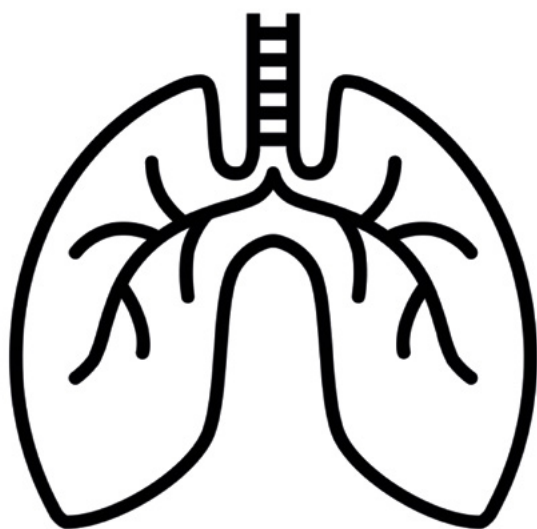


Living with breathlessness

Information leaflet



This leaflet was developed collaboratively with:

Introduction

This leaflet has been developed collaboratively by members of the palliative care teams across Oxfordshire, Berkshire and Buckinghamshire.

The aim of this leaflet is to provide information about why people become breathless and to offer strategies that can help people living with long-term breathlessness.

Having knowledge and understanding of what is happening in your body when you experience breathlessness can help increase your sense of control. Practising a range of techniques and finding those that work for you may also help you feel more in control of your breathing and breathlessness.

You should not stop taking any medications prescribed for you by your specialist team to treat the underlying cause of breathlessness. This leaflet is intended to work alongside your current treatments to help manage the symptoms of breathlessness.

This leaflet does not replace the need to seek medical advice in the case that there is sudden worsening of breathlessness. In the case of a sudden worsening in breathlessness that differs to your normal symptoms please contact the following:

- In hours: Your GP, Specialist team or Palliative Care team.
- Out of hours: NHS 111
- **In an emergency: 999**

Section 1:

Understanding breathlessness

Why do we breathe?

Breathing moves air containing oxygen into our lungs, allowing the blood to take the oxygen it needs to the rest of the body.

Breathing also allows carbon dioxide (a waste product) to be removed from the blood supply in the lungs and blown out into the atmosphere.

How do we breathe?

The diaphragm (a large sheet of muscle covering the base of our ribs/lungs) is the main muscle involved in breathing. As you breathe in, it moves down to help draw the air into your lungs, and your tummy rises.

When you breathe out, it relaxes, returning to its natural dome shape, and allowing your tummy to rest back in.

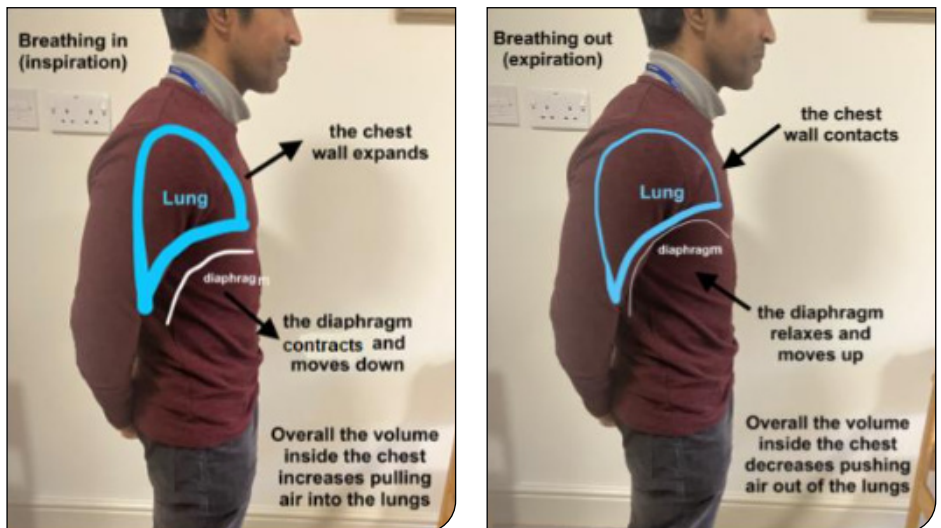


Image 1: Movement of the diaphragm with inspiration and expiration.

