ASTHMA+
LUNG UK

LIVING WITH PULMONARY FIBROSIS

Contents

We feature real life stories in this booklet. Some names have been changed and some pictures are posed by models. The information in this booklet has been reviewed by independent experts. We have made every effort to ensure that the information provided is correct. Asthma + Lung UK cannot accept liability for any errors or omissions, and policy, practice or medical research may change. If you are concerned about your health, you should consult a doctor.

In this booklet, you can find out the basic facts about pulmonary fibrosis in adults, its symptoms, and how it's diagnosed and treated.

Pulmonary fibrosis is the end result of many different conditions that cause scarring in the lungs. This reduces the amount of oxygen that gets into your bloodstream every time you breathe.

pulmonary = it affects your lungs

fibrosis = a build-up of scar tissue, which makes your lungs stiff

The right care can help you feel better and improve your quality of life.

We've put this information together for you, your family, carers and friends.

Children: There are rare lung diseases that cause scarring in children's lungs too. They can be very different from those in adults. Find out more at **blf.org.uk/children**

What is pulmonary fibrosis?

Pulmonary fibrosis is the end result of many different conditions that cause scar tissue to build up in your lungs and make breathing increasingly difficult. All types of pulmonary fibrosis are considered rare.

Pulmonary fibrosis is an interstitial lung disease (ILD). There are more than 200 different ILDs.

- pulmonary: it affects your lungs
- fibrosis: a build-up of scar tissue, which makes your lungs stiff
- interstitial: affects your interstitium, the network of tissue that supports air sacs in your lungs

Some types of pulmonary fibrosis have an identifiable cause. But for many types, a definite cause cannot be found, for example idiopathic pulmonary fibrosis.

Interstitial lung diseases cause scarring in your lungs, inflammation in your lungs or a mix of both. Some mostly cause scarring. Some mostly cause inflammation. Often there is a combination of scarring and inflammation. It's important to know which is the major cause of your symptoms to help decide the best treatment for you.

The treatment and outlook for different types of pulmonary fibrosis vary considerably, so if you're not sure about your diagnosis, check with your doctor or nurse for the exact name of your lung condition.

If you want to know about a type of pulmonary fibrosis or ILD that is not covered in this booklet, call our helpline on **0300 222 5800**.

This information covers those seen most often:

- idiopathic pulmonary fibrosis or IPF
- hypersensitivity pneumonitis, formerly called extrinsic allergic alveolitis
- pneumoconiosis, also known as an occupational interstitial lung disease
- pulmonary fibrosis associated with connective tissue and autoimmune diseases
- drug-induced pulmonary fibrosis

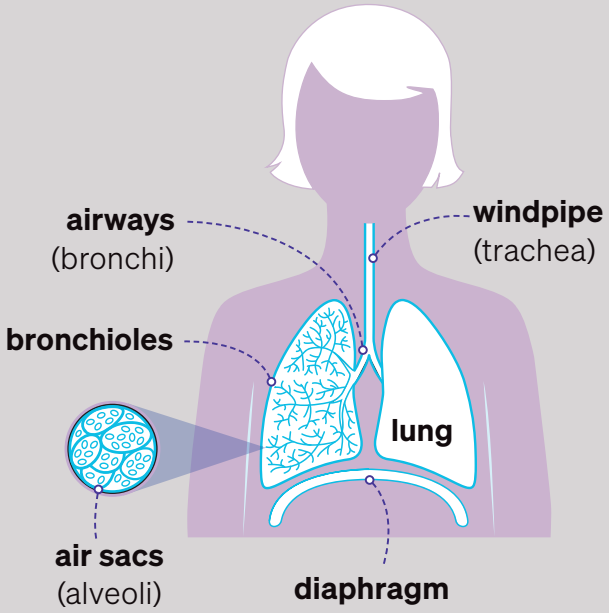
We do not always know what causes pulmonary fibrosis. We do know it is not a form of cancer or cystic fibrosis, and it is not contagious.

Cystic fibrosis is not a type of ILD or pulmonary fibrosis.

How does pulmonary fibrosis affect your breathing?

