

# FND Hope

## BALANCING ENERGY AND PACING

### What is pacing?

Pacing is all about balancing activity and rest to bring about improvements in the way you feel. The word 'activity' is used in a broad sense, to include mental and emotional activity, as well as the more obvious physical sort. Taking a balanced steady approach to activity counteracts the common tendency to overdo things. It avoids the inevitable ill effects that follow. Pacing gives you awareness of your own limitations which enables you positively to plan the way that you use your energy, maximising what you can do with it. Over time, when your condition stabilises, you can very gradually increase your activities to work towards recovery.

To understand pacing it can help to think of your available energy as being like a mobile phone battery. If you completely drain the battery you have to wait to recharge it before you can use the phone again. If you use some of the battery and make regular top ups, then your phone will always be ready to use. Managing your energy through planned periods of activity and rest will mean that you are more likely to be able to do the activities that you want to do.

It can be as important to understand early on what pacing is not about. It does not give you a free hand to push through activities, banking on rest and recuperation afterwards. Pacing takes an altogether smoother approach. If you are prone to trying to cram in as much activity as you can in the morning, then have to sleep during the afternoon or the next day to recover, pacing helps you to break this habit. Similarly it discourages you from gathering energy through the day and then attempting a burst of activity later in the afternoon or evening.

### How can pacing help?

So far, pacing may not seem very appealing. You've gathered that it requires planning and discipline, which probably doesn't sound easy when you're ill. It may also seem restrictive – the last thing you need when you are already coping with the limitations imposed by your illness.

**Stability** – Some days you can feel slightly better and at other times you can feel a lot worse, perhaps for no obvious reason. When illness reduces your activity levels it's very easy to try to make up for lost time on better days. But cramming in too much activity on a day when you are feeling better often leads to a setback in your symptoms. It becomes a vicious circle that is damaging to the recovery process and both frustrating and unpleasant to live with. This is sometimes called the 'boom and bust' or 'activity cycling' and it's easy to fall into this cycle.

**Control** – When you're ill it can feel like you're on a roller coaster that's running out of control. Life can be turned upside down. Pacing helps you to take charge of your health, increasing your confidence and reducing the unpredictability. Understanding and accepting where your limits lie allows you to plan ahead with more confidence. Keeping your activity levels within sensible limits avoids overly aggravating your symptoms and so prolonging your recovery period. You also know that if the activity is within your limits, you have a realistic chance of achieving the activity planned.

**Better coping** – Dealing with any long term illness is a challenge. Pacing gives you a greater understanding of your health and its combined benefits can make coping easier. Pacing helps you to rethink your approach to tasks so that you resist the natural tendency to keep going until you are forced to stop by fatigue or other symptoms.

**A focus on recovery** – Pacing is not a cure, but by balancing activity and rest in a measured way you are supporting the body's natural recovery process, stepping up your rate of recovery. Many people find that they begin to improve once they accept their illness, understand how it works, and follow a realistic and achievable approach to getting better.

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## **Understanding the basics**

Activity  
Rest  
Baselines  
Increasing as able

### **Activity**

If you only associate activity with quite physical, active pastimes then pacing requires you to take a fresh look. In pacing terms activity incorporates any action that uses energy, whether this is a physical, mental or emotional demand. So everyday activities might range from getting up or having a shower, to watching TV, to worrying or feeling angry. In fact, many people who suffer with chronic fatigue find that it is emotional activity that is the most draining, and also the hardest to measure or control.

The types of activities that you will be pacing will depend on how the illness affects you, your circumstances and preferences. For some people it will be the basic tasks of daily living, for others it will be the physical exercise or brain activities, or work and family activities. Activity means listening, talking, laughing, concentrating, making eye contact, watching TV, coping with light and noise, lifting a magazine, etc.

### **Rest**

Short, regular rest periods throughout the day are essential to give you time to recharge your batteries. Rest and relaxation are as central to pacing as activity, although the amount of rest that you need will vary at different stages of the illness.