When you are breathless, muscles around your shoulders and neck can pull on your ribs to help with breathing. These muscles are called breathing accessory muscles and they fatigue quickly. They can become stiff and if used too much, can be unhelpful to your breathing pattern. It is important therefore to relax these muscles once breathlessness has passed to focus on breathing in the most efficient way.

What is breathlessness?

Breathlessness is the unpleasant awareness of a difficulty in breathing. This can be frightening. It can affect our day-to-day life if we feel we are losing control of our breathing. Chronic breathlessness is breathlessness that continues despite having appropriate treatment for its underlying cause.

Breathlessness can become a vicious cycle. When breathlessness worsens, we often focus more on our breathing and may change our behaviour to cope. While some of these changes can be helpful, others can sometimes make breathlessness feel worse over time.

For example, an activity may make us feel breathless. This can make us feel anxious and lead to unhelpful thoughts. Fear of becoming breathless may cause us to avoid activities, which can reduce our fitness and make breathlessness worse over time.

What causes chronic breathlessness?

Breathlessness is a common symptom for people living with long-term or life-limiting conditions and is often seen in palliative care. There are several conditions that can cause breathlessness including:

- Lung diseases like COPD and bronchiectasis
- Cancer in the lungs or surrounding structures
- Heart diseases like heart failure and stiff heart valves
- Anaemia
- Clots in the lungs
- Anxiety and panic
- Deconditioning (reduced fitness and muscle strength)

Section 2:

Tool kit for managing breathlessness

This section provides a list of techniques that may help you feel more in control of your breathing. You can use them before, during and after activity. You can use them individually or combine the techniques to suit your needs.

It is useful to practice these techniques at times when you feel less breathless, to learn what works for you and make them natural responses in periods of breathlessness.

Using the people around you

Sharing this information and practising these techniques with your family, carers and those close to you can be very helpful, as it allows them to support you when needed. Breathlessness can cause anxiety both for the person experiencing it and for those supporting them. When the people around you feel more confident in understanding and using these techniques, it can help create a calm and supportive environment.

Recovery breathing

Recovery breathing is used when you feel breathless, especially after activity. It involves using a comfortable position and controlled breathing to help your breathing settle.

If you have a restrictive breathing condition such as Interstitial Lung Disease (ILD), heart failure or neuromuscular weakness then it may be helpful to remember:

- Fan.
- Flop (drop your shoulders and let your body relax).
- Relaxed breaths out.

If you have an obstructive condition such as asthma or COPD, it may be helpful to remember:

- Fan.
- Forward leaning.
- Focus on long gentle breaths out (with pursed lip breathing).

If you are unsure what type of breathing condition you have, your healthcare professional can advise you on which techniques are most suitable for you.

Contents in this toolkit:

1. Fan therapy

Fan therapy is proven to help relieve the feelings of breathlessness.

2. Positioning your body to improve breathing

If you are positioned correctly, your muscles will be more effective in opening up your rib cage and allowing movement of the diaphragm for efficient breathing.

3. Breathing exercises

These are helpful to learn to be used when you are breathless to help regulate your breathing.

1. Fan therapy

- Evidence shows that cooling the face, cheeks and nose sends messages to the brain to help reduce feelings of breathlessness.
- It is most effective to use a fan with 3 blades, about 15 centimetres (6 inches) in front of the face and by moving the fan side to side for maximal air flow.
- You can use this as often as you need to, for however long you need to before, during and after activity.
- You can buy portable battery operated or USB charging handheld fans online or in shops for a small price, to use wherever you need it most.
- As well as using a fan, you can cool your face with a cool flannel or by gently misting your face with water.