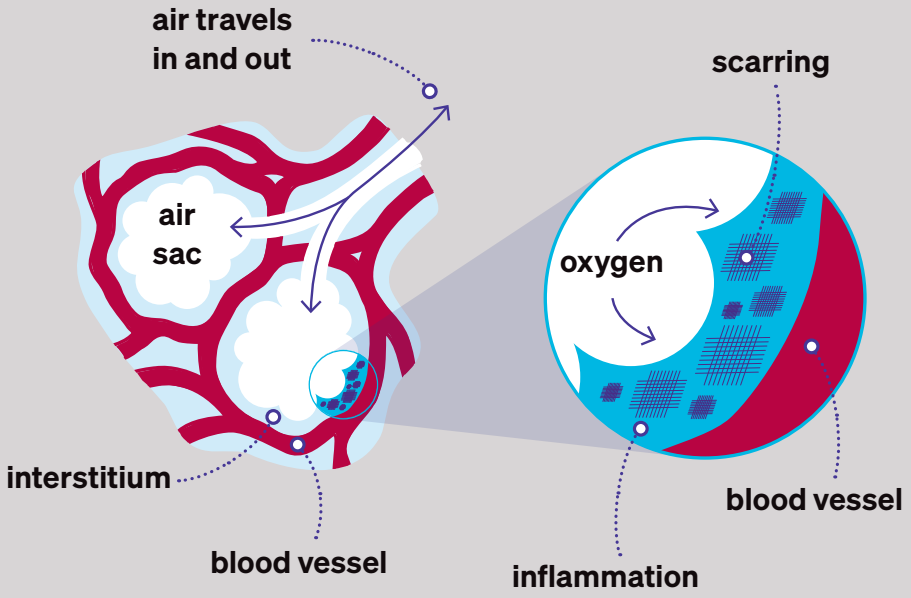
All kinds of pulmonary fibrosis result in scars in your lungs that make it harder for you to breathe. Scarring makes your lungs stiffer and less elastic so they're less able to move and take oxygen from the air you breathe.

Each time you breathe in, you draw air into your nose or mouth, down through your throat and into your windpipe. Your windpipe splits into two smaller air tubes called bronchi, which go to your lungs. The air passes down the bronchi, which divide again and again, into thousands of smaller airways called bronchioles.



The bronchioles have many small air sacs, called alveoli. Inside the air sacs, oxygen moves across paper-thin walls to the capillaries – tiny blood vessels – and into your blood. The air sacs also pick up the waste gas, carbon dioxide from your blood, ready for you to breathe it out.

If you have pulmonary fibrosis, scarring affects the air sacs in your lungs. The air sacs are supported by the interstitium, a network of supporting tissues. Scarring happens in the gaps between and around the air sacs and limits the amount of oxygen that gets into the blood.



As scarring increases, your lungs are less able to expand to allow you to take deep breaths and the level of oxygen in your blood can start to drop. Breathing may feel like harder work and you can feel breathless from everyday activities like walking.

What causes pulmonary fibrosis?

In most types of pulmonary fibrosis a specific cause cannot be found. One of the commoner types is idiopathic pulmonary fibrosis (IPF). The word 'idiopathic' means there is no known cause.

In a few cases, it's possible to identify a specific cause, such as:

- being exposed to certain types of dust – including wood or metal dusts or asbestos
- being exposed to allergens carried in the air – such as bird feathers or mould
- a side effect of a drug

