

A practical guide to coping with breathlessness

Information for patients



Leeds Centre for
Respiratory Medicine

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Breathing problems are very common in people who have heart and lung conditions. Breathlessness can be disabling, frightening and distressing for all those concerned.

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 from your GP.

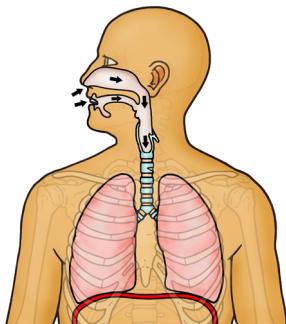
Breathing methods and positions to ease breathlessness

How do we breathe?

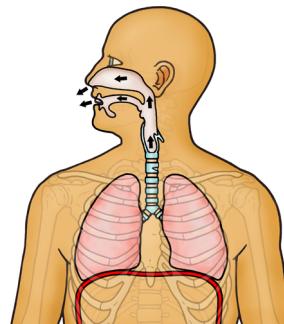
The diaphragm

The main muscle of breathing is the diaphragm. This is a large flat sheet of muscle covering the base of your rib cage. As you breathe in, it moves down to help draw the air into your lungs, pushing your tummy forward as it moves. When you breathe out it relaxes, moving upwards, returning to its natural dome shape and allowing your tummy to rest back in. The diaphragm muscle does not tire easily and therefore can move up and down all day, every day without getting tired.

breathing in



breathing out



The breathing accessory muscles

There are many muscles around your neck and shoulders with the role of moving your neck and arms. However, when you are breathless these muscles can pull on your upper ribs to help you draw air into your lungs. This is a normal response to breathlessness. These muscles are therefore called breathing accessory muscles.

The main role of breathing accessory muscles is to move the neck and arms. They are not designed to be used for long periods, unlike the diaphragm. Therefore long term overuse of these muscles for breathing can make them become tight, stiff and sore.

General advice

- **Avoid breath holding** during activities i.e. climbing stairs or bending.
- **'Blow as you go'**, breathe out on effort i.e. blow out when bending, lifting, reaching or standing up from a chair.
- **Avoid rushing**. Breathless patients sometimes rush as they wrongly believe if they move quicker they will be less breathless when they get there.
- **Paced breathing** i.e. take a breath in and out on each step when climbing the stairs.

Breathing Control

How it works

This breathing method aims to make your breathing as efficient as possible by focusing on breathing from your diaphragm. This method also guides you to take in only the air that you need, to avoid unnecessary effort and to relax and calm your breathing.

When to use

Breathing control may help you recover quicker from breathlessness after activity. It may also help your breathing to settle if you feel panicky. You may wish to use this breathing method with the hand held fan.

Breathing control

Preparation

- Place one hand on your tummy, just above your belly button.
- Relax your shoulders and upper chest.
- Rest your elbows in by your side.

Spend as long as you need on each of the following points:

- Feel the breathing movement under your hand.
- Breathe in smoothly through your nose; allow your tummy to swell.
- Take in only the air you need.
- Breathe out through your mouth, relax and let your tummy fall.
- Release each out breath until it comes to its natural end.
- As you breathe out narrow your mouth slightly, if this helps.
- Each time you breathe out; relax your upper chest a little more.

Forward lean positions

How they work

Forward lean positions fix the shoulders still to support the breathing accessory muscles so they can pull on your ribs to help draw the air in. Leaning forward may also improve the movement of your diaphragm.



When to use

Use a forward lean position to help you recover from breathlessness after activity. When using these positions try to keep your back straight but let your head drop so your neck is relaxed. Also try to relax your wrists.

Recovery breathing method

For severe breathlessness or panic

How it works

The recovery breathing method encourages you to allow time for the air to leave your lungs as you breathe out, therefore creating more room for the next breath in. The aim of recovery breathing is to calm your breathing until you can breathe smoothly and quietly from your tummy.

When to use

Use the recovery breathing method when you feel extremely breathless or panicky. This is a good method to use with the hand held fan.

Recovery breathing method

- Take up a forward lean position.
- Use your hand held fan.
- Focus on the out breath, breathe out onto the fan.
- Don't worry about the in breath; it will take care of itself.
- As you breathe out narrow your mouth slightly, if it helps.
- When you feel ready, breathe out for longer. Once your breathing has eased move up into a straight back position.
- Relax your shoulders and upper chest.
- Bring your breathing back to your tummy.
- Stay still for a minute after you have got your breath back before moving.