Image 3: Fan Therapy.

2. Positioning to improve breathing

The following positions support your arms so the muscles that help with breathing can work more effectively. Leaning forward may also help your diaphragm (the main muscle used for breathing) move more easily. Not all positions will suit everyone, so choose the one that feels most comfortable for you.

At rest

- Make sure you are fully over on your side.
- Resting your upper arm on a pillow may also help.
- Relax down onto the pillows as much as possible.
- Having your legs apart may also help.



Image 4.



Image 5.

During activity

- Mobility aides can encourage a forward leaning position and may help to ease breathlessness by taking pressure off the diaphragm.
- This diagram shows how a zimmer frame can support this position. A 3 or 4 wheeled walker or walking stick may also help.
- If you are unsure whether a mobility aid would be suitable for you, please speak to a healthcare professional, physiotherapist or occupational therapist for advice.



Image 6.

Positions of ease after activity

You can achieve a forward leaning position and support the accessory muscles in sitting or standing after activity. Here are some ideas (see images 7 to 11):



Image 7.



Image 8.



Image 9.



Image 10.



Image 11.

3. Breathing exercises

Try to practice these exercises when you are comfortable and relaxed. This can help you feel more confident using them when your breathlessness worsens.

Relaxed breathing (also known as abdominal or diaphragmatic breathing)

Aim: To concentrate on relaxing the accessory muscles and using the diaphragm for effective breathing.

What to do: Make sure you are sat comfortably with head, neck and arms supported. You can place a hand on your tummy or by the sides of the ribs to feel the rise and fall.

Rise the tummy as you breathe in.

Relax the breath out.

Rest and wait for the next breath to come.

You are aiming for your tummy to rise and fall in controlled, regular waves.

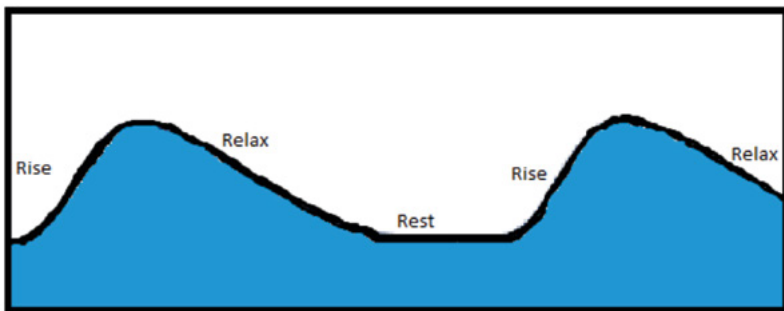


Image 12: Illustration of rise and fall in the stomach with relaxed breathing.

“Blow as you go” and pacing your breathing

It is natural to hold your breath when doing something you expect to be difficult, but this can make you feel more breathless. Try to breathe slowly and evenly throughout the task.

Pace your breathing with your activity and slow the activity down if needed. Breathe out during the most effortful parts of the task. For example, when climbing the stairs, try to breathe in as you lift your leg and breathe out as you step up.

Rectangular breathing technique

When we become breathless, we often do not breathe out fully, which can make our breathing feel more rapid and less effective.

The rectangular breathing technique encourages a longer, more controlled breath out and can also help distract from the sensation of breathlessness and the anxiety that can come with it.

Rectangles are generally everywhere we look – picture frames, windows and screens.

What to do:

- Start in a corner of the rectangle.
- Follow the long side of the rectangle first as you breath out to empty the lungs and make room for you next breath.
- Follow the short side of the rectangle and take a shorter, gentle breath in through the nose.
- Follow the rectangle around at your own pace, as many times as you need to until you feel the breathlessness ease.

