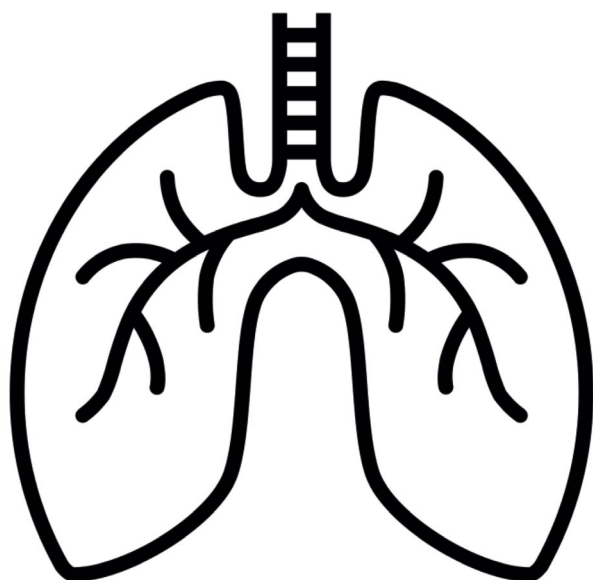


# Living with breathlessness

Information leaflet



KATHARINE  
HOUSE  
HOSPICE



SOBELL  
HOUSE  
HOSPICE

## Introduction

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

Having knowledge and understanding of what is happening in your body when you experience breathlessness can provide an increased sense of control. Practicing a variety of techniques and finding those that work for you, may also help you regain a sense of control of your breathing and breathlessness.

You should not stop taking any medications prescribed by specialists designed to treat the underlying cause of breathlessness. This leaflet instead aims 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 a sudden worsening of your breathlessness. In the case of a sudden worsening in breathlessness that differs to your normal symptoms please contact the following:

- In hours GP, your specialist team or the Palliative Care Hub:  
Palliative Care Hub telephone: 01865 857 036
- Out of hours 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.

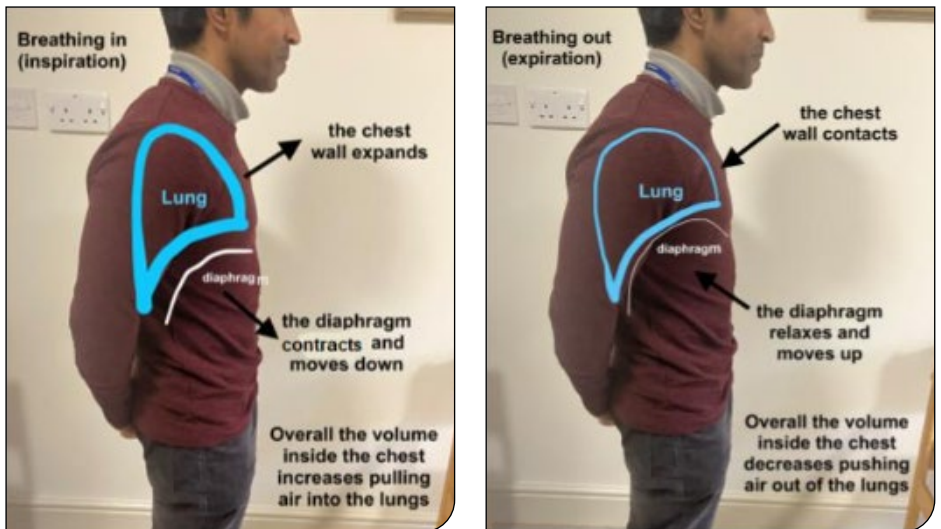


Image 1: Movement of the diaphragm with inspiration and expiration.

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 can fatigue quickly. They can also 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 be a vicious cycle. Worsening breathlessness makes us think about our breathing and changes our behaviour to compensate with being breathless. The change in behaviour can be helpful but it can also be unhelpful.

For example, an activity may make us breathless, and being very breathless can make us anxious which creates unhelpful thoughts. Being fearful of being breathless may make us stop doing an activity, which may make our muscles decondition and worsen our breathing.

## **What causes chronic breathlessness?**

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.

## **Section 2:**

# **Tool kit for managing breathlessness**

This section provides a list of techniques that may help you feel more control in your breathing. You can use them before, during and after activity. You can use them individually or combine the techniques to what suits 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 practicing these techniques with your family and carers is helpful, allowing them to support you when needed. Breathlessness can cause anxiety for both the person experiencing it and those trying to support them. When everyone around you feels confident in using these techniques, this helps to create a calm, supportive environment.

### **Recovery breathing**

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 shoulders).
- 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).

