



Action for  
Pulmonary Fibrosis

Pirfenidone

Antifibrotic medication



## What is pirfenidone and how does it work?

Pirfenidone is an antifibrotic medication. This means it can help to slow down the rate of scarring in the lungs, which may preserve your lung function for longer. Pirfenidone does not reverse the scarring that has already happened or stop future scarring.

There are several different brands of pirfenidone available.

## Who can and can't take pirfenidone?

The National Institute for Health and Care Excellence (NICE) decides the eligibility criteria for antifibrotics. Their decision is based on the results of research studies.

Some people with idiopathic pulmonary fibrosis (IPF) can be prescribed pirfenidone. To be prescribed pirfenidone if you have IPF, you need a certain breathing test score. Your forced vital capacity (FVC) score must be above 50% of what is normal for someone of your age and gender and below 80%. FVC is the amount of air that you can breathe out in one breath, after fully inhaling. This is a measure often used to see how well your lungs are working. Pirfenidone isn't suitable for everyone with IPF, however.

It can't be used by people who:

- are allergic to any of the ingredients of pirfenidone (the ingredients are listed on the information sheet within the packaging)
- have severely impaired liver function
- are under the age of 18
- are pregnant, planning a pregnancy or might get pregnant. We do not know enough about the risk to an unborn child. If you are breastfeeding, speak to your doctor to discuss the risks and benefits.



There may be other conditions that make pirfenidone unsuitable for you. Make sure to tell your interstitial lung disease (ILD) or respiratory team if you:

- have any other current or previous medical conditions
- have had any problems with your heart
- have any recent or planned surgeries
- have any allergies
- take any other medications.

If you are unable to take pirfenidone, your healthcare team will discuss other options to help manage your pulmonary fibrosis.



# How to take pirfenidone

Always follow the advice given by your healthcare team.

## What dose should I take?

Pirfenidone is available in 267mg tablets/capsules and 801mg tablets/capsules.



The maximum dose of pirfenidone is 801mg three times a day.

Most people will start on a low dose and gradually increase it. This usually takes around three weeks, but it might take longer for some people. YourILD or respiratory team will give you advice on how to do this, but it might be similar to this:

- **Week one:** One 267mg tablet, three times a day.
- **Week two:** Two 267mg tablets, three times a day.
- **Week three:** Either one 801mg tablet, three times a day OR three 267mg tablets, three times a day.

## When should I take pirfenidone?

Pirfenidone should be taken with, or straight after, food and the tablets should be swallowed whole. Do not chew or crush the tablets. This can alter how it works in your body.

## What food can I take it with?

Generally, the food you take with your medication doesn't need to be anything specific. Some people find that a large snack works well, for example, a sandwich or a banana. If you need to take several tablets at once, take one tablet, eat a little, then take another tablet, repeating this until you've taken them all. This may help to reduce side effects.

## What if I miss a dose?

If you forget to take a dose, read the information in the packet for guidance. It will usually suggest:

- If it is **more** than three hours until your next dose, take the missed dose as soon as possible, with food.
- If it is **less** than three hours until your next dose, wait until your next dose is due and take this as normal.



Do not take two doses together to make up for a missed dose.

If you stop taking pirfenidone, it's very important that you let yourILD or respiratory team know as soon as possible.

## How long will I have to take pirfenidone for?

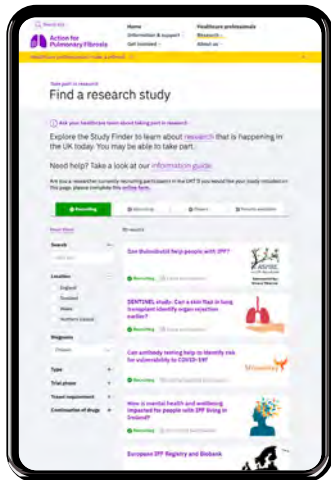
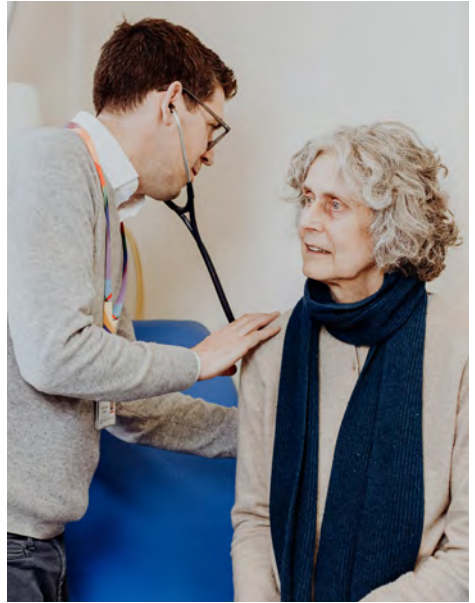
You will usually continue to take pirfenidone as long as:



- it's working to reduce the rate of lung scarring
- the side effects are manageable.