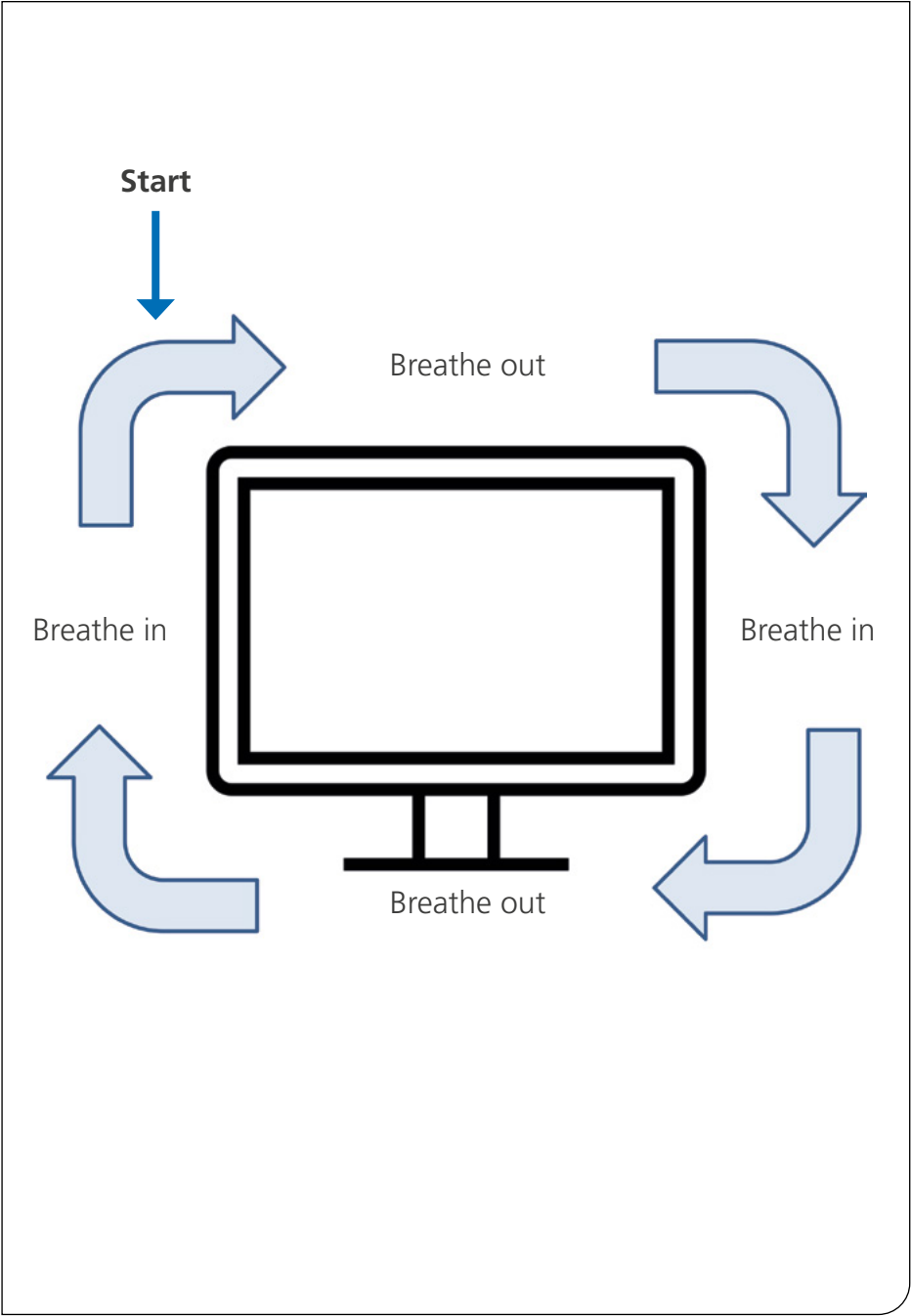


Image 13: Illustration of rectangular breathing technique.