## 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 slow your breathing down.

## 1. Fan therapy

- Evidence shows that cooling the face, cheeks and nose sends messages to the brain to reduce feelings of breathlessness.
- It is most effective to use a fan with 3 blades, about 6 inches / 15 centimetres 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.
- Other ways you can cool the face are by using a cool flannel or misting your face.



Image 3: Fan Therapy.

## 2. Positioning to improve breathing

The following positions place the arms, so that our accessory muscles are in a better position to help with breathing. Leaning forward may improve the movement of your diaphragm, the main muscle of breathing. Not all positions work for all people, do what is 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 encourage a forward leaning position, and can help to ease breathlessness.
- This diagram shows how a zimmer frame achieves this. A shopping trolley, 3 or 4 wheeled walker or walking stick can also aid this position.



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

It is best to practice these breathing exercises when you are comfortable and relaxed. This way you will know how to use them at the times you most need them.

#### 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.

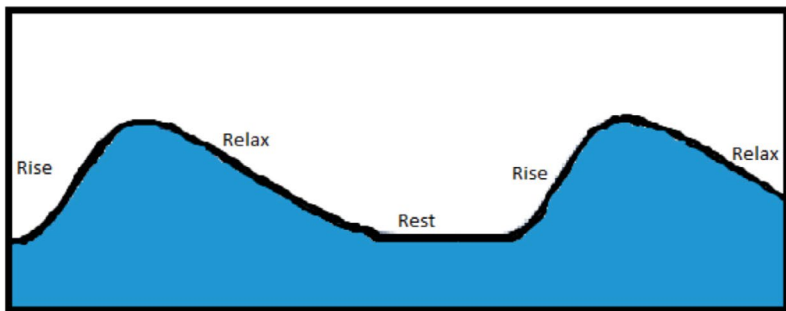


Image 12: Illustration of rise and fall in the stomach with relaxed breathing.

## **“Blow as you go” and pacing your breathing**

It can be natural to hold your breath when you are trying to do something you know is going to be difficult, but this will make you more breathless. Try to remember to breathe slowly and evenly throughout the task. Pace your breathing with your activity and slow your activity down. Try breathing out through the hardest parts. For example, breathe in and out rhythmically with the steps you take up the stairs.

## **Rectangular breathing technique**

When we become breathless, we often do not breath out fully and our breathing becomes less efficient.

The Rectangular Breathing Technique improves effective exhalation and provides a distraction from the sensation and the anxiety of being breathless.

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.

