



Action for
Pulmonary Fibrosis

Nintedanib

Antifibrotic medication

What is nintedanib and how does it work?

Nintedanib is an anti-fibrotic medication. This means it can help slow down the rate of scarring in the lungs, which may preserve your lung function for longer. Nintedanib does not reverse the scarring that has already happened or stop future scarring.

The brand name for nintedanib is Ofev®.

Who can and can't take nintedanib?

The National Institute for Health and Care Excellence (NICE) decides the eligibility criteria for antifibrotics. Their decision is based on the results of research studies.

Nintedanib may be prescribed to treat various interstitial lung diseases (ILDs) involving pulmonary fibrosis (PF).

These diseases may include idiopathic pulmonary fibrosis (IPF).

To be prescribed nintedanib if you have IPF, you need a certain breathing test score. Your forced vital capacity (FVC) score must be above 50% of what is normal for someone of your age and gender. FVC is the amount of air that you can breathe out in one breath, after fully inhaling.

This is a measure often used to see how well your lungs are working.

If you have a different ILD that is not IPF, nintedanib can be prescribed in some situations. Your ILD or respiratory team will monitor you over time. If there is evidence that your lung condition is not stable, they might suggest treatment with nintedanib.

Nintedanib isn't suitable for everyone with pulmonary fibrosis, however. It can't be used by people who:

- are allergic to peanuts, soya, or any ingredients of nintedanib (the ingredients are listed on the information sheet within the packaging)
- have severely impaired liver function



- are under the age of 18
- Are pregnant, planning a pregnancy or might get pregnant. We do not know enough about the risk to an unborn child. If you are breastfeeding, speak to your doctor to discuss the risks and benefits.

There may be other conditions that make nintedanib unsuitable for you. Make sure to tell your ILD or respiratory team if you:

- have any other current or previous medical conditions
- have had any problems with your heart
- have any recent or planned surgeries
- have any allergies
- take any other medications.

If you are unable to take nintedanib, your healthcare team will discuss other options to help manage your pulmonary fibrosis.

Nintedanib tablets contain gelatine. This may be relevant for people with dietary or religious restrictions (although religious restrictions may permit exemptions for healthcare). Please discuss with your healthcare team, who can provide guidance around alternate products.

How to take nintedanib

Always follow the advice given by your healthcare team.

What dose should I take?

The usual dose of nintedanib is 150mg twice a day. Your healthcare team might reduce the dose to 100mg twice a day if you have side effects that are difficult to manage.

When should I take nintedanib?

Nintedanib should be taken twice a day, as close to 12 hours apart as possible. It should be taken with, or straight after, food and the tablet should be swallowed whole. Do not chew or crush the tablets. This can alter how it works in your body.

What food can I take it with?

Generally, the food you take with your medication doesn't need to be anything specific. Some people find that a large snack works well, for example, a sandwich or a banana.

What if I miss a dose?

If you forget to take a dose, read the information leaflet in the packet for guidance. It will usually suggest you wait until your next dose is due and take this as normal. Don't take two tablets together to make up for a missed dose.

If you stop taking nintedanib, it's very important that you let your ILD team know as soon as possible.

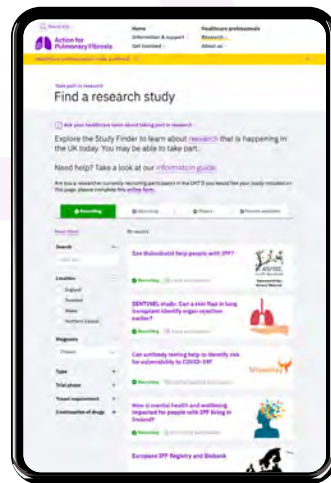
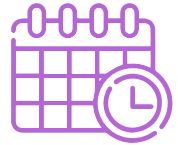
How long will I have to take nintedanib for?

You will usually continue to take nintedanib as long as:

- it's working to reduce the rate of lung scarring
- the side effects are manageable.

Why isn't there an inhaler version?

Currently, there are no inhalers that can treat PF. This is because scarring is found deep within the lungs and further research is needed to prove that medications delivered by inhalers can reach here. Studies are looking at inhaled versions, but results aren't available yet.



Action for pulmonary fibrosis Study Finder

www.actionpf.org/research/take-part/studies



Side effects

What are the possible side effects of nintedanib?