Handheld fan

Will using a fan help my breathlessness?

Research studies have shown that a cool draft of air from a handheld fan can be very helpful in reducing the feeling of breathlessness.

You may also find that the following can also help ease breathlessness:

- desktop or floor standing fans
- opening windows, for example in a car,
- Some people like to use a cool flannel on their face.

How should I use the handheld fan?

- Fans with three or more rotating blades seem to be most effective as the airflow is stronger.
- When you feel breathless adopt a comfortable position (as detailed previously).
- Hold your fan approximately six inches or 15cms from your face. Aim the draft of air towards the central part of your face so that you feel the draught around the sides of your nose and above your top lip. You should feel the benefit within a few minutes.



Pursed lips breathing

When using either of the above breathing techniques some people find narrowing their mouth slightly as they breathe out makes their breathing feel easier. This is called pursed lips breathing. It helps by creating a backpressure that supports your airways open, allowing air to leave your lungs more easily. When practicing pursed lips breathing narrow your mouth gradually until you feel your breathing become a little easier. Pursed lips breathing does not help everybody. Ask your physiotherapist or healthcare practitioner for advice.

Relaxation

Learning to relax

Breathlessness can often cause anxiety and feelings of panic. Anxiety tends to make the feeling of breathlessness stronger, which in turn leads to more anxiety. It is important to remember that breathlessness in itself is not harmful and you will recover your breathing on resting.

It is also possible to try to control the level of anxiety you are feeling and relaxation is one way of helping with this. Relaxation is a useful skill that you can learn. This section will go through some ways to help you to learn how to relax.



How does my body react to a stressful event?

It is normal for our bodies to experience some degree of anxiety and these feelings are caused by the body preparing itself to perform (known as "fight or flight"). Imagine you are crossing a road, when you notice a car coming towards you. It is your anxiety that helps you get out of the way. So some anxiety is useful.

However, when this anxiety begins to affect life to an extent where you are experiencing unpleasant symptoms and unable to do what you want to do, it is helpful to understand the reasons why this is happening so that you are able to address these difficulties.

When we become anxious, the eyes and ears sense a threat and alert our brain. This then stimulates the adrenal glands situated next to the kidneys to produce adrenaline and release it into our blood stream. It reaches the heart, lungs and muscles and causes the reactions needed to help an individual fight or flee.

Because of your body responding like this, when you feel anxious you might experience some of the following things.

Body - symptoms such as tensed muscles, rapid heart beat, difficulties breathing, chest pains, sweating, dizziness, nausea, dry mouth, blurred vision or the need to go to the toilet more frequently.

Thoughts - negative thinking for example imagining the worse, appearing foolish, worrying about "going mad", thinking that you are having a heart attack, etc.

Actions - behaviour can be affected by thoughts and actions. Anxiety induced behaviours include avoiding situations or people, poor concentration, aggression, irritability and sleep problems.

How can I control my anxiety?

- Recognise what triggers your anxiety.
- Are there certain situations that make you feel more anxious?
- Write down the kinds of things that worry or concern you.
- Try not to worry about future events, concentrate on the present.
- Try to identify problems and solve them one at a time.
- Mention how you are feeling to health professionals.
- Learn a way of relaxing that works for you.

For example:

- Counting in your head,
- Listening to music,
- Ask someone to give a light hand or back massage,
- Meditation,
- Looking outside.



Managing your energy

Why do I feel more tired / fatigued?

Fatigue or tiredness can be a common symptom in many long term conditions, especially when you are experiencing breathlessness too. Tiredness makes you feel less motivated to keep active, which means that often you avoid activities. This can lead to you having less energy, which in turn can make you more tired. When this behaviour becomes a habit, the cycle can often be difficult to break. When you have a condition that affects your lungs, it becomes more difficult to breath and this extra effort uses up more energy. We can not necessarily take away your tiredness completely, but there are a number of ways in which you can manage it, which in turn may help you to continue to do some of the things that you would like to do.



What can I do to help my fatigue?

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 at once. Use your energy on the things that you really want to do so this means deciding what your priorities are.

Energy levels

Learn to understand your energy levels and try to get to know where your limits lie. Think about it in terms of having a fixed amount of energy to use each day, some people imagine this to be a jar or jug of energy or liken it to a battery. This energy is only topped up overnight. Consider what you would like to use your energy on, but always leave something in the jar so that it is never empty. Even if 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.

