

# Managing breathlessness 7: Managing your energy levels

The information given below is designed to help you manage your stable long-term breathlessness. If your breathing is getting worse or you are experiencing breathlessness as a new feeling, it is important to seek medical advice.

## Why do I feel more tired?

Tiredness can be a common symptom in many long-term conditions, especially when you are experiencing breathlessness too. When you have a condition that affects your lungs, the extra effort of breathing uses up more energy.

Tiredness makes you feel less motivated to keep active, which means that often you avoid activities. This can lead to you having even less energy, which in turn can make you more tired. If this behaviour becomes a habit, the cycle can often be difficult to break.

We can not necessarily take away your tiredness completely, but there are a number of ways in which you can manage it. These, in turn, may help you to do some of the things that you would like to do.

## What can I do to help my energy levels?

- Understand why you have less energy
- Understand energy levels
- Monitor your energy levels
- Conserve energy
- Keep active
- Make life easier

## Energy levels

Learn to understand your energy levels and try to get to know where your limits lie. Think about how much energy you have to use each day. Some people imagine having a 'jug of energy' or liken their energy levels to a battery. Consider what you would like to use your energy for, but always leave something in the jug so that it is never completely empty. Even when you make the best plans, there is always a chance that something unexpected might crop up that uses more energy, so it is always good to keep some energy in reserve.



Imagine your energy in terms of having a 'jug of energy'. Some activities will top up the energy in your jug and other activities will use up the energy in your jug. What would you like you use your energy on? Try to keep at least 20% of your energy in your jug at all times.

## Monitoring your energy

It is often useful to keep track of the activities that you do within your day and week, and monitor how you are feeling at different times. This might enable you to see if there are any patterns and if there are any times of the day and week which are better or worse for you. You can use the weekly diary at the end of this leaflet for this purpose.

It can be helpful to note down what kind of activities give you energy - 'energy givers' - and which activities drain your energy - 'energy depleters'. See how many of these activities you do in your day or week. This may also help you to make changes to help manage your energy.

Try to avoid all or nothing or 'boom and bust' patterns of activity. Overdoing it leads the body to require more recovery time. Try to hold back on a good day to enable you to do more on a less good day.

## Conserving your energy

It is important to keep a balance between activity and rest and alternate the type of activities that you do in your day so that you are not trying to do too many strenuous things all at once. Use your energy on things that you really want to do, so this means deciding what your priorities are.

It is also important to try not to use up any energy unnecessarily and there are many ways in which you can do this. You might do things in a slightly different way which takes less effort or ask someone else to help. When thinking about how to save your energy, it might be useful to consider the following things.

### Planning

Consider which times of the day are best for you and plan your activities around this. Try to space activities out during the week and not concentrate all your activities into one day.

### Pacing

Slow down your activities, as this will take less energy. Slow down when you talk, laugh, eat or cough - these actions can affect your breathing pattern. Break down your activities into smaller tasks that are more manageable. Allow yourself some time each day to try to relax. Remember that it is better to take a little extra time to complete one task and be able to continue, than to finish one task quickly and feel too tired to continue.

## **Prioritising**

When you have a fixed amount of energy to use, it is worth having a think about which activities are most important to you. Sometimes it can help to write everything down that you would like to or need to do. Then think about whether these activities are high, medium or low priority for you. When planning which activities you are going to do, concentrate on the high priority things first and then work your way through to the medium priority activities. It might be that you don't get round to doing the low priority ones or you ask someone else to do these. You might want to use the prioritising sheet at the end of this leaflet for this purpose.

## **Positioning**

Try to avoid too much bending and twisting which can be tiring. Don't sit or stand for too long without changing your position. Think about trying to organise your home so that things are easily accessible (for example in the kitchen, have frequently used items to hand). It is less effort to push, pull or slide objects, so try to avoid carrying heavy things.

## **Permission**

If you are placing high expectations on yourself, it is worth having a think about allowing yourself to do things in a different way that helps with your energy levels. Try to be patient with yourself and give yourself time to do things. Whilst it is normal to reflect back sometimes, it is not so helpful to think about the things that you can't do or about the way in which you could do something before your energy levels were limited. Try to recognise the things that you are achieving.

## **How active should I be?**

Regular exercise has been shown to help with energy levels and prevents your muscles becoming weaker. It is important to stay as active as you can. A little regular, gentle exercise each day can make all the difference.