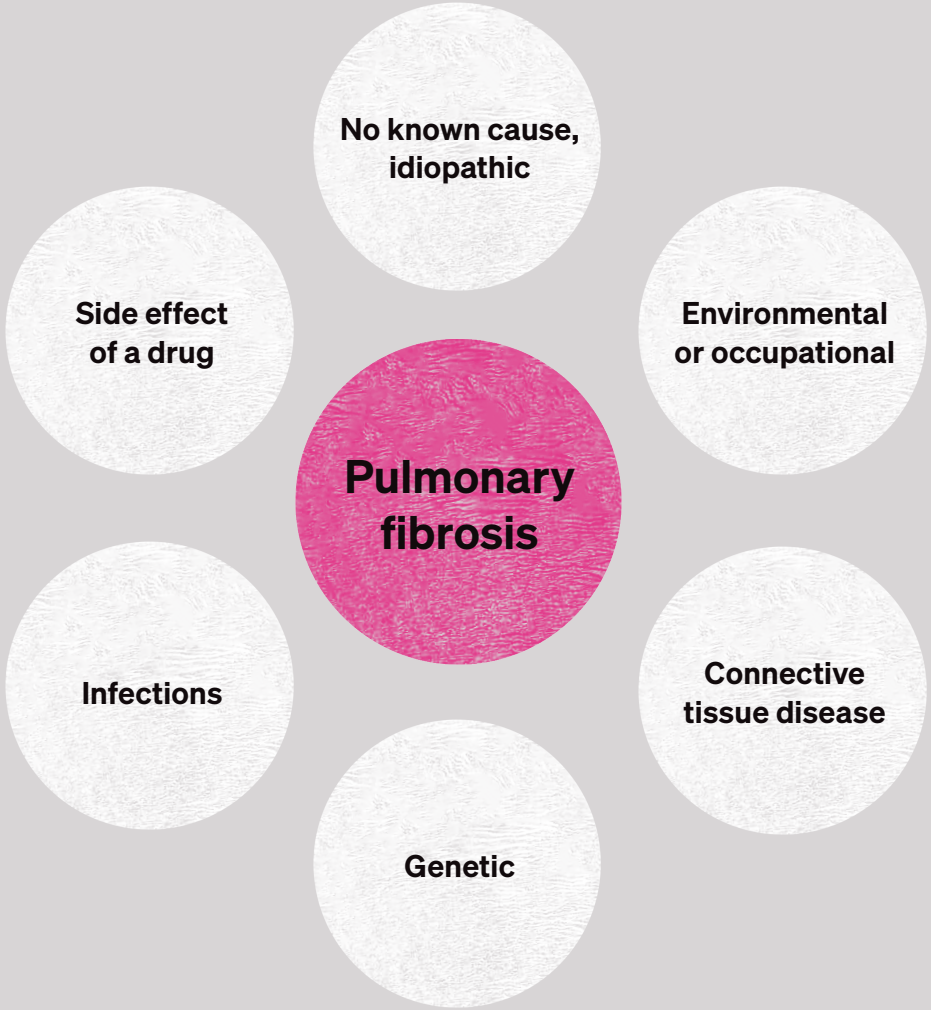
Some types of pulmonary fibrosis are more likely to occur when you have another condition such as rheumatoid arthritis or scleroderma. These are sometimes called connective tissue disease related ILDs or CT-ILD.

In a very few cases, two or more members of a family may develop pulmonary fibrosis. There are many complex ways in which it's possible to inherit a tendency to pulmonary fibrosis, and not all are well understood.

Current UK data sets suggest that less than 10% of people with pulmonary fibrosis have inheritable disease. Genetic testing isn't routinely available for people with pulmonary fibrosis. But there are some rare but well-known inheritable conditions that cause pulmonary fibrosis, such as dyskeratosis congenita. If you or a family member has one then you may be offered genetic screening.

Causes of pulmonary fibrosis

There are lots of different types of pulmonary fibrosis, with different causes, but often with no known cause.



Smoking can cause some very specific kinds of pulmonary fibrosis such as desquamative interstitial pneumonia and respiratory bronchiolitis-interstitial lung disease.

What are the symptoms of pulmonary fibrosis?

The different types of pulmonary fibrosis have similar symptoms. You'll have tests and speak to a specialist consultant to find out exactly which type you have.

The first symptom a lot of people notice is getting out of breath when they're exerting themselves, such as climbing a hill or stairs. But you might feel constantly short of breath, and not just when you're moving about. Many forms of pulmonary fibrosis tend to occur after the age of 60, so some people wrongly think they're getting breathless because they are getting older. Don't assume this is the case – it may well get worse untreated.

Shortness of breath can also be caused or affected by other long-term conditions, such as chronic obstructive pulmonary disease (COPD), heart disease and being overweight.

A cough that doesn't go away and feeling very tired all the time are two other symptoms of pulmonary fibrosis.