You should tell your ILD team about any side effects you're experiencing.


As with all medications, nintedanib can have side effects. Many of these can be managed with the help of your ILD or respiratory team. Some side effects will get better over time. In some cases, gut side effects of Nintedanib can be very delayed, sometimes starting a few months after medication is started.

If you're experiencing side effects, taking your medication with or straight after food may help.

Common side effects

• Diarrhoea

Some people find the following helpful for managing diarrhoea:

- Speak to your medical team for advice. You may be able to take an anti-diarrhoea medication. Some centres may prescribe this at the same time in case it is needed alongside nintedanib.
- Stay hydrated by drinking plenty of fluids.
- Going out can be a worry if you might need to go to the toilet quickly. The National Key Scheme (NKS) gives access to about 9,000 locked public toilets across the UK. You can buy a key from [Disability Rights UK](#) , who can also provide a list of where these toilets are.

• Vomiting

Some people find the following helpful for managing vomiting:

- Speak to your medical team for advice. You may be able to take medication for nausea.
- Home remedies, such as ginger.
- Stay hydrated by drinking plenty of fluids.

• Abdominal pain or headache

Speak to your medical team for advice. You may be able to take pain relief medication.

• Weight loss

Some people lose weight while taking nintedanib. This is often because of a loss of appetite. It can be helpful to weigh yourself regularly to check for changes. If you are losing weight and are concerned, talk to a healthcare professional.



Uncommon side effects

- unexplained bruising or bleeding
- yellowing of your skin or eyes
- severe itching.

It's very important to seek medical advice before your next dose. Call 111 if this is out of hours.

Can these medicines affect my mood or mental health?

Studies haven't shown that antifibrotics directly affect mood or mental health. Taking nintedanib may indirectly affect your mental health. For example, having diarrhoea and vomiting caused by nintedanib may affect your mental health.

This booklet does not list all the side effects of nintedanib. Follow the information leaflet included with your medication.



Side effects

Can you take breaks from nintedanib?

Sometimes people take short breaks if side effects become difficult to manage. This might happen, for example, if you are travelling. The benefits of nintedanib generally come from long-term treatment. If you take short breaks between long periods of taking the medication, it's unlikely to have a big effect.

If you need regular or frequent breaks, your ILD or respiratory team can check if the medicine is still right for you.

What happens if my dose is reduced – will I get worse?

Some people still benefit from nintedanib at a lower dose.

The standard dose is 150mg. Research shows that this dose is effective. The lower dose (100mg) hasn't been tested in the same way.

However, the lower dose can be helpful for people who get bad side effects from the higher dose. It may reduce these side effects enough so they can continue taking the drug.

In practice, many healthcare professionals aim to keep people on treatment at whatever dose they can manage. Some research suggests that a lower dose may still be effective, but further research is needed to be sure.

Can I switch to another antifibrotic?

There are currently two antifibrotic medications - nintedanib and pirfenidone. Sometimes it's possible to switch between them if you are experiencing side effects. This depends on several factors, including your lung function, your specific diagnosis and any other medical conditions you have. Your ILD or respiratory team can advise if this is an option for you.

What if side effects still don't go away?

If side effects continue, please speak to your ILD or respiratory team. There may be other options to help you manage.

Monitoring and check ups

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

You will have monthly blood tests for the first few months that you are taking nintedanib. If the results are okay, you'll continue to have regular blood tests. The blood tests are to check your liver function, as this can be affected by nintedanib. Depending on your local services, they might be carried out by your local GP, respiratory team or ILD team.

It's very important that you have these blood tests. They allow your ILD or respiratory team to check that it's still safe for you to take nintedanib. It can be helpful to record in your calendar when your appointments are due so that you don't miss any. Make sure that you know whom to contact to check the results of your blood tests.

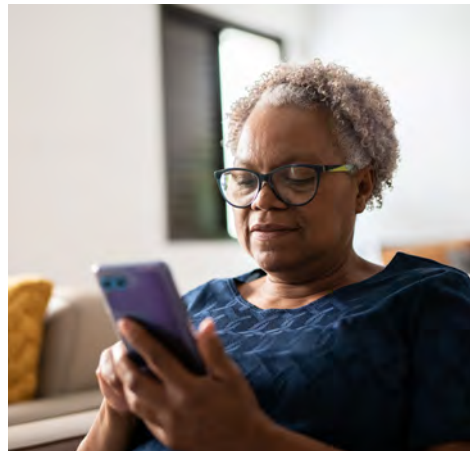
How will I know if nintedanib is working?