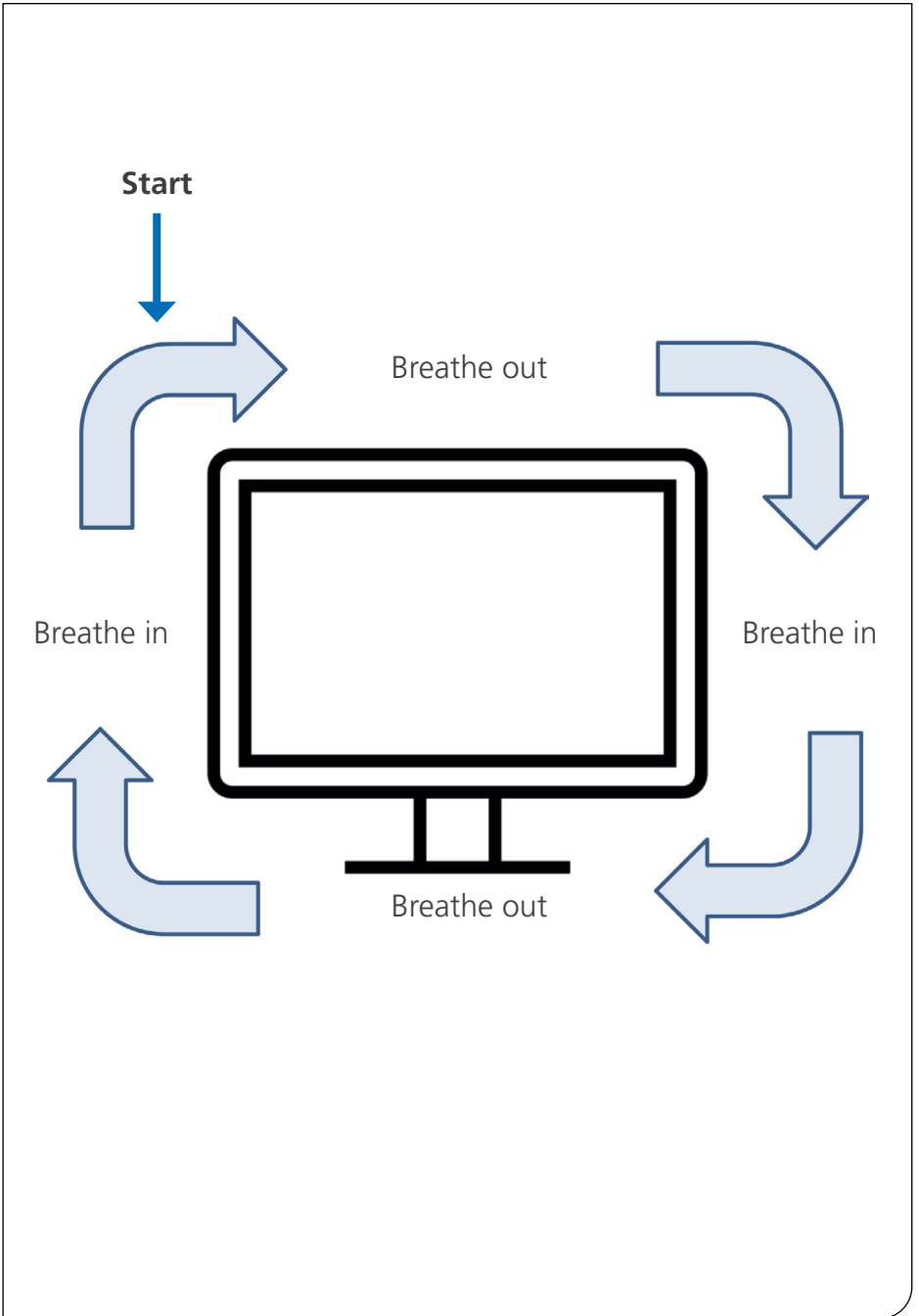


Image 13: Illustration of rectangular breathing technique.

## Pursed lip breathing (useful in conditions such as COPD)



Images 14 and 15: Illustration of pursed lip breathing.

- Pursed lip breathing helps to support the airways to open, therefore allowing the air to leave the lungs more easily.
- This creates more room for the next breath in.
- You can use pursed lip breathing at the same time as relaxed tummy breathing or recovery breathing.
- In some conditions, this may make you feel like coughing, if this is the case do not use this technique.

## Section 3: Managing unhelpful thoughts

Breathlessness and anxiety can be a vicious cycle. Being very breathless can make us anxious creating unhelpful thoughts. This can then make our breathlessness worse.

Recognising our unhelpful thoughts and reframing them to understand what is happening in our body can be helpful. There are various techniques that can improve how we cope with being breathless. Below are some examples of common unhelpful thoughts and some suggestions of what you can try to think or do instead.

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

### Calming hand (an example of a relaxation exercise)

#### 1. Recognition and acceptance:

first recognise the signs that you are starting to panic, hold your thumb firmly and remind yourself of what you need to do next to regain control. This will help calm your breathing.

**2. Sigh out:** this relaxes your shoulders, arms and upper chest.

**3. Inhale:** take a slow and gentle relaxed 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.

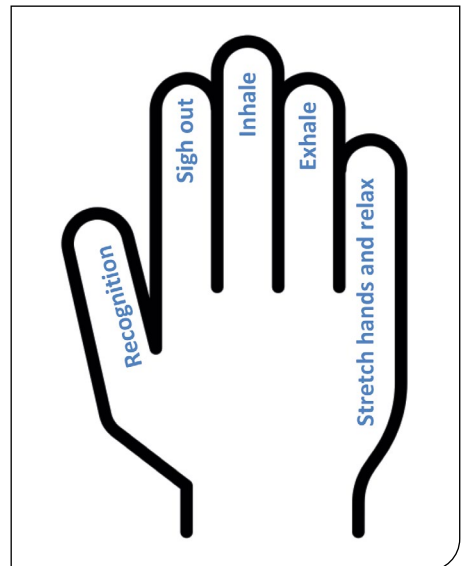


Image 16: Illustration of the Calming Hand.