Some people with conditions associated with pulmonary fibrosis can lose weight or have a fever or aching or stiff joints and muscles. Others might have rashes, dry mouth and eyes, or poor circulation in fingers and toes (Raynaud's).

Another sign is finger and toenail nail clubbing. You or your doctor may notice your nails changing shape to become like a drumstick: the tips of the fingers get bigger and the nails curve around the finger tips, and the base of the nail feels spongy.

How is pulmonary fibrosis diagnosed?

Go to see your GP if you have symptoms that might be due to pulmonary fibrosis.

Your doctor will examine you, looking for other causes of breathlessness. They'll listen for crackles in your lungs and arrange a chest X-ray if they hear any.

If you have IPF, doctors listening to your chest can often hear crackles in your lungs that sound like opening velcro.

If there is any suspicion you may have lung fibrosis, your doctor will refer you to a chest specialist at your local hospital. You may be referred on again for further investigation or specialist treatment to a specialist in ILD if there isn't one in your local hospital.

The hospital doctor will ask questions about your medical, family and work history and your symptoms. They will examine you, listen to your chest and assess the need for tests. They may include:

- a CT scan of your lungs, which uses X-rays to produce detailed images of your lungs
- breathing and lung function tests to measure how well your lungs are working
- blood tests.

For some types of pulmonary fibrosis, the results from a CT scan can be very clear and allow a diagnosis to be made.

On a CT scan, IPF often shows up as a distinctive pattern on the lungs. You might hear your doctor call this honeycomb lung. The image shows lots of empty pockets or bubbles appearing where more solid-looking lung tissue would normally appear.

For information about lung function tests have a look at **blf.org.uk/breathing-tests** or call our helpline.

Looking inside your lungs

Your doctor may need to look inside your lungs and possibly remove some cells or tissue for testing. Different procedures can be used to get some lung tissue:

- **flexible bronchoscopy** involves inserting a narrow tube through your nose or mouth, down into your lungs. You will have a local anaesthetic sprayed inside your nose and throat and often a sedative injection into your vein for your comfort. The tube has a camera on the end so the doctor can see inside your lungs. The doctor may flush some water through the tubing to remove and collect cells for analysis. Your doctor may also remove samples of tissue. These are called biopsies and are painless. This is usually an outpatient or day case procedure.
- **video-assisted thoracoscopy (VATS)** involves surgery under a general anaesthetic to get a larger piece of lung tissue. A surgeon makes keyhole incisions in your chest for a video-assisted surgical telescope to enter, and to remove tissue samples from your lungs.

It has higher risks than a bronchoscopy. It's undertaken only if your specialist needs more tissue to make a diagnosis and treatment plan. You'll stay in hospital for a few days for this test.

Diagnosing pulmonary fibrosis is a joint effort by your specialist team. It will include doctors who are experts in lung conditions, surgery, X-rays and scans, and laboratory tests. The specialist nurse is an important part of this team and a good source of information and support for you. This multidisciplinary team (MDT) will review all your test results to reach a diagnosis.

What's the outlook?

Most forms of pulmonary fibrosis tend to get worse over time. The likelihood of this happening and how quickly it happens varies with the type, but also varies from person to person. This makes it difficult to predict exactly how fast symptoms may progress and change. The aim of treatment is to slow down this rate of change. The chance of success depends on the exact diagnosis and how well you can tolerate treatment. You will be monitored and have regular tests of your lung function to look for changes.

In some people, pulmonary fibrosis progresses very quickly, while others live with stable disease for many years. Some conditions progress at a steady rate, in others, apparently stable conditions can change suddenly. This sudden worsening of symptoms is called an exacerbation.

Treatment

Treatment of your condition

Your treatment will depend on the cause of the fibrosis. Once lung scarring occurs in the lungs it cannot be reversed, so there is no cure for existing fibrosis, whatever the cause.

- Drug treatments aim to stabilise or slow down the rate of scarring in the lungs. Specific drugs can be used to treat IPF for people whose lung function tests fall within a certain range.
- Steroids or other immunosuppressant drugs are used to suppress inflammation in the lungs.
- In conditions like hypersensitivity pneumonitis, it's key to avoid being exposed to the allergen causing symptoms, if the allergen can be identified.
- Any drugs causing problems with your lungs will be stopped.