Monitoring your energy

It is often useful to keep a 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.



Conserving your energy

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

Planning

Consider which times of the day are best for you and plan activities around this time. Try to space activities out during the week and not concentrate all 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 what 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 activities or ask someone else to do these.

Positioning

Try to avoid too much bending and twisting which can be tiring. Don't sit or stand in the same position 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 usual to reflect back at times, it is not so helpful to think about the things that you could do or the way in which you could do it before your energy levels were limited. Try to recognise the things that you are achieving.

How active should I be?

It is important to stay as active as you can. This will prevent your muscles becoming weaker. Getting a balance between activity and rest is important as is trying to maintain your fitness levels. A little regular gentle exercise each day can make all the difference. Regular exercise has also shown to help with fatigue as it will help maintain your strength to deal with daily activities.



Shortness of breath and your diet

We all know how important it is to eat a varied and nourishing diet. When we are unwell this is particularly important, yet people who experience difficulties with their breathing often find it difficult to eat enough.

This leaflet answers some of the questions people with breathing difficulties often ask about their diet and suggests ways to help.

Some commonly asked questions include:

My appetite is poor – what can I do?

- Small, frequent meals may be more manageable than three meals a day – eat or drink something every two to three hours.
- If you cannot manage a main meal, a nourishing soup or pudding would be a good substitute.
- Try to maximise the nutritional content of all foods/drinks by adding high calorie ingredients such as cream, full cream milk, butter, yoghurt, evaporated milk etc. wherever possible.
- If you feel full up quickly avoid drinking at meal times.
- Build-up, Complan or Vitafood can be a useful meal replacement and can be purchased from most chemists and large supermarkets.
- Nutritional supplements (for example, Ensure Plus, Fortisip, or Enlive) are sometimes prescribed by GPs or dieticians for



individuals who find it particularly difficult to eat sufficient amounts – please ask to see your dietician.

- Use a small plate for meals, large meals can often put you off your food completely. You can always have second helpings.
- Take advantage of times when you do have an appetite. Keep nutritious snacks handy, eat when you feel able and treat yourself with any foods you particularly enjoy.
- A glass of wine, sherry or brandy before meals may help to stimulate your appetite. However, do check with your doctor first.
- Try not to drink too much tea, coffee, squash or water as these are low in energy and can fill you up. Instead, try full cream milk, milky coffee, yoghurt drinks, or supplement drinks such as Build-up, Complan or Vitafood.



What about when I'm feeling sick?

- Eating small, frequent meals may also help if nausea is a problem.
- Try to eat or drink something every two to three hours.
- Cold food and drinks are often more acceptable and allow you to avoid cooking smells.
- Eating in a well-ventilated room may also prove helpful.
- Dry foods such as toast, plain or ginger biscuits and chilled drinks can also help.

How can I eat when I have to wear an oxygen mask?

- Nourishing drinks and soups can be drunk through a flexible straw placed under your mask.
- You may wish to ask your doctor about the possibility of using a nasal tube for your oxygen.
- It may be possible to remove your mask for short periods to allow you to eat. You may wish to discuss with your doctor.

I find it tiring preparing and eating food.

- Frozen, chilled or packet convenience meals can be useful and can be as nutritious as freshly prepared meals.
- Make several portions of meals and freeze them for use on days when you feel less like cooking – but make sure you reheat food thoroughly.
- You may be entitled to have meals delivered to your house – check with your doctor, dietician or social worker.
- Try to choose soft foods, such as well cooked egg dishes, soups, puddings, crustless bread with butter or margarine and a tasty topping (for example meat/fish paste, mashed banana, cream cheese, smooth peanut butter), or you may like to experiment with mashing, mincing or liquidising foods.
- Try chopping food into bite sized pieces to make chewing easier.
- Nourishing drinks can also be useful.



My mouth or throat is sore or dry

This is a problem for individuals with breathing difficulties, but may also be due to one or more of your medications.

If your mouth or throat is dry...

- Try to sip small amounts of fluid often.
- Make your meals moist by adding gravies, sauces, cream, evaporated milk, or fruit juices. Chewing gum can also help.
- Sucking ice cubes, fruit drops or even tinned pineapple chunks can help moisten your mouth.
- If mouth dryness is a severe problem, your GP may prescribe sprays or lozenges.

If your mouth or throat is sore...