Pursed lip breathing (useful in conditions such as COPD)



Images 14 and 15: Illustration of pursed lip breathing.

- Pursed lip breathing helps to keep your airways open for longer, allowing the air to leave the lungs more easily.
- This creates more room for the next breath in.
- To practice:
 - Breathe in gently through your nose
 - Purse your lips as if you are gently blowing out a candle (see images 14 and 15)
 - Breathe out slowly and gently through your lips (breathe out for longer than your breath in)
- You can use pursed lips breathing at the same time as relaxed tummy breathing or recovery breathing.
- In some conditions, this may make you feel like coughing. If this happens, stop and use a different breathing technique that feels more comfortable.

Section 3:

Managing unhelpful thoughts

Breathlessness and anxiety can form a vicious cycle. Feeling breathless can make us anxious, and anxiety can make our breathing feel worse.

Noticing unhelpful thoughts and gently changing how we respond to them can help us feel more in control of our breathing. There are different techniques that can help you cope with breathlessness. Below are some examples of common thoughts and what you could try to think or do instead.

Using relaxation exercises, mindfulness or having a comforting smell, object or phrase to hand can also help.

1. Calming hand (an example of a relaxation exercise)

1. Recognition and acceptance: Hold your thumb and recognise the signs that you are starting to panic or feel anxious. Remind yourself of what you need to do next to regain control. This will help calm your breathing.

2. Sigh out: Hold your index finger and breathe out slowly. This helps to relax your shoulders, arms and upper chest.

3. Inhale: Hold your middle finger. Take a slow, deep and gentle breath in, focusing on filling your lungs with air.

4. Exhale: Take a slow and gentle breath out until your breath comes to its natural end.

5. Stretch hands, relax and stop: Stretch and relax your hand, to remind you that you can and will regain control.

Sometimes it is necessary to repeat the calming hand exercise as it may take longer than the exercise for the panic to go away.

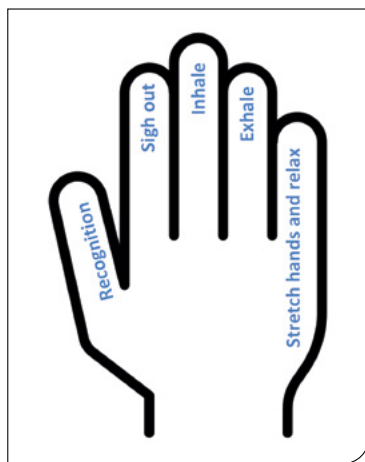


Image 16: Illustration of the Calming Hand.

2. Reframing thoughts

When we feel breathless, it is common to have worrying or unhelpful thoughts. These thoughts can increase anxiety and make breathlessness feel worse. Learning to gently reframe these thoughts can help you feel more in control. Here are some examples of common thoughts and how they can be reframed.

Unhelpful thought	Reframing thought
"I won't be able to get my breath back"	Reframing thought: It is normal to feel breathless during activity and this is not usually harmful. My breathing will settle, as it has done before. What may help: Using techniques that work for me, such as a fan, positions of ease, or rectangular breathing, can help me feel more in control and support my recovery.
"I'm going to faint"	Reframing thought: When I feel very breathless, I may be breathing quickly and shallowly, which can make me feel lightheaded. This does not mean I am going to faint. What may help: Slowing my breathing using techniques I am familiar with, such as relaxed breathing, pursed lip breathing, or rectangular breathing, can help me regain control and reduce light-headedness.
"I'm going to have a heart attack"	Reframing thought: Breathlessness can make me feel anxious, which triggers my body's "fight or flight" response. This can make my heart beat faster and increase my sense of panic and breathlessness, but it does not mean I am having a heart attack. What may help: Understanding what is happening in my body and talking myself through my symptoms can reduce fear. Using relaxation and breathing techniques can also help calm my breathing and anxiety.