Lung transplant

For a very few people, having a lung transplant might be an option if the pulmonary fibrosis progresses and isn't stabilised by treatment. Transplants are rare – 214 lung transplants were carried out in England in 2017-18. 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. If your doctor thinks you might be suitable, you'll be referred to a transplant unit for further assessment and a decision.

As well as existing therapies, 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.

Best supportive care

Treating just the symptoms, rather than the cause of a disease, is called best supportive care. As soon as you are diagnosed, your doctor, nurse or physiotherapist should talk to you about ways to reduce your symptoms and support your mental wellbeing. They may be able to do this at your usual place of care or you may be referred to a specialist in this area, usually a palliative care consultant.

Palliative care specialists are experts in symptom management and may help at various times during your illness, not just in the final stages. Palliative care focuses on controlling your symptoms, such as breathlessness, fatigue and anxiety. It may also stop treatments that are not working or causing side effects. The focus is on addressing issues to improve the quality of life for you, your family and carers.

Controlling your symptoms

For coughing, your doctor might treat problems that could be making it worse, such as heartburn (acid reflux) or a stuffy nose.

Tell your doctor if you have symptoms of acid reflux, such as **heartburn**, indigestion or a sour taste at the back of your mouth. There's evidence this may make inflammation and fibrosis worse and also make a cough worse.

“I was amazed at how helpful pulmonary rehabilitation was. It told me things I needed to know. It gave me the confidence to go to the gym, even with my oxygen. I made a friend on the course and we went together.”

Lesley

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 way to help you cope with breathlessness by increasing your fitness and ability to cope with feeling out of breath. The course 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 generally feel more positive. Ask your team about this. Read more at **blf.org.uk/pr**

If your condition gets worse, the level of oxygen in your blood may fall. This may make you feel more breathless. If this happens, your doctor will refer you for an assessment for oxygen therapy. Using oxygen is a way of keeping more active, and some people will use it at rest too. Your oxygen prescription will be tailored to meet your individual needs. Find out more at **blf.org.uk/oxygen**

If you have distressing symptoms of breathlessness and really troublesome coughing, tell your doctor. They may prescribe you low doses of morphine and sedatives to help.

You may struggle to cope emotionally with having a serious condition like pulmonary fibrosis. You are not alone. Many people with a long-term lung condition feel anxious, have a low mood or symptoms of depression. It’s important to look after your mental wellbeing. Your doctor or nurse will understand and can help. Have a look at our information about looking after your mental health at **blf.org.uk/mental-health**

Help to stop smoking

If you smoke, **stopping is very important**. Your GP can refer you to free help to stop smoking or visit **blf.org.uk/smoking**

Looking after yourself

If you have pulmonary fibrosis, you can do a lot 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.

- Have a flu jab each year and avoid people with colds.
- Ask your nurse for a one-off pneumonia vaccination.
- Stay as fit as you can. There are many different ways to be active – find one that you enjoy. We have ideas at **blf.org.uk/keep-active**
- Eat a healthy, balanced diet and maintain a healthy weight. Ask your doctor or nurse to refer you to a dietician, who can give you tailor-made advice, especially if you are losing weight. Read more at **blf.org.uk/eating-well**
- Try techniques and positions 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 to help you recover when you do get out of breath.

Try the different breathing techniques to find what helps you and practise the ones that help. Talk to your respiratory physiotherapist or nurse for help to find out what works for you.

Have a look at the techniques and positions online at **blf.org.uk/breathlessness**

Types of pulmonary fibrosis

This section looks at specific types of pulmonary fibrosis and how they're treated.

Idiopathic pulmonary fibrosis (IPF)

IPF is the most common type of pulmonary fibrosis. It's called 'idopathic' because no one knows what causes it. But researchers now believe the body creates fibrosis in response to injury to the lung. The initial injury might be from:

- acid reflux from the stomach
- viruses
- environmental factors such as breathing in certain kinds of dusts. It's more common if you've been exposed at work to dust from wood, metal, textiles or stone, or from cattle or farming.