## Why isn't there an inhaler version?

Currently, there are no inhalers that can treat PF. This is because scarring is found deep within the lungs and further research is needed to prove that medications delivered by inhalers can reach here. Studies are looking at inhaled versions, but results aren't available yet.



Action for pulmonary fibrosis Study Finder



 [www.actionpf.org/research/take-part/studies](http://www.actionpf.org/research/take-part/studies)

# Side effects

You should tell your ILD team about any side effects you're experiencing.

## What are the possible side effects of pirfenidone?

As with all medications, pirfenidone can have side effects. Many of these can be managed with the help of your ILD or respiratory team. Some side effects will get better over time. If you're experiencing side effects, make sure you're taking your medication with or straight after food as prescribed. You should tell your ILD or respiratory team about any side effects you're experiencing.

### Common side effects

#### • Sun sensitivity (photosensitivity)

Pirfenidone can make your skin more sensitive to sunlight. Take extra precautions such as:

- Avoid being in direct sunlight, especially during 11am–3pm.
- Wear SPF 50 (5-star, blocking UVA and UVB rays) sun cream all year round. Remember that sunlight is still present on cloudy days.
- Cover up with clothing such as long sleeves and a hat.

#### • Diarrhoea

Some people find the following helpful for managing diarrhoea:

- Stay hydrated by drinking plenty of fluids.
- Going out can be a worry if you might need to go to the toilet quickly. The National Key Scheme (NKS) gives access to about 9,000 locked public toilets across the UK. You can buy a key from [Disability Rights UK](#) [\[7\]](#), who can also provide a list of where these toilets are.



- **Vomiting**

Some people find the following helpful for managing vomiting and nausea:

- Speak to your medical team for advice. You may be able to take medication for nausea.
- Home remedies, such as ginger.
- Stay hydrated by drinking plenty of fluids.

- **Abdominal pain or headache**

Speak to your medical team for advice. You may be able to take pain relief medication.

- **Weight loss**

Some people lose weight whilst taking pifrenidone, often because of a loss of appetite. It can be helpful to weigh yourself regularly to check for changes. If you are losing weight and are concerned, talk to a healthcare professional.

### **Uncommon side effects**

- unexplained bruising or bleeding
- yellowing of your skin or eyes
- severe itching

It's very important to seek medical advice before your next dose. Call 111 if this is out of hours.

### **Can these medicines affect my mood or mental health?**

Studies haven't shown that antifibrotics directly affect mood or mental health. Taking pifrenidone may indirectly affect your mental health. For example, having diarrhoea and vomiting caused by pifrenidone may affect your mental health.

**This booklet does not list all the potential side effects of pifrenidone. Make sure you read the drug information sheet that comes in the packaging of your medication.**

# Side effects

## Can you take breaks from pirfenidone?

Sometimes people take short breaks if side effects become difficult to manage. This might happen, for example, if you are travelling. The benefits of pirfenidone generally come from long-term treatment. If you take short breaks between long periods of taking the medication, it's unlikely to have a big effect. If you need regular or frequent breaks, your ILD or respiratory team can check if the medicine is still right for you.

## What happens if my dose is reduced – will I get worse?

Some people still benefit from pirfenidone at a lower dose.

The standard dose is 801mg. Research shows that this dose is effective. The lower dose (534mg) hasn't been tested in the same way.

However, the lower dose can be helpful for people who get bad side effects from the higher dose. It may reduce these side effects enough so they can continue taking the drug.

In practice, many healthcare professionals aim to keep people on treatment at whatever dose they can manage. Some research suggests that a lower dose may still be effective, but further research is needed to be sure.

## Can I switch to another antifibrotic?

There are currently two antifibrotic medications - nintedanib and pirfenidone. Sometimes it's possible to switch between them if you are experiencing side effects. This depends on several factors, including your lung function, your specific diagnosis and any other medical conditions you have. Your ILD or respiratory team can advise if this is an option for you.



## What if side effects still don't go away?

If side effects continue, please speak to your ILD or respiratory team. There may be other options to help you manage.

# Monitoring and check ups

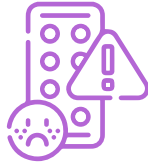
## How will I be monitored for the side effects of pirfenidone?

You will have monthly blood tests for the first few months that you are taking pirfenidone. If the results are okay, you'll continue to have regular blood tests. Blood tests are taken to check your liver function, as this can be affected by pirfenidone. They may be carried out by your local GP, respiratory team or ILD team, depending on your local services.