For your mind and body to get real benefit you need to be fully relaxed and properly resting your brain. This may call for a new perspective on what you consider to be relaxation. Before you became ill you might have used mental activities to relax, like reading or watching TV, or you might have enjoyed physical exercise. For healing rest, aim to be quiet and still, both physically and mentally.

In general, it is better to avoid sleeping during the day, as this may disrupt your night time sleep cycle. However, sometimes, it may be a necessary and useful way of 'recharging the batteries'.

### **Baselines**

A baseline is a level of activity that you can comfortably manage on a regular basis without making your symptoms significantly worse. Activity must be sustainable. In other words, you must be able to do the same amount of activity whether you are having a good or bad day. In this way you won't be tempted to do more on a good day, or forced to do less on a bad day. Once a sustainable baseline has been established you can find that your symptoms ease and your energy levels increase.

People usually find that their starting baseline is considerably lower than their current level of activity. Your illness has probably forced you to give up lots of things but you may still be trying to hang on to doing too much.

### **Increasing as able**

As natural recovery occurs you should find that you are able to increase your activity. Any increases should be very gradual and the process should be initiated and controlled by you.

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## **Pacing in practice**

**Activities** - How you carry them out

When you are doing a specific task, such as preparing a meal, it's very tempting to try to complete it in one burst of activity. Instead, split the activity into a series of small stages, with periods of rest and relaxation in between. Only attempt one activity at a time.

## **Energy use**

As well as being able to class activity as physical, mental or emotional, you can also rate an activity according to how much energy it uses. Activities will be low, medium or high consumers of energy. You need to consider this when you are planning your day.

## **Be energy wise**

Look at whether there is anything you can do to make an activity easier and less taxing. If you are washing up, can you sit rather than stand? Try soaking dishes first so that they are easier to clean, then leave them to dry on the draining board. In this way you might be able to modify a high-energy activity into a medium-energy activity.

It is particularly important to take this approach with demanding activities that may be taxing in a number of different ways. Shopping will include travelling, sitting, walking, carrying and coping with busy environment with bright lights and noise.

Don't just do things the way you have always done them. Only stick to old routines if they are manageable. If you get up in the morning and have breakfast, build in a rest before you get dressed. Activities that you may have previously carried out automatically, such as showering, drying your hair etc now need to be included in your plan.

## **Review your priorities**

Look at each activity and judge how essential it is. You may need to adjust your usual thinking as you won't be able to do everything that you did before you became ill. Can you put off the activity to a later date? Can you ask friends or family to help you? Perhaps you can drop it altogether? This can free up time and energy to choose an activity that you really enjoy. When you are ill and your activities are limited, it's very easy for the boring things in life to take over. You may feel guilty if you let them go, or you might think that's where your focus should lie. In fact, it's very important for your well-being that you allow yourself time for enjoyable activities, so make sure you have a balanced mix of those that you have to do, and those that you want to do. Don't feel guilty!

## **Balance**

Balance is the key not only in the activities that you choose, but also their type. Your day should include a balanced mix of physical and mental activity and you should deliberately alternate or 'switch' between the two.

## **Rest and relaxation**

Good quality rest and relaxation is an essential part of a successful pacing programme and you need to build this into your day. The amount of rest that is needed varies from person to person. Some people need a lot of rest while others find that if they are getting good quality rest they can cope with frequent but short 'mini rests', perhaps lasting as little as five to ten minutes.

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Relaxation is about achieving complete rest of the body and mind. If you feel that your brain or body is being stimulated, you are not achieving true relaxation. It can take some time to learn to 'switch off' both physically and mentally. Some people find it very difficult to relax properly and feel guilty if they're not busy or doing something 'useful'.

There are several techniques or skills that you can learn to help achieve a state of relaxation:

**Make room for relaxation** – Set aside a time and place to relax. You don't need to go to bed to relax and in fact it can be best to save your bed for night time sleep. Where you choose will depend on your home circumstances but you need to find a place where you won't be disturbed. Switch off the phone and let those around you know that you don't want to be interrupted. Get yourself really comfortable, either lying down on a mat, or sitting in a chair with your neck, feet and arms well supported. Make sure you are warm enough.