Most people have regular lung function (breathing) tests to see how well their lungs are working. Nintedanib does not reverse existing scarring or make you feel better each day. Its purpose is to slow down new scarring rather than get rid of the disease.

What if my condition gets worse while taking it?

If your disease keeps getting worse, your team can discuss other options. This may include things like:

- clinical trials
- focusing on managing symptoms.



Daily life and nintedanib

How do I get my medication?

Nintedanib is not available at most local pharmacies. It will usually be delivered to your home.

Speak to your healthcare team about how to get your medication. This may vary depending on where you live.

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



Before starting nintedanib, it's important to tell your ILD or respiratory team if you take any medications. Some medications can affect how nintedanib works. This includes:

- any medications prescribed by your GP or another healthcare professional
- any medications or supplements that you buy over the counter or online
- any herbal medications or supplements.

Some medications can increase the risk of side effects. Whoever prescribes nintedanib will check that it's safe to take with your current medications.

Don't start taking any medications or change a medication's dosage without first checking with your doctor or pharmacist. Make sure your GP or pharmacist knows that you're taking nintedanib if they prescribe or advise any other medications.

Digestive side effects of nintedanib such as vomiting and diarrhoea can affect how other medications work, including oral contraceptives (also known as 'the pill').

What if I work shifts or have an irregular routine?

Discuss this with your ILD or respiratory team. They can advise you on how to time your medication around your routine. Some people also find it helpful to:

- set alarms or reminders on your phone
- keep your medication in the same place and somewhere that is easy to see
- use a medication organiser (or 'pill box').

I fast for religious or cultural reasons. Can I still take nintedanib?

Many people continue to take nintedanib whilst fasting, as exemptions are often made for health requirements. You should follow the advice of your healthcare team.

Many people will be advised to keep taking their regular doses twice daily, with 12 hours between each dose.

As mentioned above, the benefits of nintedanib generally come from long-term treatment. If you take short breaks between long periods of taking the medication, it's unlikely to have a big effect.

How do I balance taking it with my quality of life?

Managing side effects of nintedanib can be difficult and affect your quality of life. If taking nintedanib is affecting your quality of life, please speak to your ILD or respiratory team. There may be changes that can help reduce your side effects or maintain your quality of life.

What if I need surgery or get another illness?

Tell your ILD or respiratory team as soon as possible. They will work with other healthcare professionals to decide if your treatment needs to change.

What if I want to have children? Could these medicines affect fertility or pregnancy?

People who are taking nintedanib and could get pregnant are usually advised to use contraception during treatment and for three months after. There may be risks to an unborn child.

Diarrhoea or vomiting may make oral contraceptives (sometimes known as 'the pill') less effective.


There's no evidence that nintedanib affects fertility once you stop taking it.

Can I have immunisation injections (vaccines) whilst taking nintedanib?



Taking nintedanib doesn't change vaccination advice. Vaccinations, including live vaccines, are generally safe to have if you take nintedanib. However, other factors may affect which vaccines are suitable for you. Please discuss this with your healthcare team.

Can I drink alcohol whilst taking nintedanib?

Most people can drink alcohol whilst taking nintedanib. The NHS recommends that you should drink no more than 14 units of alcohol per week. Further guidance available at www.nhs.uk/better-health/drink-less 

Where can I find out more about nintedanib?

If you want to know more about nintedanib or have any questions, please speak to your ILD or respiratory team.

About Us

Action for Pulmonary Fibrosis (APF)

is the UK's leading charity dedicated to supporting everyone affected by pulmonary fibrosis. APF provides expert information, support services and funding, alongside promoting vital research and campaigning to improve understanding, treatment and care.

Working closely with healthcare professionals, policymakers and those living with pulmonary fibrosis, APF aims to reduce the time to diagnosis, remove barriers to life-saving treatments and ensure that all patients receive the comprehensive support they need. The charity's OneVoiceILD network unites a diverse group of stakeholders to drive consistent standards of care across all regions of the UK.

actionpf.org

If you need this information in another format such as large print, easy read or another language, please contact us.

This leaflet provides general information only and is not a substitute for medical advice. Always follow the advice of your healthcare team and ask them if you are unsure.



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