It's very important that you have these blood tests. They allow your ILD or respiratory team to check that it's still safe for you to take pirfenidone. It can be helpful to record in your calendar when your appointments are due so that you don't miss any. Make sure that you know whom to contact to check the results of your blood tests.

## How will I know if pirfenidone is working?

Most people have regular lung function (breathing) tests to see how well their lungs are working. Pirfenidone does not reverse existing scarring or make you feel better each day. Its purpose is to slow down new scarring rather than get rid of the disease.



## What if my condition gets worse while taking it?

If your disease keeps getting worse, your team can discuss other options. This may include things like:

- clinical trials
- focusing on managing symptoms.



# Daily life and pirfenidone

## How do I get my medication?

Pirfenidone is not available at most local pharmacies. It will usually be delivered to your home.

Speak to your healthcare team about how to get your medication. This may vary depending on where you live.

## Can I take other medicines at the same time as pirfenidone?

Before starting pirfenidone, it's important to tell your ILD or respiratory team if you take any medications. Some medications can affect how pirfenidone works. This includes:

- any medications prescribed by your GP or another healthcare professional
- any medications or supplements that you buy over the counter or online
- any herbal medications or supplements.

Some medications can increase the risk of side effects. Whoever prescribes pirfenidone will check that it's safe to take with your current medications.

Don't start taking any medications or change a medication's dosage without first checking with your doctor or pharmacist.

Make sure your GP or pharmacist knows that you're taking pirfenidone if they prescribe or advise any other medications.

## You should avoid grapefruit and grapefruit juice whilst taking pirfenidone. Grapefruit affects how pirfenidone is processed in the body.

Digestive side effects of pirfenidone such as vomiting and diarrhoea can affect how other medications work, including oral contraceptives (also known as 'the pill').

## What if I work shifts or have an irregular routine?

Discuss this with your ILD or respiratory team. They can advise you on how to time your medication around your routine. Some people also find it helpful to:

- set alarms or reminders on your phone
- keep your medication in the same place and somewhere that is easy to see.

## I fast for religious or cultural reasons. Can I still take pirfenidone?

Many people continue to take pirfenidone whilst fasting, as exemptions are often made for health requirements. You should follow the advice of your healthcare team.

Many people will be advised to keep taking their regular dose three times a day, with similar intervals of at least 3 hours between doses.

As mentioned above, the benefits of pirfenidone generally come from long-term treatment. If you take short breaks between long periods of taking the medication, it's unlikely to have a big effect.

### **How do I balance taking it with my quality of life?**

Managing side effects of pirfenidone can be difficult and affect your quality of life. If taking pirfenidone is affecting your quality of life, please speak to your ILD or respiratory team. There may be changes that can help reduce your side effects or maintain your quality of life.

### **What if I need surgery or get another illness?**

Tell your ILD or respiratory team as soon as possible. They will work with other healthcare professionals to decide if your treatment needs to change.

### **What if I want to have children? Could these medicines affect fertility or pregnancy?**

People who are taking pirfenidone and could get pregnant are usually advised to use contraception during treatment and for three months after.

There may be risks to an unborn child.


Diarrhoea or vomiting may make oral contraceptives (sometimes known as 'the pill') less effective.

There's no evidence that pirfenidone affects fertility once you stop taking it.

### **Can I have immunisation injections (vaccines) whilst taking pirfenidone?**

Yes, taking pirfenidone doesn't change vaccination advice. Vaccinations, including live vaccines, are generally safe to have if you take pirfenidone. However, other factors may affect which vaccines are suitable for you. Please discuss with your healthcare team.

### **Can I drink alcohol whilst taking pirfenidone?**

Most people can drink alcohol whilst taking pirfenidone. The NHS recommends that you should drink no more than 14 units of alcohol per week. Further guidance available at [www.nhs.uk/better-health/drink-less](http://www.nhs.uk/better-health/drink-less) 

### **Where can I find out more about pirfenidone?**

If you want to know more about pirfenidone or have any questions, please speak to your ILD or respiratory team.

# About Us

## Action for Pulmonary Fibrosis (APF)

is the UK's leading charity dedicated to supporting everyone affected by pulmonary fibrosis. APF provides expert information, support services and funding, alongside promoting vital research and campaigning to improve understanding, treatment and care.

Working closely with healthcare professionals, policymakers and those living with pulmonary fibrosis, APF aims to reduce the time to diagnosis, remove barriers to life-saving treatments and ensure that all patients receive the comprehensive support they need. The charity's OneVoiceILD network unites a diverse group of stakeholders to drive consistent standards of care across all regions of the UK.

[actionpf.org](https://actionpf.org)

**If you need this information in another format such as large print, easy read or another language, please contact us.**

This leaflet provides general information only and is not a substitute for medical advice. Always follow the advice of your healthcare team and ask them if you are unsure.



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