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

<b>Unhelpful thought</b>	<b>Reframing thought</b>
"I won't be able to get my breath back"	<p>It is normal to get breathless on exertion and not normally harmful. I will recover my breathing as I have done before.</p> <p>You will feel more confident in this when you identify techniques that are helpful to you – such as using a fan, or positions of ease or rectangular breathing.</p>
"I'm going to faint"	<p>When I am extremely breathless I am likely to be breathing shallowly and quickly, that's why I feel I can't get my breath back.</p> <p>Practice slowing your breathing with techniques you feel confident with to regain control and reduce the feeling of being lightheaded such as relaxed breathing, pursed lip or rectangular breathing.</p>
"I'm going to have a heart attack"	<p>When I get breathless, I become anxious which triggers a "fight or flight response". This can cause adrenaline to be released which makes my heart beat faster and produce unhelpful thoughts about what is happening. This can increase breathlessness further and make anxiety worse.</p> <p>Understanding what is happening and talking yourself through how breathlessness impacts on our body, thoughts and feelings this can help ease this fear.</p> <p>Using techniques for relaxation and relaxed breathing can also help.</p>

The calming hand exercise can be a very helpful technique when you suffer with feelings of panic and can be done without requiring any equipment. It can also be useful during episodes of breathlessness when feeling out of control of your breathing.

## Section 4: Medications for breathlessness

Some conditions need specific treatments to help manage breathlessness e.g. inhalers and nebulisers in COPD or furosemide in 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 symptom of breathlessness (not the underlying disease) or the panic associated with being breathless. Common medications used in this way include:

<p><b>Opioids</b> e.g. morphine or oxycodone</p>	<p>Opioids are medications traditionally used to manage pain but can be used at low doses to help with management of breathlessness.</p> <p>They work by reducing the body's response to signals that would usually trigger breathlessness.</p> <p>Opioids can be given in different ways, including as tablets or liquid solutions orally. Alternatively, opioids can be given as injections / infusions under the skin.</p>
<p><b>Benzodiazepines</b> e.g. diazepam, lorazepam or midazolam</p>	<p>Benzodiazepines are anxiolytic medications that are sometimes used in addition to non-medication techniques to manage anxiety.</p> <p>They work best in helping manage breathlessness when there is a significant anxiety component.</p> <p>Benzodiazepines can be given orally or as injections / infusions under the skin.</p>
<p><b>Antidepressants</b> e.g. SSRIs (citalopram, sertraline) or Mirtazapine</p>	<p>SSRIs (selective serotonin reuptake inhibitors) and Mirtazapine are medications used to treat depression and anxiety.</p> <p>They are useful in managing chronic breathlessness when there is a significant component of anxiety.</p> <p>SSRIs and Mirtazapine are given orally.</p>
<p><b>Oxygen</b></p>	<p>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.</p> <p>Oxygen can be given to be used on walking / exertion or to be used at rest.</p> <p>Many patients find airflow from a fan or a draught from an open window / doorway gives a similar result to prescribed oxygen.</p>

If your palliative care team or specialist nurse/doctor feels 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 patients find it useful to write down the things that help them when they are breathless. This is useful for the patient as well as their friends, family, carers and health care professionals.

The following example has a blank copy of a plan for you to fill in for yourself. You can ask a member of your family or a health care professional to help you with this if you would like.

### Example:

<b>How to help me when I'm breathless</b>	
<b>Please be aware:</b>	
<ul style="list-style-type: none"> <li>• I feel frightened when I'm breathless.</li> <li>• I can't answer many questions as I need to focus on my breathing.</li> </ul>	
<b>Step 1</b>	<ul style="list-style-type: none"> <li>• Open the windows.</li> <li>• Use fan(s).</li> <li>• I need to sit on the edge of the bed and lean forward on the side table.</li> <li>• Gently rub between my shoulders.</li> <li>• Keep me company.</li> </ul>
<b>Step 2</b>	<p><b>If step 1 is not adequate:</b></p> <ul style="list-style-type: none"> <li>• Oral morphine liquid (oramorph) 2mg.</li> </ul>
<b>Step 3</b>	<p><b>If step 2 is not adequate:</b></p> <ul style="list-style-type: none"> <li>• Oral loraxepam tablet 0.5mg.</li> </ul>

<b>How to help me when I'm breathless</b>	
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<b>Please be aware:</b>	
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<b>Step 1</b>	
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<b>Step 2</b>	<b>If step 1 is not adequate:</b>
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<b>Step 3</b>	<b>If step 2 is not adequate:</b>
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## **Section 6:**

# **Final thoughts on managing breathlessness**

- Breathlessness can feel frightening and / or be debilitating.
- Understanding normal breathing patterns and how breathlessness can impact on our functioning, thoughts and feelings can help us regain control of our breathing.
- Practicing different techniques can help regain a sense of control and mastery in recovering your breath.
- Different patients find some techniques for helping with breathlessness more useful than others. It is important to try and work out what is most helpful for you and put this down in a plan so others can help you.
- When breathless, it takes a lot more of our energy to complete daily tasks. Be kind to yourself and consider what you need and want to do in the day to make the most of your energy.

### **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](http://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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