- Avoid rough, crisp, spicy or salty foods and try using a little sugar to tone down acid foods and drinks.
- Warm foods may be easier to eat than hot or cold ones.
- Try eating soft foods, or try mincing, mashing or liquidising your meals.

My ability to taste food appears to have changed

- Try eating foods with stronger smells and flavours. Experiment with seasonings, herbs and spices.
- Avoid hot foods – food often tastes better at room temperature.
- Fish, chicken, eggs or bean and lentil dishes may be more palatable than meat.
- For some a ‘metallic’ taste in the mouth can be a problem so avoid any foods that make this worse.

Will any foods make my coughing worse?

Some people believe that certain foods may stimulate coughing. However, this varies from person to person and no proven links have been found with any particular foods. If you find that certain foods/drinks cause you to cough more than others, you may wish to avoid them but you should discuss this with your dietician to ensure that you continue to have a nutritionally adequate diet.

Remember that it is common to have 'good' and 'bad' days so don't get too worried if you don't manage to eat as much as on others – eat to enjoy your food.

Sex and breathlessness

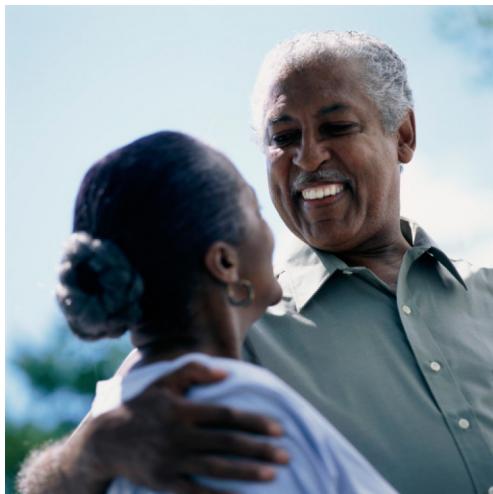
This section is aimed at helping you to enjoy a fulfilling sex life. It is normal for people with a lung condition to worry about having sex. You might be afraid that it will make you short of breath or that you will need to cough up phlegm. Sex is an important part of life for many people, and this doesn't have to change because you or your partner has a lung condition. It's normal to worry about getting tired or out of breath. However, both you and your partner should take responsibility for your sexual relationship, so it's important to talk to each other about your concerns and wishes and remain open-minded. However some people may need professional advice. The doctors and nurses involved in your care will be very willing to help you overcome your fears.

As you and your partner become more aware of those activities that make you short of breath you can plan to avoid them during sex by using positions that minimise breathlessness. For example you may find it easier to be in a sitting position. You may find it difficult to lie underneath your partner or you may find that standing to make love is easier.

Try to ensure that you are in a comfortable and well supported position, this should help you feel more relaxed and in less need to rush.

Taking things slowly will not only prevent breathlessness but will also help you feel more confident about making love. If you have been prescribed bronchodilators (Blue inhaler / reliever) try using them before and after having sex.

For further information about sex and breathlessness visit the British Lung Foundation website: www.blf.org.uk - lung-health-information section or pick up a leaflet in clinic.



How to make your life easier

At home

- Keep things you use frequently downstairs and close to hand.
- Have a phone point close to your bed or armchair.
- Consider using a trolley or carrier bag for shopping.
- Plan your daily activities, such as bathing or shaving, to make sure you gather all you need before you start.
- Pace your breathing to your steps; breathe in over one step, breathe out over the next two steps.
- Move at a comfortable pace and breathe steadily. Avoid holding your breath or trying to move too fast.
- 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 and remember to count your breathing.
- 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

- Take 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 periods - get just as much sleep as you need to be 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.
- If you are not sleeping at night, try not to sleep during the day. If you need to sleep during the day, try to keep this down to a short nap rather than a prolonged sleep.

Frequently asked Questions

Is being breathless harming me?

Breathlessness is not harmful, but it is very unpleasant and frightening. It is important for you to remain as active as your illness allows you to be. This information sheet will help you to manage your breathlessness.

Is there anything I can do to stop myself feeling frightened?

It is very common for people who are breathless to feel frightened and anxious. These feelings can make your breathing worse. It is important to remind yourself that breathlessness is not in itself dangerous. There are techniques which you can use to help reduce anxiety and control it. These include relaxation, positioning and breathing exercises.

Are there any drugs that will help my breathlessness?