**Good breathing** – Learning techniques for good breathing, and remembering to put them into practice, is important. When you are feeling stressed, anxious or worried, your breathing can be shallow and quick. This is called hyperventilation. When you hyperventilate you use on the upper part of your chest, whereas good breathing uses your whole chest and lung area. A lot of people are unaware that they are hyperventilating and it can become a habit. It alters the blood chemistry and causes symptoms such as pins and needles, dizziness, palpitations, breathlessness and chest pain, and heightens anxiety and panic. Naturally these symptoms can cause further worry and anxiety and a vicious circle is created.

## **Become aware of your breathing:**

Place one hand on the top of your chest and the other hand at the bottom of your rib cage/abdominal area. Breathe in slowly through your nose and into the 'bottom' of your lungs. You should feel your abdominal area rise while your chest should only move slightly.

When you take a breath in, pause for a moment and then breathe out slowly either through your nose or mouth. Make sure you breathe out fully. Repeat this slowly 10 times. You might need to build up to this number.

It's a good idea to practice breathing like this on a regular basis.

## ***Tackle tension***

There are a number of different techniques to help tackle tension so you will need to find out what works best for you. Some people find that focusing on a pleasant or relaxing image can help to calm the mind and body. Another method is to consciously relax tension in your muscles. Your aim is to recognise when your muscles are tense, then to relax them in response to this. One way of doing this is to clench a fist for a few moments and then unclench. Note how tense and uncomfortable it felt when clenched and how good it feels when fully relaxed. Try this with other muscles in the body, e.g. your neck, shoulders and back. Focus on whichever area you think might be tense. Clench for a few moments and then unclench. Some people find it helpful to systematically work their way around the body from head to toe. As you get better at the technique, it's possible to bypass the clenching and just 'let go' of each muscle group in turn. This can also be used alongside deep, slow breathing as a 'first aid' measure in stressful situations.

## ***Unwind***

Deep relaxation takes practice, and relaxation tapes or CDs can be a good guide. Gentle music can be helpful if you find that your mind starts to race. Some people benefit from practising meditation and yoga. Complementary therapies such as reflexology, aromatherapy and massage can also help.

The important thing is to find a way of resting that works for you.

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## **Finding a baseline and stabilising activity**

To find the amount of activity that you can confidently manage on a day to day basis, you first need to have a good awareness of your current activity patterns and their impact on your symptoms and how you feel. How do your symptoms change and fluctuate in relation to what you have been doing? Remember to consider not just physical activity but also mental and emotional activities.

### ***Keep a diary***

It can help to keep a simple diary of activity and rest. This will help you to understand what is going on and enable you to reflect on your own particular circumstances. The effects of 'overdoing it' may not show up for a day or two but your diary will help you to identify what triggered your symptoms. After a while you should be able to recognise peaks and troughs in your activity levels.

You will need to keep your diary until you are able to spot patterns or are able to apply the pacing and planning principles in your head, or build them into your routines. A diary may also need to be temporarily restarted during a setback or relapse and can also be helpful when attempting to start a significant activity change, e.g. returning to work or study, or starting to drive a car again.

### **Calculate your baseline**

There are several ways to work out the length of time you can do a particular activity, and you may need to experiment to find the best one to suit your situation. This can take some time.

You will need to work out a baseline for each different activity you undertake.

### **Techniques include:**

The 75% rule. If you think that you can carry out an activity for 20 minutes, try reducing your activity time by 5 minutes to 15 minutes (75% of 20 minutes). The aim would then be to maintain 15-minute blocks of activity interspersed with rest/relaxation periods throughout the day.

An even simpler way is to set your baseline at about 50% of what you think you can do on an average day.

Split each activity up with 5-10 minute rest breaks.

When setting a baseline, the golden rule is to remember that all activities must be set at a level than can be maintained on both a good and a bad day.

It can be very disappointing to find that your baseline is lower than you expected but remember that you are taking a step back in order to go forward!

'Know your limits. Set a small target for the day and if you complete it, congratulate yourself. Don't think, "I've done this so I can do more", there's always tomorrow. You should be pleased with the smallest of tasks. Keep positive.'

