

YOUR HEALTH

LIVING WITH BREATHLESSNESS & FATIGUE



The aim of this booklet is to provide advice for managing fatigue and breathlessness. Both these symptoms can have a huge impact on how you live your daily life. There are tips and coping strategies which may help you to manage your day to day routine or change your thinking around tasks and activities. The leaflets entitled 'Breathlessness Management' and 'Anxiety Management' may also be useful.

Fatigue

The word fatigue can describe a range of feelings of tiredness. Fatigue affects different people in different ways. Your fatigue may be due to your illness itself, or the result of symptoms caused by your illness. It can also be a side effect of treatment, for example chemotherapy, radiotherapy, or medication. Being very breathless a lot of the time can drain your energy. You may feel more tired if you are having difficulty sleeping, are not eating well or feel stressed and anxious.

Energy & Fatigue

Everyone has a fixed limit of energy that is available for them to use on any one day or week. This amount varies from person to person; you will know some people with boundless energy, whilst others always tire more easily.

Since your diagnosis, and any treatments that you may have had, your energy amount may have decreased.

It is important, if you are going to use your energy wisely, that you know how much of it you have at your disposal. By sticking to your limits rather than using too much you may find that you have much more consistency. There are different ways to explain our energy:

Your energy as a 'bank account'

Rechargeable batteries also have a set amount of energy in them. As the battery is used, its energy decreases. You then plug it into the electricity to recharge the battery to full energy capacity again. It's the same with your energy. Sleep or rest is like plugging you into the electricity and topping up your 'battery'. During the day, the things you do drain your battery of energy. One strategy you can use here is to top up your battery a little bit by resting and relaxing frequently.

LIVING WITH BREATHLESSNESS & FATIGUE

Rechargeable batteries will not give more energy than they have. Likewise, you need to think about not using more energy than is available to you. Before you were ill, you would drain your battery of energy throughout the day through activity. At night, with sleep you would recharge your battery for the next day.

Now you are ill you have a smaller battery of energy available to you. If you stop and have lots of rests in your day before you get too tired you may find you can expand your available energy

Summary

Fatigue can come from a range of causes and can have a variety of effects on your life. It may be useful for you to keep a diary as this will help you to identify if your fatigue has a pattern or occurs after specific activities.

Coping with Breathlessness & Fatigue

There are some strategies which may help you manage your fatigue, so that it has less impact on your life. Finding and maintaining a balance: If you manage your energy wisely, it will:

- Bring structure to your day
- Make you feel more productive

- Potentially give you a sense of control
- Reduce extreme periods of fatigue by spreading activities out and taking regular short breaks before fatigue takes over

Setting Goals

It is useful to think of an activity that you would like to be able to do.

- Look at what steps are needed to complete it
- Think about simplifying or adapting each step
- Adopting the 3 P's principles of Pacing, Prioritising and Planning may help

Pacing

Pacing your activities allows you to make good use of your energy and avoids 'Boom and Bust'.

- Practice stopping an activity before you feel tired. Do not continue until pleasant tiredness becomes unpleasant or when you start to feel weak or unwell. Our bodies give us signals to let us know we are overdoing it.
- Take breaks and rest between tasks to allow the body to recuperate before finishing the task (recharging your 'battery' or depositing in your 'energy bank account'). For instance, rather than sweeping the floor immediately after washing the dishes, sit down and read the paper first. A 10 minute rest each hour can help prevent fatigue.

LIVING WITH BREATHLESSNESS & FATIGUE

- It is also important to pace the rate at which you do an activity. A moderate pace consumes the least energy and breath – ‘pace don’t race’. Playing slow music can help you maintain a moderate pace.
- Extreme temperatures can also affect your energy level; therefore try to avoid being outside during very hot or cold temperatures.

Prioritising

Put activities in order of importance including personal care, work, and leisure activities. We all value activities differently. For some, making the bed each morning is essential, while others may place more importance on a morning walk, gardening or playing golf.

It is important to prioritise activities so that your most important tasks get done first. This way if you are unable to finish every task, then at least the most important tasks are finished. Also, try to leave yourself plenty of time to complete each task.

Planning

- **Avoid planning to do too much in one day.** Plan to spread activities out evenly, and remember to include rest periods. Keep in mind the time of day you have more energy and plan to do strenuous tasks at that time.
- **Make a list.** List things that need to be done per week. Make sure you allow some space between the most tiring of the activities. Also, try to include at least one quiet day after something particularly stressful or exhausting.
- **Keep a diary.** This could include details of activities and symptoms and any stressful events. It is important to make a note of the time spent on an activity in a day in case it causes a considerable increase in breathlessness, pain or fatigue.
- **Use a calendar.** Organise your list of essential activities into daily and weekly schedules. Keep all family events, hospital appointments on one calendar.
- **Inform family and friends.** Let them know that because of your illness, your plans can change from minute to minute and to not take it personally if something happens and you have to cancel at the last minute.
- **Delegate.** Some tasks could be more difficult and can be delegated to someone else. This may include changing the bed, hoovering or mowing the lawn.

