

## Patient information factsheet

# Pirfenidone (Esbriet)

We have given you this factsheet because you have a condition called idiopathic pulmonary fibrosis (IPF). Your doctor has prescribed a medicine called pirfenidone (also known as Esbriet), which can slow down the progress of IPF.

We hope this factsheet will help to answer some of the questions you may have about taking pirfenidone.

### What is idiopathic pulmonary fibrosis (IPF)?

Idiopathic pulmonary fibrosis (IPF) is a serious lung condition in which the lungs become scarred and breathing becomes increasingly difficult. 'Idiopathic' means that the cause is unknown.

As scar tissue (known as 'fibrosis') increases in the lungs, the lungs become smaller and stiffer. This leads to coughing and increasing breathlessness. IPF is a progressive disease, which means that it will get worse over time, but the rate at which it progresses varies from person to person. If it is not treated, it may be life-limiting.

### What is pirfenidone?

Pirfenidone is an anti-fibrotic medicine which has been shown to slow down the progress of IPF. It doesn't cure the condition or reverse any existing scarring but it can effectively slow down the rate of lung function decline by about 50%.

In the UK, Pirfenidone is currently only approved for treating IPF, and not for other forms of pulmonary fibrosis.

### Taking pirfenidone

#### Week one

You will start taking pirfenidone as one 267mg tablet, three times a day for one week.

#### Week two

You will increase to two tablets, three times a day for the second week.

#### Week three and onwards

You will start taking the full dose of three tablets, three times a day from week three onwards). Pirfenidone is only effective for as long as you take it, so if you have a good response, we may recommend that you continue taking it for a long time.

Pirfenidone should always be taken with meals.

If you develop any side effects from pirfenidone, we may reduce your dose until the side

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effects disappear. After this we would try to increase the dose again. If you cannot tolerate the medicine, we will stop the treatment. We may offer alternative treatments instead.

## Side effects

The most common side effects are:

- a loss of appetite
- nausea
- indigestion
- weight loss

Some people also develop a skin rash on sun-exposed areas, which can be quite severe. Cover up sun-exposed areas with light clothing and a hat, and use sunscreen on other exposed body parts. We recommend using a minimum of SPF 50.

If you believe you are experiencing any side effects please ring our interstitial lung disease (ILD) nurse specialist for advice, using the contact details at the end of this factsheet.

## Blood tests

You will need to have blood tests every month for the first six months to monitor for changes in your liver. After the first six months, if the blood results remain stable, you will only need to have blood tests every three months. You can have the blood tests done at your local surgery or hospital.

## Other medicines

Tell your doctor about all the medicines that you are taking (including over-the-counter medicines) before you start pirfenidone.

Make sure your doctor knows if you are being treated with:

- amiodarone
- fluconazole
- chloramphenicol
- ciprofloxacin
- fluoxetine
- paroxetine
- propafenone
- omeprazole (this will need to be changed to an alternative)

**Do not take a medicine called fluvoxamine or drink grapefruit juice while you are on pirfenidone.**

## Stopping pirfenidone

We will give you breathing tests (PFTs) to see how you are responding to pirfenidone. If it isn't helping to slow the progress of IPF as measured by breathing tests (PFT's), your respiratory consultant will talk to you about stopping it. We may offer alternative treatments.

If you want to stop taking pirfenidone for any reason, please discuss this with us. It can safely be stopped immediately, but we can advise and prevent further medication being delivered.

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## Useful links

[www.nhs.uk/conditions/idiopathic-pulmonary-fibrosis](http://www.nhs.uk/conditions/idiopathic-pulmonary-fibrosis)

[www.wildsupport.co.uk](http://www.wildsupport.co.uk)

[www.actionpulmonaryfibrosis.org](http://www.actionpulmonaryfibrosis.org)

## Contact us

If you have any questions or concerns, please contact us.

ILD nurse specialist  
The Respiratory Centre,  
D level, West Wing,  
Southampton General Hospital,  
Tremona Road,  
Southampton.  
SO16 6YD

Telephone: **023 8120 6277** (answerphone)

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For help preparing for your visit, arranging an interpreter or accessing the hospital, please visit **[www.uhs.nhs.uk/additionalneeds](http://www.uhs.nhs.uk/additionalneeds)**