Pirfenidone for idiopathic pulmonary fibrosis

This document is about when pirfenidone should be used to treat people with idiopathic pulmonary fibrosis in the NHS in England and Wales. It explains guidance (advice) from NICE (the National Institute for Health and Care Excellence). It is written for people with idiopathic pulmonary fibrosis but it may also be useful for their families or carers or for anyone with an interest in the condition.

It does not describe idiopathic pulmonary fibrosis or the treatments in detail – your specialist should discuss these with you. You can get more information from the organisation listed on page 4.
What has NICE said?
NICE recommends pirfenidone as a possible treatment for some people with idiopathic pulmonary fibrosis (see below).

Who can have pirfenidone?
You should be able to have pirfenidone if your forced vital capacity (FVC; a test of your lung function) is between 50% and 80% of the value expected for you.

Pirfenidone should be stopped if your disease gets worse, that is, if your FVC falls by 10% or more in 12 months.

Why has NICE said this?
NICE looks at how well treatments work, and also at how well they work in relation to how much they cost the NHS. NICE applies special considerations to treatments that can extend the lives of people who are nearing the end of their life, but pirfenidone did not qualify for special consideration. NICE recommended pirfenidone because the benefit to patients justifies the cost.

Idiopathic pulmonary fibrosis
Pulmonary fibrosis is caused by problems with the immune system. It results in scarring of the tissues inside the lungs that gets worse over time. It is called ‘idiopathic’ because the cause of the scarring is unknown. The scarring means that it is hard for the person to breathe, making everyday activities more difficult.
Pirfenidone

Pirfenidone (also known as Esbriet) is a type of drug that reduces the action of the body’s immune system. It is thought to slow the development of scarring in the lungs and stop lung function getting worse.

What does this mean for me?

When NICE recommends a treatment, the NHS must make sure it is available to those people it could help, normally within 3 months of the guidance being issued.

So, if you have idiopathic pulmonary fibrosis, and you and your doctor think that pirfenidone is the right treatment for you (see ‘What has NICE said?’ on page 2), you should be able to have the treatment on the NHS. Please see www.nice.org.uk/aboutguidance if you think you are eligible for the treatment but it is not available.

If you are not eligible for treatment as described in ‘What has NICE said’ on page 2, you should be able to continue taking pirfenidone until you and your specialist decide it is the right time to stop.
More information

The organisation below can provide more information and support for people with idiopathic pulmonary fibrosis. NICE is not responsible for the quality or accuracy of any information or advice provided by this organisation.

- British Lung Foundation, 03000 030555
  [www.blf.org.uk](http://www.blf.org.uk)

NHS Choices ([www.nhs.uk](http://www.nhs.uk)) may be a good place to find out more. If you live in Wales you should speak to NHS Direct Wales for information on who to contact.
About NICE

NICE provides national guidance and advice to improve health and social care. The guidance is written by independent experts, including healthcare professionals and people representing patients and carers. They consider the evidence on the disease and treatments, the views of patients and carers and the experiences of doctors, nurses and other healthcare professionals, and consider the costs involved. Staff working in the NHS are expected to follow this guidance.

To find out more about NICE, its work and how it reaches decisions, see www.nice.org.uk/aboutguidance

This document and other versions of the guidance aimed at healthcare professionals are available at www.nice.org.uk/guidance/TA282

The NICE website has a screen reader service called Browsealoud, which allows you to listen to our guidance. Click on Accessibility at the bottom of the NICE homepage to use this service.

We encourage NHS and voluntary organisations to use text from this document in their own information about idiopathic pulmonary fibrosis.

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