



Action for
Pulmonary
Fibrosis

Nintedanib

Patient Information



What are the aims of this leaflet?

This leaflet has been written to help you understand more about nintedanib. 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 nintedanib and how does it work?

Nintedanib is a medicine that aims to slow down the development of scar tissue in the lungs. It does not cure or reverse the scarring but, by slowing down how quickly the scarring occurs, nintedanib may slow down the progression of idiopathic pulmonary fibrosis (IPF).

The brand name for nintedanib is Ofev®.

What dose of nintedanib should I take?

The usual dose of nintedanib is 150 mg twice a day. Your medical team may reduce the dose to 100 mg twice a day if you do not tolerate the full treatment dose, if they think that it might be of clinical benefit to you.

When should I take nintedanib?

Nintedanib should be taken twice a day, as near to 12 hours apart as possible. Take the medication with, or straight after food and swallow the capsule whole (do not chew or crush).



Action for
Pulmonary
Fibrosis

How long will I have to take nintedanib for?

You will take nintedanib for as long as it is working. You will be monitored at regular intervals whilst you are on nintedanib. The Interstitial Lung Disease (ILD) team, who look after your idiopathic pulmonary fibrosis, 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 nintedanib?

Nintedanib can cause some side effects. Many of these can be managed with the help of your ILD team. The most common side effect is diarrhoea (an increased number of loose or liquid bowel movements). Diarrhoea can be managed. Your ILD team will advise you how to do this.

You might also experience nausea, vomiting or abdominal pain or discomfort.

You may also experience a loss of appetite, liver inflammation and bleeding such as nose bleeds.

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

You will be under the care of an ILD team who will arrange monthly blood tests for the first 3-6 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 ILD 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 that you might have.

Does nintedanib affect pregnancy?

Do not take nintedanib 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 nintedanib?

Before starting treatment, it is important to tell the person prescribing the treatment from your ILD team if you are on any blood thinning medications. This is because there may be an increase risk in taking this medication if you are. You should let them know if you have had any problems with your heart or any recent or planned surgery and if you have any allergies.

Sometimes other tablets can make your nintedanib work less effectively or make it too strong. It is important to tell your 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 nintedanib include:

Some medications can increase the risk of side effects. These include:

- Non-steroidal anti-inflammatory drugs (NSAIDS) e.g. **ibuprofen**
- **rifampicin** and **erythromycin** (antibiotics)
- **ketoconazole** (anti-fungal)
- **cyclosporine** (immunosuppressant)

Inform your medical team if you are on **carbamazepine** or **phenytoin** which are treatments for seizures.

Avoid **St John's wort**, which is a herbal treatment.

Can I have immunisation injections while on nintedanib?

Yes you can.

Can I drink alcohol whilst taking nintedanib?

You can drink alcohol whilst taking nintedanib, 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 nintedanib?

If you want to know more about nintedanib, 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 nintedanib. For more detail 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.

PRODUCED October 2018

REVIEW DATE October 2021



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@actionpulmonaryfibrosis.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

Contact us:



01543 442152



info@actionpulmonaryfibrosis.org