There are three main families of drugs used to help breathlessness. The most commonly used drugs from these groups are:

- **Prednisolone or Dexamethasone (which are steroids):** You may have already taken steroids for another condition as they are commonly used in medicine. Your doctor can advise you on how to take them.
- **Morphine:** We usually think of morphine as a drug to treat pain, but it can also be very helpful for breathlessness. You will need a much smaller dose and sometimes you will take it less frequently than when used for pain relief.

- **Lorazepam & Diazepam:** Lorazepam & Diazepam are usually used to treat anxiety, but it can also help breathlessness. Lorazepam is often started at a low dose, building up to a higher dose depending on how it suits you. This maybe switched to diazepam which is usually prescribed at night as it can make you sleepy.

Will oxygen help me?

When you feel breathless, it often feels like you need “more air” or that you are not getting enough oxygen. This is not always the case and often trying other self-management techniques such as using a fan, practising breathing control and positioning can help to recover your breathlessness more quickly. Oxygen may help breathlessness in some people, but it does not help everyone.

Further support and Information

Patient information Videos

Patient information videos on the management of breathlessness can be found on the Leeds Breathlessness Service Website

<http://www.chestmedicine.co.uk/breathlessness>

British lung foundation - Asthma + Lung UK

www.blf.org

Association of Chartered Physiotherapists in Respiratory Care

www.acprc.org.uk

British Thoracic Society

www.brit-thoracic.org.uk

Buteyko Breathing Association

www.buteykobreathing.org

Leeds pulmonary fibrosis support group

www.ipfleeds.org.uk

Email: info@ipfleeds.org.uk

Action for pulmonary fibrosis

www.actionpulmonaryfibrosis.org

You can find your local breath easy support group at the following web address:

www.blf.org.uk/support-for-you/breathe-easy

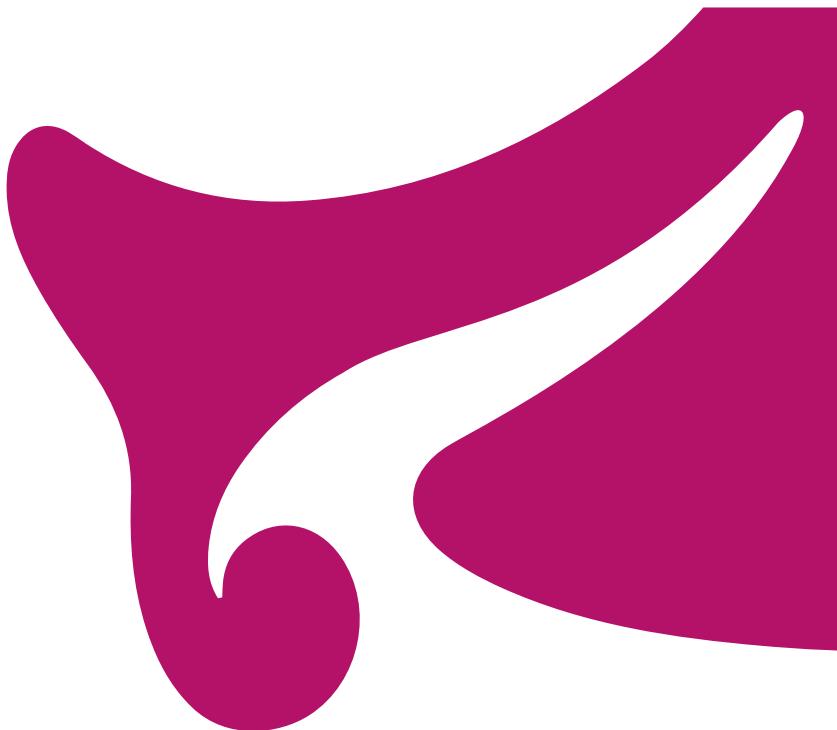
Acknowledgements

This leaflet has been adapted from information from the following organisations;

- Cambridge breathlessness service
- Association of Chartered Physiotherapists in Respiratory Care
- Asthma + Lung UK

With thanks to colleagues at

- Leeds Community Respiratory Team
- Sue Ryder Wheatfields Hospice, Leeds
- St Gemmas's Hospice Leeds
- Leeds Palliative Care Network



What did you think of your care?

Scan the QR code or visit bit.ly/nhsleedsfft

Your views matter



© The Leeds Teaching Hospitals NHS Trust • 3rd edition (Ver 1)

Developed by: Dr Alison Boland, Respiratory Services

Produced by: Medical Illustration Services • MID code: 20230317_017/EP

LN004005

Publication date

07/2023

Review date

07/2026