## **Stabilising your activity**

When you have set your baseline you need to give your body time to settle into the level. How long this takes will vary from person to person but it can take weeks. You will be ready to gradually increase your activities when you feel your body has acclimated to the level and you can confidently sustain it.

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## **Increasing as able**

As natural recovery occurs and you have found a sustainable baseline, you should find that you are able to gradually increase your activity. You could do this by adding one small extra task or by lengthening an existing activity. Any increases should be very gradual and the process should be initiated and controlled by you.

If you decide to extend an activity, do this by 10% and no more. If you can currently carry out housework for 10 minutes, try increasing it to 11 minutes. Or you could break this up into two five and a half minute activity periods with a rest/relaxation period in between. Increasing from 5 to 10 minutes would not be advisable as this is a 100% increase! Remember 10%.

Over time, repeat this process so that your activity periods are gradually lengthened and your rest periods shortened.

Whichever approach you choose; remember not to be too ambitious and to only increase activities little by little.

## **Side effects and listening to your body**

Learning to pick up on the signals that your body gives you and making sense of them is an important part of pacing. You will need to learn to distinguish between the normal effects of increasing activities and the negative effects of having over-done it. You are likely to notice a temporary increase in stiffness or fatigue when increasing your activity levels. This is normal and your body will need a few days to adjust and adapt. However if your fatigue and other symptoms continue for a week or longer this might indicate that you have increased the activity too quickly. Stretching after exercise can help to reduce muscle soreness.

The signals that your body gives out can be quite subtle and are not necessarily physical, such as pain or fatigue. Feeling irritated, stressed or starting to lose concentration can equally be an indication that you are doing too much. You need to learn to recognise these early warning signs and become an expert at reading your own signals so that you can take action.

It can be helpful to think again about the mobile phone analogy, using up some battery power, may actually aggravate some symptoms to some extent, but the key focus is to ensure a quick enough recovery period. Some successful pacers feel that they cannot achieve anything if they don't aggravate their symptoms somewhat, but pace their activity to make sure they 'bounce back' and recharge quickly.

## **Priority setting**

To help increase your activities, set priorities or targets against which you can measure your progress. These goals must be realistic, achievable and sustainable.

If concentration and memory problems make reading difficult, you might set yourself a specific reading goal. Choose a book that is enjoyable and not too taxing, then build in small stages – tackle a couple of pages at a time, or a chapter and build in quality rest periods. Similarly, you could choose a newspaper or magazine.

If you want to build up a physical activity, such as walking to the shops, consider your current capacity or baseline and then set yourself a realistic and measurable goal. If your baseline is currently set at walking regularly around your home, build in several small stages before the end goal of getting to your local shop. Your first stage may be to walk outside to the garden or to the pavement. You might then have several stopping points along the way.

Don't be tempted to make big jumps or increases, however well you may be feeling. In the end, a slow and steady approach will help you to reach your goals more quickly.

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## **Stumbling blocks**

Now that you understand how pacing works, you can probably imagine how hard it can be to put into practice. There is likely to be pressure from everyday life and from yourself or others to deviate from your plans.

If your lifestyle makes pacing extra difficult you will need to take some time to stand back and reflect. Think about whether everything you are attempting to do is essential.

## **Taking on too much**

It can be hard to let of things that might be preventing you from pacing effectively. There are likely to be demands and pressures from other people and you may also be battling with your own expectations. If you have standards that are getting in the way of pacing you will need to adapt and change them. It's all too easy to push yourself to finish a task you have started, or to feel bad about 'letting somebody down'. It's important to learn to let go and to make fewer demands on yourself. It just isn't possible to do all the things you did before you were ill.

You may have people in your life who drain you emotionally, or you may be the sort of person who is always available in a crisis. Do you always put other people first, regardless of how you are feeling? Remember that emotions are far harder to account for when learning to pace. If you are struggling with delegating, saying 'no' or dealing with other people's reactions and attitudes, counselling or cognitive behavioural therapy (CBT) can be useful.