Some people may be genetically predisposed to develop IPF. This link is only found in about 10% of cases.

Symptoms

The main symptoms of IPF are breathlessness and coughing. It's a progressive condition and usually gets worse over time. In some people, symptoms get worse gradually over several years. For others, the symptoms get worse more quickly.

It's difficult to predict how rapidly IPF will progress in each person affected. Sometimes when the condition has been stable, people can get sudden flare-ups of symptoms, called exacerbations.

Treatment

At present, the scar tissue cannot be repaired by the body or any drugs, so there is no cure yet.

Current drug treatments can slow the rate of scarring, but they do not stop it. Before specific treatments were available, studies showed that almost half of people with IPF in the UK died within three years of their diagnosis. But about one in five lived for more than five years. Clinicians believe treatments available now will mean that people diagnosed today will survive longer.

Medication to slow lung scarring

Currently two drugs, pirfenidone and nintedanib, can be prescribed. In clinical trials, both drugs slowed down the loss of lung function in most people with IPF, decreased the rate at which their symptoms got worse and also improved life expectancy.

At present, both can only be prescribed in the UK to people whose lung function is within a set range, due to The National Institute for Health and Care Excellence (NICE) guidelines. If your lung function is outside this, you might be able to access them in a clinical trial. The BLF is campaigning for the range to be extended.

Both drugs slow down the development of scar tissue in the lungs of people with IPF. Your specialist can discuss the pros and cons of each with you to help decide which drug is best for you. If you take either drug and your lung function gets worse and outside the recommended range, these drug treatments may be stopped.

Clinical trials are looking at possible new treatments, including combinations of existing treatments, so other options may be available in future. You may want to discuss with your specialist team if you can take part in trials studying new treatments and therapies.

Pirfenidone – brand name Esbriet

This treatment comes as capsules or tablets taken with meals. Scientists don't know exactly how pirfenidone works yet, but they think it slows down inflammation and the build-up of scar tissue in the lungs.

It has some common side effects: feeling sick or nauseous, tiredness, indigestion and sometimes skin reactions to sunlight. Talk to your doctor about possible side effects if you're considering taking pirfenidone and ask about using sunscreen to prevent skin problems.

Nintedanib – brand name Ofev

Nintedanib has also been shown in trials to slow the rate at which lungs become scarred in IPF.

It also comes in capsules. Common side effects include diarrhoea, abdominal pain and nausea. If you're taking certain medications such as blood thinners, you may be advised not to take nintedanib.

Treatment of specific IPF symptoms

Along with best supportive care for your symptoms described earlier, if it's difficult for you to cough up mucus, you may have a medicine such as carbocisteine or N-acetyl-cysteine (NAC) to help loosen and thin secretions in the lungs. Some people find it helps their cough, but others have side effects such as stomach discomfort, trapped wind or nausea.

Our IPF support service

Our IPF service gives you, your family and your carers a chance to talk regularly to a dedicated IPF advisor about topics that are important to you. Find out more at **blf.org.uk/ipf-support-service** or call our helpline.

“I adapt and stay positive.”

John was diagnosed with IPF four years ago.

I was invited to take part in a pulmonary rehabilitation study run by research physios and designed specifically for interstitial lung disease (ILD). It was a great help. I remain convinced exercise is a key way to help preserve my lung function.

I was first prescribed pirfenidone. I had a lot of side effects: nausea, vomiting, diarrhoea and a skin rash which required the regular application of SPF50 sun screen whenever I went out in the sun. I also felt very fatigued sometimes.

When test results indicated it wasn’t slowing the scarring as much as was hoped, I was switched to nintedanib. I was a bit nauseous initially, but I’ve found a good regime and manage my diet, which includes a good meal before taking the tablets.

I know the condition is progressing. I get more breathless when I do just normal everyday activities. I still work part-time, as this is important to me, but it is becoming more difficult. My recently acquired wheelable rucksack has made the one-hour commute a good bit easier. Little changes like these can make life easier.