## **How to make your life easier**

### **At home**

- Keep things you use frequently close to hand
- Have a phone close to your bed or armchair
- Consider using a trolley for shopping
- When bathing or shaving, make sure you gather all you need before you start

### **Walking and climbing stairs**

- Align your breathing rhythm with your steps - breathe in over one step, breathe out over the next two steps
- Move at a comfortable pace and avoid holding your breath
- Use walking aids if they help you. You can discuss this with your physiotherapist or occupational therapist
- Stop and rest whenever you need to
- Have resting points at the top and bottom of the stairs
- Use the handrail when climbing stairs, take the steps slowly, one at a time and stop to rest when you feel the need to

## **Eating and drinking**

- Have frequent small meals, rather than one large one
- Eat smaller mouthfuls
- Avoid foods that are difficult to chew, add sauces when possible
- Drink sips of fluid frequently to avoid becoming dehydrated
- Consider using frozen vegetables / mixes or pre-prepared foods
- Freeze food left over to be used another day
- Try to cook vegetables together to avoid using lots of saucepans
- Use a vegetable basket to drain water rather than lifting heavy pans

## **Sleeping**

- Maintain a comfortable temperature in the bedroom
- Try not to sleep for too long a period - get just as much sleep as you need to feel refreshed
- Try to get into a routine of going to bed and getting up at the same time
- Try to eliminate noise in the bedroom
- Activity or exercise promotes a balance between activity and rest, and may assist with sleeping
- Avoid drinking caffeine-based drinks / food before going to bed
- Even if you are not sleeping at night, try not to sleep during the day. If you do need to sleep during the day, try to keep this down to a short nap rather than a prolonged sleep.

## Weekly diary

List the activities that you have carried out and then rate your level of tiredness on a scale of 1 to 10, with 0 being not tired at all and 10 being extremely tired.

Day	Activity	Scale (0-10)
Monday		
Tuesday		
Wednesday		
Thursday		
Friday		
Saturday		
Sunday		

## Prioritising table

Think about the activities that you do and try to prioritise these according to what you consider to be of high, medium and low importance (i.e. put the tasks most important to you in the high priority category).

Activity	High	Medium	Low

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## Useful sources of information

### Contact us

Interstitial Lung Disease Service

**t:** 020 7188 8635 (Monday to Friday, 9am to 5pm)

**e:** [gst-tr.khpildservice@nhs.net](mailto:gst-tr.khpildservice@nhs.net)

For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit [www.guysandstthomas.nhs.uk/leaflets](http://www.guysandstthomas.nhs.uk/leaflets)

### Pharmacy Medicines Helpline

If you have any questions or concerns about your medicines, please speak to the staff caring for you or call our helpline.

**t:** 020 7188 8748 9am to 5pm, Monday to Friday

### Your comments and concerns

For advice, support or to raise a concern, contact our Patient Advice and Liaison Service (PALS). To make a complaint, contact the complaints department.

**t:** 020 7188 8801 (PALS)      **e:** [pals@gstt.nhs.uk](mailto:pals@gstt.nhs.uk)

**t:** 020 7188 3514 (complaints)      **e:** [complaints2@gstt.nhs.uk](mailto:complaints2@gstt.nhs.uk)

### Language and accessible support services

If you need an interpreter or information about your care in a different language or format, please get in touch.

**t:** 020 7188 8815      **e:** [languagesupport@gstt.nhs.uk](mailto:languagesupport@gstt.nhs.uk)

### NHS 111

Offers medical help and advice from fully trained advisers supported by experienced nurses and paramedics. Available over the phone 24 hours a day.

**t:** 111

### NHS Choices

Provides online information and guidance on all aspects of health and healthcare, to help you make choices about your health.

**w:** [www.nhs.uk](http://www.nhs.uk)

### Get involved and have your say: become a member of the Trust

Members of Guy's and St Thomas' NHS Foundation Trust contribute to the organisation on a voluntary basis. We count on them for feedback, local knowledge and support. Membership is free and it is up to you how much you get involved. To find out more, please get in touch.

**t:** 0800 731 0319      **e:** [members@gstt.nhs.uk](mailto:members@gstt.nhs.uk)      **w:** [www.guysandstthomas.nhs.uk/membership](http://www.guysandstthomas.nhs.uk/membership)

**Leaflet number: 4576/VER1**

Date published: April 2018

Review date: April 2021

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A list of sources is available on request