



Action for
Pulmonary Fibrosis

Pirfenidone

Patient Information



What are the aims of this leaflet?

This leaflet has been written to help you understand more about pirfenidone. It will tell you what it is, how it works, how it is used to treat lung conditions, and where you can find out more about it.

What is pirfenidone and how does it work?

Pirfenidone is a medicine that aims to slow down the development of scar tissue in the lungs. We do not know how this process works. It does not cure or reverse the scarring but, by slowing down how quickly the scarring occurs, pirfenidone may slow down the progression of idiopathic pulmonary fibrosis (IPF).

The brand name for pirfenidone is Esbriet®.

When should I take pirfenidone?

Pirfenidone is taken three times a day with, or straight after food. Swallow the capsule/tablet whole (do not chew or crush).

What dose of pirfenidone should I take?

Pirfenidone is available in 267 mg capsules/tablets and 801 mg tablets. The full dose of pirfenidone is 801 mg three times a day. You will build up to this dose by starting at a low dose and working up gradually to the full dose. This usually takes three weeks but might take longer if your Interstitial Lung Disease (ILD) team decide to do this more slowly. This will be explained to you by the ILD team who look after your idiopathic pulmonary fibrosis. You should only take the dose advised by your specialist ILD team.



How long will I have to take pirfenidone for?

You will take pirfenidone for as long as it is working. You will be monitored at regular intervals whilst you are on pirfenidone. Your ILD team will advise you about how this works in your area. You will be monitored regularly with lung function (blowing) tests.

What are the possible side effects of pirfenidone?

Pirfenidone can cause some side effects, but many of these can be managed with the help of your ILD team. Pirfenidone can cause photosensitivity (a skin reaction to daylight), therefore you should avoid sun exposure and wear Factor 50 (5 star) sun cream all year round. Sunscreens are not an alternative to clothing and shade, rather they offer additional protection. No sunscreen will provide 100% protection and you should cover up with long sleeves, gloves and a hat.

You might experience nausea, vomiting or indigestion and you may feel more tired. You may also experience loss of appetite and inflammation of the liver. Some of these effects wear off in time and can be helped by making sure you take your tablets with or after food.

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

You will be under the care of an ILD team who will arrange monthly blood tests for the first six months that you are taking the medication. After this, you will have your blood checked every three months. The blood tests are taken to check your liver remains healthy. Your specialist team will let you know if there are any problems with your blood tests and will tell you what you need to do. Your specialist ILD team will also be able to give you advice about managing any other side effects you may have.

Does pirfenidone affect pregnancy?

Do not take pirfenidone if you are pregnant, planning a pregnancy or might get pregnant. We do not know enough about the risk to the unborn child.



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

Sometimes other tablets can make your pirfenidone work less effectively or make it too strong. It is important to tell your ILD specialist team about all the medicines that you take. This includes medicines that you have had prescribed by your GP or any other health care professional. It also includes any medications that you buy over the counter and any herbal medications that you are taking.

Do not begin any medicine or change its dosage without first checking with your doctor or pharmacist.

Medications that can cause problems when taking pirfenidone include:

Some medication can stop pirfenidone working properly these include;

- **omeprazole** (used to manage indigestion or to protect the stomach)
- **rifampicin** (an antibiotic)

You should also avoid grapefruit and grapefruit juice.

Some medications can increase side effects. These include;

- **ciprofloxacin** (an antibiotic)
- **doxycycline** (an antibiotic that may make you more sensitive to the sun)
- **amiodarone** and **propafenone** (medicines that treat heart disease)
- any other medicines that are known as **CYP1A2 inhibitors**.

Can I have immunisation injections while on 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 try to drink no more than 14 units of alcohol per week. Further guidelines available at:

www.nhs.uk/live-well/alcohol-support/calculating-alcohol-units/

Where can I find out more about pirfenidone?

If you want to know more about pirfenidone, or if you have any questions about your treatment, you should speak to your doctor, nurse or pharmacist in your ILD team.

This information sheet does not list all of the side effects of pirfenidone. For more details and information, look at the drug information sheet which comes as an insert with your prescription.

This leaflet aims to provide accurate information about the subject. It has been approved by ILD-INN and Action for Pulmonary Fibrosis. Individual patient circumstances may differ, which might alter both the advice and course of therapy given to you by your doctor.

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Action for
Pulmonary Fibrosis

About Action for Pulmonary Fibrosis

Action for Pulmonary Fibrosis was founded in 2013 by a group of patients, family members and medical professionals with a personal or professional connection to pulmonary fibrosis. Since 2013, we have worked hard to support patients, raise funds for research, educate health care professionals, raise awareness of the disease and campaign on behalf of those who don't have a voice.

actionpulmonaryfibrosis.org



About ILD-INN

The ILD Interdisciplinary Network (ILD-INN) 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-inn.org.uk

To request this document in larger print, please contact info@actionpf.org

You can find out more about pulmonary fibrosis at:
actionpulmonaryfibrosis.org/about-pulmonary-fibrosis

For more about living with pulmonary fibrosis visit:
actionpulmonaryfibrosis.org/living-with-pulmonary-fibrosis

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