I keep as active as I can. Badminton remains an important passion and I have many other hobbies and interests, I also exercise at home and do yoga.

I’ve started using ambulatory oxygen. I’d struggled with the concept, as I saw it as a sign my condition was progressing. But now I see it as a way of allowing me to continue to do the things I want to do.

My support group is vital

I’ve set up a support group for people with all types of ILD – and their families. I’m very aware that we don’t travel this road alone. Everyone has their own unique story about the impact of IPF on them.

Groups like ours can be a great way to get psychological support in a friendly and mutually supportive environment. It’s a way for people affected by IPF to take back some control and get support from others who are genuinely interested to hear how they are.

Pulmonary fibrosis caused by occupational or environmental exposure

Hypersensitivity pneumonitis

Hypersensitivity pneumonitis (HP) happens if your lungs develop an immune response – hypersensitivity – to something you breathe in which results in inflammation of the lung tissue – pneumonitis. It used to be called extrinsic allergic alveolitis (EAA).

One example is **farmer's** lung. This is caused by breathing in mould that grows on hay, straw and grain. Another is **bird fancier's lung**, caused by breathing in particles from feathers or bird droppings. Many other substances can cause similar disease patterns. In many cases it can be very difficult to find the exact cause.

Symptoms

The symptoms include cough, shortness of breath and sometimes fever and joint pains. They can come on suddenly after you've been exposed. This is called acute HP. It goes away – without leading to fibrosis of the lung – if you can recognise and completely avoid the substance that caused the attack.

Other people may get symptoms of breathlessness and cough more gradually, perhaps over many years, because their lungs are permanently scarred. This is called chronic, or long-term, HP. Often a specific cause cannot be found.

Treatment

HP is regarded as a more treatable cause of pulmonary fibrosis, but it can cause progressive symptoms and become hard to treat.

If a specific cause is identified, it's really important to completely avoid exposure to it. You may need to take anti-inflammatory medication called steroids for a few weeks or months. If you need steroids to control the condition for longer, your doctor may recommend more drugs to reduce the risk of side effects associated with steroids.

"I may never know what's causing my condition."

Jane, 61, was first diagnosed with hypersensitivity pneumonitis 10 years ago

When I moved to London, I developed a cough. It got so bad I ended up in hospital and was diagnosed with hypersensitivity pneumonitis. I took high dose steroids – and my symptoms disappeared! For seven years I had no symptoms at all.

But when the symptoms came back they didn't go away. So now my hypersensitivity pneumonitis is long-term. Tests showed I have a hypersensitivity to pigeon and budgie droppings, but my doctor says there are thousands of other things that I could be reacting to. I may never know what's causing my condition.

I get unpleasant bouts of coughing. And a small things makes me tired – like carrying shopping home.

I found my work as a lawyer more and more difficult. My employers suggested I claim on their permanent health insurance policy. My claim was accepted and I'm now on long-term sick leave.

I take steroids and immune-suppressing drugs every day. I'll probably take drugs for the rest of my life.

Occupational interstitial lung diseases

Pneumoconiosis is a term for a group of lung diseases caused by breathing in specific dusts in your workplace. They get lodged inside your lungs and cause scarring.

The most common type is coal worker's pneumoconiosis, caused by breathing in coal dust. Other forms are silicosis, caused by exposure to silica dust, and asbestosis, caused by breathing in asbestos.

There is often a long delay (20 years or more) between breathing in the dust and showing symptoms, so new cases usually reflect past working conditions. You'll often be retired before you're diagnosed.

Symptoms

Symptoms may include:

- shortness of breath
- persistent cough
- tiredness
- chest pain
- coughing up black phlegm (coal worker's pneumoconiosis only)

Treatment

The main treatment is avoiding the dust or fumes causing the condition. There are no specific drug treatments. Oxygen therapy and pulmonary rehabilitation may help with your symptoms.

If you have been exposed to certain substances in the course of your work, you may be entitled to compensation or benefits. Call our helpline on 0300 222 5800 to find out more.

Pulmonary fibrosis associated with connective tissue diseases

For reasons that we don't fully understand, sometimes the immune system turns against the body. This is called autoimmune disease. When your immune system attacks your body's own connective tissues, they scar.

