



# Pulmonary fibrosis

## Treatment and support

### Treatment of your condition

There are treatments for most of the different types of pulmonary fibrosis, and your treatment will depend on the specific form of pulmonary fibrosis you have. You can find out more about the different treatments in our downloads for the specific conditions – *IPF, hypersensitivity pneumonitis, occupational interstitial lung diseases, pulmonary fibrosis associated with connective tissue and autoimmune disease and drug-induced pulmonary fibrosis*.

You might be invited to take part in a medical study, also called a clinical trial, to investigate new treatments. It's not an option for everyone – if you want to know more, ask your doctor.

### Treatment of your symptoms

You'll also be offered treatment for specific symptoms, such as coughing, alongside disease-specific therapies.

**For coughing**, your doctor might treat problems that are making it worse, such as heartburn or a stuffy nose.

Do tell your doctor if you have symptoms of gastro-oesophageal reflux, such as **heartburn** or a sour taste at the back of your mouth. There's some evidence this may make any inflammation and fibrosis worse, as well as make a cough worse.

**Feeling out of breath** can have a serious effect on your everyday life. It can be a frightening experience, too. Pulmonary rehabilitation is an important treatment to help you cope with breathlessness.

### Help to stop smoking

If you smoke, stopping is very important. The NHS offers a free stop smoking service – your GP can refer you or visit [nhs.uk/smokefree](https://www.nhs.uk/smokefree)

## Pulmonary rehabilitation

Pulmonary rehabilitation, sometimes called PR, includes:

- a physical exercise programme, designed for people with lung conditions and tailored for you
- advice and information on looking after your body and lungs, managing your condition and coping with feeling short of breath

PR is led by a qualified respiratory professional, usually a physiotherapist. Nurses, occupational therapists, psychologists and dieticians may take part too.

PR is designed to support and reassure you, as well as help your condition. You may find you can walk farther, you feel less breathless and you feel generally more positive. Find out more at [blf.org.uk/exercising](http://blf.org.uk/exercising)

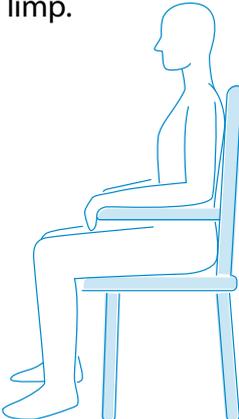
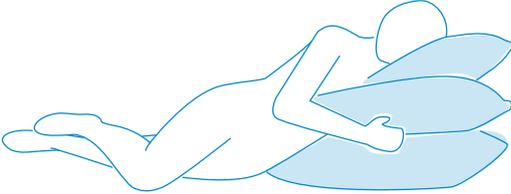
## Ways to help your breathing

If you have pulmonary fibrosis, you may tend to breathe very fast and shallowly – a bit like panting. You can use techniques and positions to help you control and slow down your breathing. You can also use them to avoid getting too breathless when you exert yourself, and help yourself to recover when you do get out of breath.

Talk to your respiratory physiotherapist or nurse for help to find out what works for you. Try the different breathing techniques to find what helps you and practise the ones that help. Our suggestions are based on what physiotherapists find works, as little research has been done with people living with pulmonary fibrosis.

## Breathing positions

Use these positions to practise your breathing control or to recover your breath.

| Position 1   | Position 2  | Position 3  |
|--|---|---|
| <p><b>Sit upright in a firm chair</b><br/>If your chair doesn't have arms, rest your arms on your thighs. Let your wrists and hands go limp.</p>  | <p><b>Stand leaning backwards or sideways</b><br/>Have your feet slightly apart, about one foot or 30cms away from the wall. Relax your hands down by your sides. If you prefer, rest your hands or thumbs in your waistband or belt loops, or across the shoulder strap of your handbag.</p>  | <p><b>High side lying</b><br/>Lie on your side with pillows under your head and shoulders. Make sure your top pillow supports your neck. Slightly bend your knees, hips and top leg.</p>  |

tip



Hold a hand-held battery fan near your face if it helps you to feel less breathless.

