



Action for
Pulmonary Fibrosis

Pirfenidone

Antifibrotic medication



This leaflet has been written to answer some questions you might have about pirfenidone. It isn't a substitute for advice from your interstitial lung disease (ILD) team so if you have any questions or concerns, discuss these with the team.

What is pirfenidone and how does it work?

Pirfenidone is an antifibrotic medication that is prescribed to slow down the rate of scarring in the lungs. Pirfenidone does not reverse the scarring that has already happened or stop any future scarring.

There are several different brands of pirfenidone available.

Who can and can't take pirfenidone?

Some people with idiopathic pulmonary fibrosis (IPF) can be prescribed pirfenidone. Their forced vital capacity (FVC) must be between 50-80% of the predicted value for someone of their age and gender. FVC is the amount of air that you can breathe out in one breath, after fully inhaling. This is a measure that's often used to see how well your lungs are working.

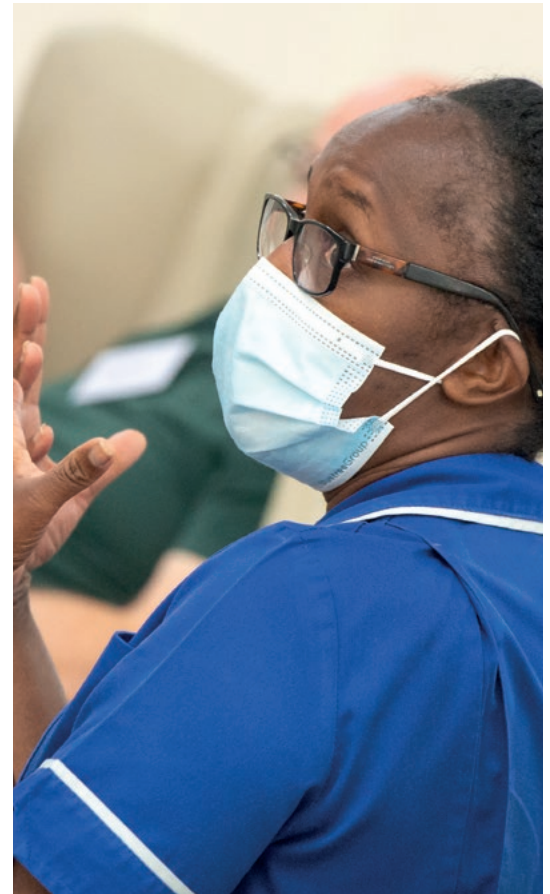


Pirfenidone isn't suitable for everyone with IPF, however. It can't be used by people who:

- Are allergic to any of the ingredients of pirfenidone (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.

You should let your ILD team know if you have had any recent or planned surgeries, and if you have any allergies.

There may be other medical conditions that make pirfenidone unsuitable for you. Make sure to tell your ILD team about any current or previous conditions.



What dose of pirfenidone should I take?

Always follow the advice given by your ILD team.

Pirfenidone is available in 267mg tablets/capsules and 801mg tablets/capsules. The full dose of pirfenidone is 801mg three times a day.

You will start on a low dose and gradually increase it. This usually takes around three weeks, but it might take longer for some people. Your ILD 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.



Take pirfenidone with, or straight after, food and swallow the capsules whole (don't chew or crush them).



What should I do if I miss a dose?

If you forget to take a dose, follow the below advice.

If it is **more than three hours** until your next dose, take the missed dose with food straight away.

If it is **less than three hours** until your next dose, wait until your next dose is due and take this as normal.

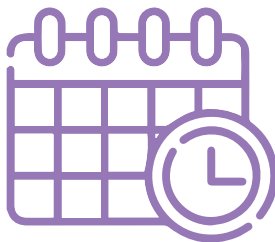
Do not take two doses together to make up for a missed dose.

If you stop taking pirfenidone, it's very important that you let your ILD team know as soon as possible.



How long will I have to take pirfenidone for?

You will usually take pirfenidone for as long as it is working to reduce the rate of lung scarring and the side effects are manageable.



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 team and 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 team about any side effects you're experiencing.

Common side effects

Sun sensitivity (photosensitivity)	Pirfenidone can make your skin more sensitive to sunlight so you should take extra precautions such as: <ul style="list-style-type: none">• Avoid being in direct sunlight, especially during 11am-3pm.• Wear SPF 50 (5-star, blocking UVA and UVB rays) sun cream all year round.• Cover up with long sleeves and a hat.
Diarrhoea	This is a common side effect of pirfenidone. You can take an anti-diarrhoea medication called loperamide, available over the counter at most pharmacies or supermarkets. Sometimes it will be sold under the brand name Imodium®. Make sure to follow the instructions in the pack. Stay hydrated by drinking plenty of fluids.
Vomiting	You may be able to get over-the-counter anti-sickness medication for vomiting and nausea. Discuss this with your community pharmacy, GP or ILD team. Home remedies such as ginger may be helpful. Stay hydrated by drinking plenty of fluids.
Abdominal pain or headache	You can take over-the-counter medications such as paracetamol. Make sure to follow the instructions in the pack.
Weight loss	Some people lose weight whilst taking pirfenidone, 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 your ILD team.

Uncommon side effects

Unexplained bruising or bleeding	Stop taking pirfenidone straight away and contact your ILD team.
Yellowing of your skin or eyes	
Excessive itching	

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

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 then have blood tests every three months instead. 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 or your ILD team, depending on your local services.



It's really important that you have these blood tests so that your ILD team can 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.

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

Before starting treatment, it's important to tell your ILD team if you are on any medications as some can affect how pirfenidone works. This includes any medications prescribed by your GP or another doctor, and any that you buy over the counter or online, including any herbal medicines. 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.

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

Yes, you can.

Can I drink alcohol whilst taking pirfenidone?

You can drink alcohol whilst taking pirfenidone, but you are advised to only drink alcohol in small amounts.

You should aim to drink no more than 14 units of alcohol per week. Further guidance is available at:
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, speak to your ILD team.

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



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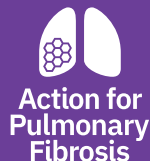
Action for Pulmonary Fibrosis is a patient-driven charity. We support patients and families and raise awareness of pulmonary fibrosis through campaigning, fundraising and education. We also fund research to improve quality of life for people living with pulmonary fibrosis and to find a cure. Our mission is to STOP pulmonary fibrosis.

actionpf.org



The ILD Interdisciplinary Network (ILD-IN) aims to provide a supportive network for health professionals of all disciplines working in interstitial lung diseases. Our purpose is to provide support, promote ILD specialty practice through education and professional development and to influence the policy of ILD care.

ild-in.org.uk



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