Connective tissues lie under the surface of your skin and around your internal organs and blood vessels. If autoimmune diseases, including rheumatoid arthritis, Sjögrens syndrome and scleroderma, affect your lungs, they can cause pulmonary fibrosis. Unfortunately some of the drugs used to treat these diseases can also cause interstitial lung disease as a side effect.

The tendency to develop some forms of auto-immune or connective tissue diseases is genetic so your doctor should ask about your family history of these as well as other lung diseases.

Symptoms

The course your lung disease will take depends on many factors, including the form of autoimmune disease you have, how severe it is and the way it affects your lungs. Some people live just a few years after their diagnosis, particularly if they develop complications such as pulmonary hypertension. But other people survive much longer.

Treatment

You might need to be under the care of both a respiratory specialist and a rheumatologist. You'll usually be treated with immunosuppressant drugs. As well as treating lung symptoms, managing your underlying condition is essential to protect your lungs from more damage.

Drug-induced pulmonary fibrosis

Any medication can have side effects; some medicines can damage the lungs and cause pulmonary fibrosis. Some of the commoner medication types known to carry the risk include certain:

- antibiotics, particularly nitrofurantoin
- immunosuppressant drugs, such as methotrexate
- drugs for heart conditions, particularly amiodarone
- cancer chemotherapy drugs
- biological agents used to treat cancer or immune disorders

There are many other drugs that can potentially cause pulmonary fibrosis. You and your doctor have to weigh up the risks and benefits before you start a medicine. Sometimes the choices are difficult, especially if it's a life-saving treatment. It's important to tell your doctor about any new symptoms you have.

The situation varies for each individual and for each drug. Breathing problems from drug-induced pulmonary fibrosis can come on suddenly or develop more slowly over time.

Treatment

If a drug has caused fibrosis, people often get better quickly if the medication is stopped before much damage is done. Identifying this problem, and stopping the drug is the key intervention. Steroid medication can help calm down your body's response to the medication. But some people may have lasting lung damage.

Getting support

Our helpline

Get in touch with our friendly helpline team for more information about pulmonary fibrosis and practical support. We can also put you in touch with your local support group.

IPF support service

We offer an IPF support service for people living with IPF, their family and carers. This gives you an opportunity to speak regularly to a dedicated IPF advisor. Our helpline can talk to you about this or visit **blf.org.uk/ipf-support-service**

Pulmonary fibrosis support groups

Being diagnosed and living with a lung condition can be challenging. Our support groups can help you to make new friends who know what you're going through. Have a look at **blf.org.uk/breathe-easy** or call our helpline.

Our online hub

We've got more information at **blf.org.uk/pulmonary-fibrosis**

Other help for pulmonary fibrosis

Pulmonary Fibrosis Trust
www.pulmonaryfibrosistrust.org

Action for Pulmonary Fibrosis
www.actionpulmonaryfibrosis.org

Versus Arthritis has information about connective tissue disease and immunosuppressant drugs
www.versusarthritis.org

Get help

Call our helpline on **0300 222 5800**

We are here to help if you want:

- answers to your questions – whether it's about coping with symptoms, your rights or finding equipment
- clear and trustworthy information about breathing problems and living with a lung condition
- to get in touch with your local support group

Our friendly team are here Monday to Friday 9am to 5pm. Ringing will cost the same as a local call. It's usually free, depending on your call package, even from a mobile.

Or visit **AsthmaAndLung.org.uk** to find support and information or to join our web community

■ get support and information	**blf.org.uk/support-for-you**
■ sign up to our newsletter	**blf.org.uk/signup**
■ find your local Breathe Easy group	**blf.org.uk/breathe-easy**
■ join our web community	**healthunlocked.com/asthmalunguk-lung**

Help others like you

You can help us to fund more research to find cures and new treatments, and make sure everyone has the support they need. We're the only UK charity looking after the nation's lungs, and we rely on your donations. Visit **AsthmaAndLung.org.uk** or call **0300 222 5800**.

Together we fight for lung health

Helpline: **0300 222 5800**

AsthmaAndLung.org.uk

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