There's more detail in patient information leaflets developed by the Association of Chartered Physiotherapists in Respiratory Care at [www.acprc.uk/publications](http://www.acprc.uk/publications).

## Breathing control using your diaphragm

Breathing control means breathing gently, using the least effort. It will help when you're short of breath or feeling anxious. This type of breathing is commonly used in yoga.

**Use this breathing control combined with any of the techniques on the next few pages.**

You use your diaphragm – a big umbrella of muscle that's under your lungs, at the bottom of your rib cage. It contracts when you breathe, so pulling the lungs down, stretching and expanding them.

To get used to this, it helps to practise when you're sitting, and are relaxed and not out of breath. You'll then be able to use it when you are breathless, or to reduce your shortness of breath when you're exerting yourself.

Get into a comfortable position, with your arms supported (position 1 on the previous page). Let your shoulders and body be relaxed and loose.

- Put one hand on your chest and the other on your abdomen (tummy)
- Close your eyes to help you relax and focus on your breathing
- Slowly breathe in through your nose, with your mouth closed. If you're relaxed, the air will reach low in your lungs. You'll feel your abdomen rise – it will move out against your hand. The hand on your chest will not move much at all
- Breathe out through your mouth, either like a sigh or through pursed lips. Your abdomen will fall gently. Imagine all the tension in your body leaving as you let the air out
- Try to use as little effort as possible and make your breaths slow, relaxed and smooth. With every breath out, try to feel more relaxed and calm. Gradually try to breathe more slowly

Try the positions on the previous page to help you practise your breathing control, or to help you recover your breath when you get breathless. Your physiotherapist can help you find the positions that work best for you too.

## Breathing techniques

|   |  |
|---|--|
| <p><b>Relaxed slow deep breathing</b> is very useful while you're active. Use it from the very start of an activity that makes you out of breath such as walking or making the bed.</p> | <p><b>How do I do it?</b><br/>As you start to exert yourself, slow down your breathing and breathe in more deeply. Breathe in through your nose if you can. Use it with blow-as-you-go or paced breathing and pursed-lips breathing if that helps.</p> |
|---|--|

|   |  |
|---|--|
| <p><b>Blow-as-you-go</b> helps make tasks and activities easier. Use it while you're doing something that makes you breathless. You can use it with pursed-lips breathing.</p>  | <p><b>How do I do it?</b><br/>Breathe in before you make the effort. Then breathe out while you're making the effort. For example, when going up a step or standing up, breathe in before you stand or step up, and then blow out as you step or stand up. Try using pursed-lips as you blow out.</p>  |
| <p><b>Paced breathing</b> is useful when you are active, for example, walking or climbing stairs. You pace your steps to your breathing. You can use it at the same time as pursed-lips breathing and blow-as-you-go.</p> | <p><b>How do I do it?</b><br/>Count to yourself as you walk (or move). For example, breathe in for one step and then take either one or two steps as you breathe out.<br/><br/>You can take more steps as you breathe in or as you breathe out, if that feels better for you. The right number for you will depend on you. It's worth trying different combinations to find the one that works best for you - for example, one step in, two steps out, or two steps in, three steps out.</p> |
| <p><b>Pursed-lips breathing</b> can be used at any time to help you control your breathing.</p>   | <p><b>How do I do it?</b><br/>Breathe in gently through your nose, then purse your lips as though you're going to blow out a candle. Blow out with your lips in this pursed position. Imagine blowing out a candle when you breathe out. Blow out only for as long as is comfortable – don't force your lungs to empty.</p>  |

There's more detail in patient information leaflets developed by the Association of Chartered Physiotherapists in Respiratory Care at [www.acprc.uk/publications](http://www.acprc.uk/publications).

## Oxygen

If your condition gets worse, the level of oxygen in your blood may fall and this may make you feel more breathless. If this happens, your doctor will refer you for an assessment for oxygen therapy, which the NHS provides for free.