Section 4:

Medications for breathlessness

Some conditions need specific treatments to help manage the disease causing the breathlessness e.g. inhalers and nebulisers for COPD or furosemide for heart failure. You should continue these medications if you have been prescribed them as advised by your doctor/specialist.

Some other medications can be used to manage the symptoms of breathlessness or panic associated with being breathless.

Opioids (e.g. morphine or oxycodone)	Opioids are medications traditionally used to manage pain. In selected patients they may help with breathlessness. Opioids can be given in different ways, including as tablets or liquid solutions orally. Alternatively, opioids can be given as injections or infusions under the skin.
Benzodiazepines (e.g. diazepam, lorazepam or midazolam)	Benzodiazepines are anxiolytic medications that are sometimes used for breathlessness in addition to non-medication techniques to manage accompanying anxiety. Benzodiazepines can be given by mouth or as injections or infusions under the skin.
Antidepressants (e.g. sertraline, citalopram or mirtazapine)	Antidepressant medications are used to treat depression and anxiety. They are sometimes useful in managing breathlessness when there is a significant anxiety component. Antidepressant medications are given by mouth.



Oxygen	A small proportion of patients with chronic breathlessness and low blood oxygen levels require oxygen to be prescribed to help with managing breathlessness. Most patients with chronic breathlessness however would not benefit from oxygen. Some people may be prescribed oxygen to use during activity (for example, walking) or when resting, depending on their needs. Many patients find the airflow from a fan or breeze from an open window/doorway gives similar results to prescribed oxygen.
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If your palliative care team or specialist nurse/doctor thinks that one of these medications would be useful they will discuss it with you, explain possible side effects, tell you how and when to take it and consider prescribing it for you.

Section 5:

My breathlessness plan

Many people find it helpful to write down the things that support them when they feel breathless. This can be useful for you, as well as for your family, carers and healthcare professionals, so they know how best to support you.

The example below can help you complete your own breathlessness plan on the next page. You can ask a family member, carer or healthcare professional to help you fill this in if you would like.

Example:

How to help me when I’m breathless	
Please be aware: • I feel frightened when I’m breathless. • I can’t answer many questions as I need to focus on my breathing.	
Step 1	• Open the windows. • Use fan(s). • I need to sit on the edge of the bed and lean forward on the side table. • Gently rub between my shoulders. • Keep me company.
Step 2	If step 1 is not adequate: • Oral morphine liquid (oramorph) 2mg (1ml).
Step 3	If step 2 is not adequate: • Oral loraxepam tablet 0.5mg.

Template:

How to help me when I'm breathless	
Please be aware:	
Step 1	
Step 2	If step 1 is not adequate:
Step 3	If step 2 is not adequate:

Section 6:

Final thoughts on managing breathlessness

- Breathlessness can feel frightening and sometimes debilitating. Understanding normal breathing patterns and how breathlessness can affect our body, thoughts and feelings can help us feel more in control of our breathing.
- Practising different techniques can help you regain a sense of control and confidence in managing your breathlessness. Different people find different techniques helpful, so it is important to discover what works best for you and record this in your plan so others can support you.
- When you are breathless, everyday tasks can take much more energy. Be kind to yourself and think about what you need and want to do each day so you can use your energy in the most helpful way.

If you would like more information:

Please speak to your specialist nurse, doctor or allied healthcare professional looking after you.

Other useful resources include:

- MacMillian cancer support managing breathlessness booklet.
- NHS choices shortness of breath web pages:
www.nhs.uk/conditions/shortness-of-breath

Further information

If you would like an interpreter, please speak to the department where you are being seen.

Please also tell them if you would like this information in another format, such as:

- Easy Read
- large print
- braille
- audio
- electronic
- another language.

We have tried to make the information in this leaflet meet your needs. If it does not meet your individual needs or situation, please speak to your healthcare team. They are happy to help.

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