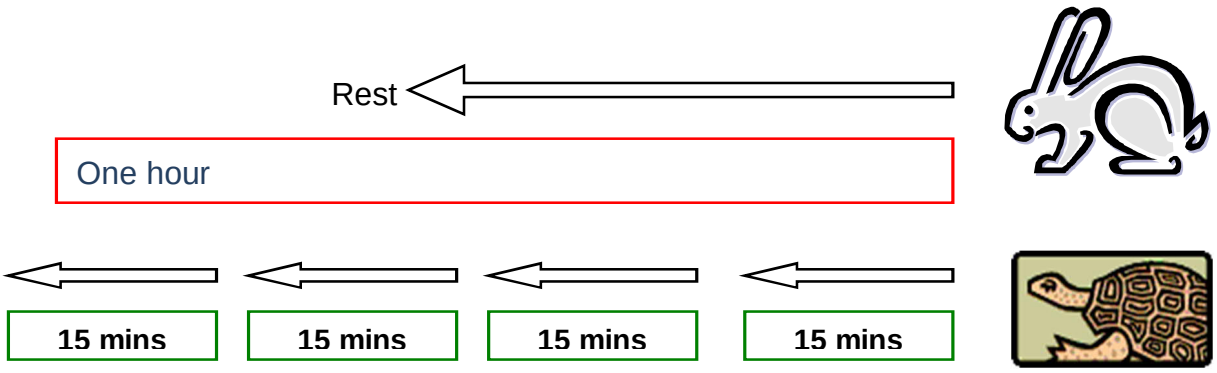
7. Complexity

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 have always lived to 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 the energy is there so you can get to the finish, but with a neurological condition, often the energy has run out part way through and people are pushing 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.

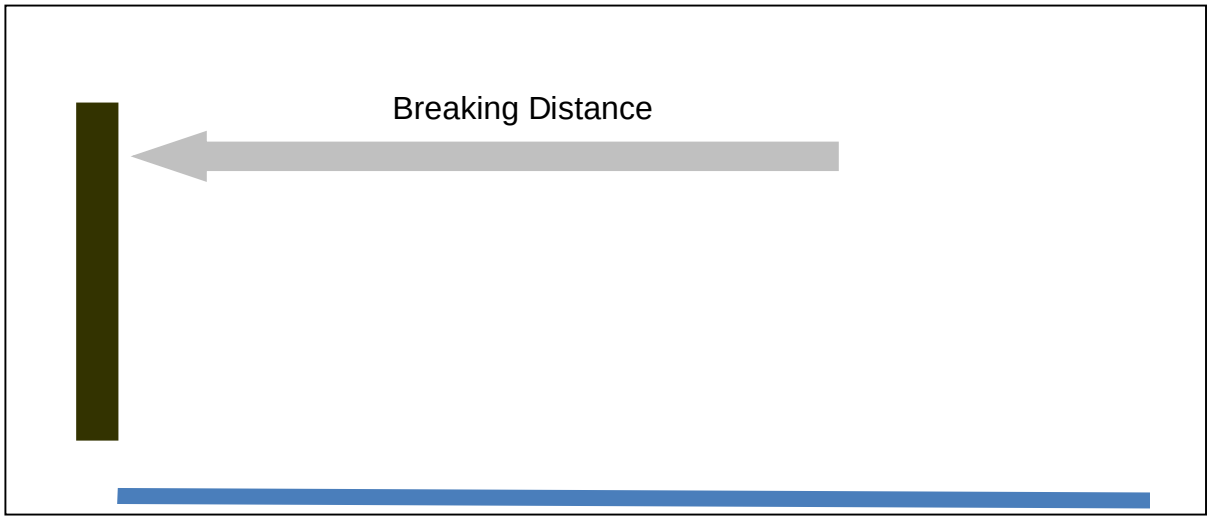


So take the example of trying to do some housework for an hour. If you tried to do this you might have to stop and give up after 30 mins or keep putting it off till you have a 'good' day and can face doing it. But if you did 15 mins at four times spread through the day you might manage it.

Setting the Stopping Point

One problem you may have is knowing when to stop an activity. Often people 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. In this situation if the car needs to stop to prevent it hitting a wall then 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 we hit the wall, not once we start to feel the effects.



Unfortunately the body has no indicators for when to stop and so the breaking distance for each person can only be found through trial and error. So you can only experiment with your stopping distance if you are measuring what you are doing in the first place. Then you know when you might hit the wall, and from that set a time / distance, etc. to stop before you hit the wall of exhaustion. You then have to 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

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 to do it, 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 again) 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 for 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.

Date	Activity / Task	Stopping Point (time/distance/etc.)	Result
Wed 4/3	Reading the paper	10 mins	Before 5, During 5, After 6. Try 8 mins
Fri 6/4	Reading the paper	8 mins	Before 6, During 6, After 6. Repeat 8 mins next time
Date	Activity / Task	Stopping Point (time/distance/etc.)	Result

Summary – Putting it all together

Try to…	Try not to…
Bank your energy – don't let that battery run flat	Be tempted to continue till you crash and the battery is flat
Accept that activities may have to wait so that your energy output is steady	Cram too much into one day so that you can "rest" the next
Plan ahead for enjoyable activities that may be tiring but important.	Give up on social activities.

If you have made it to this stage of the Pacing Booklet you will already have achieved a lot and begun to make changes. Pacing is a life time habit. Stick with it!

Torbay & South Devon Neuropsychology Service

For further assistance or to receive this information in a different format, please contact the department which created this leaflet.