You might be given a portable oxygen cylinder to use when you walk around, or have an oxygen concentrator installed in your home. The concentrator takes normal air from the room and makes it richer in oxygen before you breathe it in. The machine is attached to tubing all around the house, so you're not confined to one room.

**Some people with pulmonary fibrosis need supplementary oxygen when they move about, and sometimes later when they're resting too.**

**Your oxygen prescription will be tailored to meet your individual needs. And you'll be advised how to adjust the flow of oxygen according to how active you are.**

You can find out more about oxygen therapy at [blf.org.uk/oxygen](http://blf.org.uk/oxygen) or by calling our helpline.

## Lung transplant

For a very few people, having a lung transplant might be an option if the pulmonary fibrosis progresses and isn't controlled by treatment. This is rare - only 175 lung transplants were carried out in the UK in 2011-12. Not all of these were for people with pulmonary fibrosis.

Whether you can be considered for a lung transplant depends on factors that influence the chance of a successful outcome, such as your general health, other medical conditions and your body mass index. There is no age cut-off, but it's unusual to accept people much over 65 years old. Sadly, there are not enough donor lungs available to meet demand.

If you wish to explore this option and your doctor thinks you might be suitable, you'll be referred to a transplant unit.

**There are significant risks in having a transplant. According to recent research, the survival rate\* at one year after lung transplantation is 79%, and for five years it is 53%. The survival rate at 10 years is 33%.**

\*Survival rate means the percentage of people who survive after lung transplant surgery.

## Palliative care

Your doctor, nurse or physiotherapist should also talk to you about palliative care or symptom control, or refer you to a palliative care specialist. This care is designed to improve the quality of your life and those close to you. It includes controlling pain and other symptoms, which can be interrelated, such as breathlessness, fatigue and anxiety.

Pulmonary fibrosis tends to be progressive and you may become increasingly breathless. If you're having trouble breathing, even when you're resting, your doctor might prescribe a sedative or morphine. You might know them as painkillers or sleeping tablets but these medicines can also help with symptoms of feeling short of breath as pulmonary fibrosis progresses. You may also need oxygen all the time.

## Looking after yourself

If you have pulmonary fibrosis, there is also a lot you can do to help yourself by leading a healthy lifestyle. Feeling very tired is a common symptom and health problems that used to be minor - such as catching a cold - can become more serious. Following these tips will help keep your strength up, reduce your risk of complications and help you feel better generally:

- Have a flu jab each year, and avoid being around people with colds.
- Ask your nurse for a pneumococcal vaccination. This is a jab you have just once to protect against pneumonia and many other infections.
- Stay as fit as you can. It's recommended we all do 150 minutes of exercise each week. Find out more at [blf.org.uk/exercising](http://blf.org.uk/exercising)
- Eat a healthy, balanced diet and maintain a healthy weight. It's a good idea to ask your doctor or nurse if they can refer you to a dietician, who can give you tailor-made advice.

## Emotions and enjoying life

As well as taking good care of your body, it's important to look after your mental health. When you have a serious condition like pulmonary fibrosis, it's common to have emotional struggles too. Your doctor or nurse will understand if you are feeling low, and they can help.

It's important to keep enjoying life and we can help with practical advice on staying active. We can also put you in touch with your local Breathe Easy patient group or pulmonary fibrosis support group. Have a look at [blf.org.uk/BreatheEasy](http://blf.org.uk/BreatheEasy) or call our helpline.

**Get in touch with us to find support near you.**

Helpline: **03000 030 555**

Monday to Friday, 9am-5pm

Ringling our helpline never costs more than a local call and is usually free, even from a mobile.

[helpline@blf.org.uk](mailto:helpline@blf.org.uk)

[blf.org.uk](http://blf.org.uk)

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We value feedback on our information. To let us know your views, and for the most up to date version of this information and references, call the helpline or visit [blf.org.uk](http://blf.org.uk)