ACE Guidance Plain English Summary



Nintedanib and pirfenidone for treating idiopathic pulmonary fibrosis (IPF)

WHAT DOES THE GUIDANCE SAY?

Nintedanib and pirfenidone are not recommended for listing on the Medication Assistance Fund (MAF) for government subsidy.

WHY WERE THEY NOT RECOMMENDED FOR SUBSIDY?

ACE evaluates how well a treatment works in relation to how much it costs compared to other treatments. Nintedanib and pirfenidone were not recommended for government subsidy because there is not enough evidence to show their benefits for patients with IPF (such as increasing life expectancy and slowing down the rate at which the disease worsens), to justify their high costs.

IS THIS TREATMENT RIGHT FOR ME?

There are limited treatments available for IPF and none will cure your condition. If you have mild or moderate IPF, your doctor may recommend you take nintedanib or pirfenidone to slow down the rate at which your condition worsens.

Your doctor should give you clear information, listen to your views and concerns, and talk to you about your treatment options. Your family can also be involved in the discussion if you wish.

Some of the questions you may want to ask your doctor when making decisions about your care are:

- How will the treatment affect my day-to-day activities?
- How well does it work compared to other treatments?
- · What are the side effects and risks of treatment, and how likely are they?
- How long will I need to be on the treatment for?
- · What happens if the treatment stops working?
- What happens if I do not want to have treatment?

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WHAT IS IPF?

Idiopathic pulmonary fibrosis (IPF) is a chronic, life-limiting disease that causes scarring of the lungs. The cause is unknown (idiopathic) and there is no cure. The scarring worsens over time making it harder to breathe. Patients develop severe breathlessness, tiredness (fatigue) and cough.

WHAT ARE NINTEDANIB AND PIRFENIDONE?

You may know nintedanib as Ofev and pirfenidone as Esbriet. They belong to a group of drugs called anti-fibrotics which help to slow down the rate of scar tissue building up in a patient's lungs. They are typically prescribed for patients who have mild to moderate IPF.

Taking nintedanib may cause some side effects like diarrhoea and nausea. Pirfenidone can cause rash and itching in some patients.

Your doctor can advise if nintedanib or pirfenidone are suitable treatments for you.

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