LIVING WITH BREATHLESSNESS & FATIGUE

Tips for managing daily activities

Cleaning the house

- Sit down for as many chores as possible and delegate heavy household tasks if possible.
- Use your attendance allowance or PIP to pay a cleaner, or take cleaning one day at a time.
- Clean one room a day until your house is done. Delegate chores to others in your home and make a family rota.

Cooking and washing up

- Try microwave/pre-packed food or delivered meals or use a slow cooker as an easy way of preparing a meal.
- Use a dishwasher or sit on a chair or stool whilst washing up and then leave the plates to dry on the rack.

Shopping

- Make a list, in the order of the way the shop is laid out if possible.
- Use a shopping trolley to lean on and ask for help at the checkout and when unloading the trolley into the car
- Shop at quieter times or ask if a relative, neighbour or community scheme is able to help with one shopping trip per week, or consider using the internet for an online shop.

Getting up and dressed

Sit down to bathe, wash, dry and get dressed. Consider using a towelling dressing gown to assist with drying.

Appointments

- If you need several tests at the hospital, ask if they can arrange for you to have them all during one visit.
- 'Never stand when you can sit' while you wait.

Let equipment do the work:

- Ensure that you have all necessary equipment within easy reach before beginning a task. This prevents unnecessary walking, carrying, bending, and reaching. It may be useful to rearrange the kitchen or other areas.
- Duplicate sets of equipment in the areas in which you use them may be useful. Also obtain tools to help you with your tasks, for example equipment with handle extensions. Daily living equipment such as perching stools or bath lifts will help reduce effort.
- You can request an Occupational Therapist to assess your environment.

LIVING WITH BREATHLESSNESS & FATIGUE

Childcare

- Explain feelings of tiredness to children and plan activities to do sitting down.
- Avoid lifting children – encourage them to climb onto your knee and involve children in simple household chores.
- Use babysitters from time to time so you can do things you enjoy.

At work

- Talk to your employer and work colleagues.
- Consider requesting to change hours to arrive and leave at less busy times.
- Find lighter work if your job is physically exerting.
- Take a short break regularly or consider working from home.

Leisure activities and hobbies:

- Try to lead as full a life as possible, spending some part of each day doing something you really enjoy (include a rest period to recover). Enjoyable activities may increase your energy.
- Plan your social occasions and late nights giving you time to rest/recover. If an activity takes a long time to complete in one session, break it up into small tasks.

Posture

- The position of your body affects how quickly you tire. Good posture is not simply a matter of standing tall. It means correct use of your body at all times.
- Good posture allows muscles to work within their best range and takes the least amount of energy. Changing positions is restful; it puts a different set of muscles to work, aids circulation, and helps reduce stiffness.
- Proper work heights are important. The best work height allows you to sit or stand with the table just below the level of your elbows.
- Arrange cupboards and work areas so that frequently used and heavy objects are within easy reach without bending or stretching.
- When it is necessary to bend to reach the floor or a low cupboard, bend at the knees not at the waist.
- Activities done while sitting are 25% easier than when done in a standing position. Although cutting your vegetables while seated at the table may feel awkward at first, it will become natural with practice.
- Sliding objects requires less energy than lifting and places less strain on your body.

LIVING WITH BREATHLESSNESS & FATIGUE

Mental exhaustion

- Being fatigued or breathless does not just cause physical tiredness. It is also common to experience mental exhaustion.
- Mental exhaustion can result in difficulties with:
 - Concentration or focusing your attention
 - Remembering things
 - Multi-tasking
 - Organising things
 - Trouble thinking, speaking and making decisions
 - Word finding
 - Feeling overloaded or more emotional than usual.

Coping with mental exhaustion

- Be aware that your concentration may be affected.
- Inform others when you feel overloaded or overwhelmed.
- Minimise distractions in your environment when trying to concentrate on a task, e.g. turn off the television/radio and try to keep the room as quiet as possible.
- Minimise interruptions.
- Keep a diary/calendar or wall planner to help you remember your plan for the day/ week.

- Gain control – by asking people to repeat information or give messages more slowly.
- Write lists for activities such as shopping or work related tasks.
- Keep a note book or post-it notes with you at all times to write things down that you might forget.
- Use aids such as watches or mobile phones with alarms to remind you of appointments and to record messages.
- Pacing – take frequent rests if you are required to concentrate on something and build up your concentration gradually.
- Consider talking books, short stories or magazines if reading is a problem.
- Engage in leisure activities in a relaxing environment, e.g. gardening. There is evidence to suggest that this may help improve concentration.

Basic Information

- Remember being breathless or tired is not harmful. However, it is important that any of the following is reported to your GP:
- Fatigue levels that suddenly change or are not normal for you.