

Antifibrotic therapy for the treatment of idiopathic pulmonary fibrosis of the lungs

Interstitial Lung Disease Service

Last reviewed: September 2024

Next review: September 2027

Information for Patients

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What is idiopathic pulmonary fibrosis?

Idiopathic pulmonary fibrosis is a condition in which the tissue in the lungs become scarred over time, so less oxygen is able to enter the bloodstream. This is why you may feel out of breath during daily activities.

How well are my lungs working?

You have had a test to assess how well your lungs are working. The most common test used is a spirometry. Spirometry measures 'forced vital capacity' or FVC. FVC is the amount of air that you can blow out in one breath. If your FVC is between 50 to 80% you will meet the criteria for antifibrotics as per NICE guidelines.

What are antifibrotics?

Antifibrotics are designed to try and slow the development of scarring (fibrosis) in the lungs, they are not able to remove or reverse scarring that is already there. There are currently two antifibrotic medications available in the UK (Nintedanib and Pirfenidone). If your lung function falls by 10% or more in one year then the medication has to be stopped.

You may find it useful to record the results of your lung function test below:

	Date	FVC (%)
Current FVC		
3 months after treatment		
6 months after treatment		
12 months after treatment		

**Health information and support is available at www.nhs.uk
or call 111 for non-emergency medical advice**

Visit www.leicestershospitals.nhs.uk for maps and information about visiting Leicester's Hospitals
To give feedback about this information sheet, contact InformationForPatients@uhl-tr.nhs.uk

What monitoring do I need to have while I am on antifibrotics?

There is a risk of liver damage (hepatotoxicity) with antifibrotics. You will need to have bloods taken every month to check your liver function for the first 6 months of treatment, then reducing to 3 monthly thereafter if these remain stable. If you live within Leicestershire, the ILD team will provide you with blood forms for your blood tests. You can contact your GP or attend the hospital for your blood test. You do not need an appointment to have a blood test at the hospital. If you live outside of Leicestershire, you should contact your GP surgery to arrange appointments for your on-going blood tests. Please be mindful your GP will not contact you to arrange this. It is a good idea to mark these dates on your calendar as a reminder. If your GP cannot help you with this, please contact your local hospital to make arrangements.

If you are not compliant with your ongoing blood tests, we will discontinue treatment.

Blood test	Date	Within normal range
1 month after starting treatment		
2 months after starting treatment		
3 months after starting treatment		
4 months after starting treatment		
5 months after starting treatment		
6 months after starting treatment		

You must now continue to have blood tests every 3 months whilst you are on antifibrotic treatment.

If you live out of area we would be grateful if your GP surgery would kindly forward your blood results to the ILD team via email: uhl.ild@nhs.net

How will I get my medications?

Initially you will be supplied with 2 months of medication from the hospital. If you are able to tolerate the medication, we can organise for it to be delivered to your home via the Homecare Service. If you are interested in this service, please discuss this with the nursing or pharmacy team. If you have any queries about your deliveries you can contact the Homecare Team directly on 0116 258 4476.

You will not receive a delivery of medication if you have not had a liver function test in the last 3 months.

It is a good idea to have at least 2 weeks extra supply of medication at all times, we would ask you not to build up any more than 1 month extra supply of medication. Once a medicine is delivered to your house it cannot be returned. If you have stopped taking the medication or intend to stop taking the medication please inform the hospital ILD team.

How do I take my medication?

It is important that you take your medications at regular intervals as prescribed. Antifibrotic medications should be taken with a full glass of water with or after food.

What if I get side effects from my medication?

You should read the information provided to you and be aware of the potential side effects of the medications.

Common side effects:

- **Diarrhoea** - if you are experiencing diarrhoea, make sure you are taking your medications as prescribed with or after a meal.

You can take an anti-diarrhoeal medication called loperamide that can be purchased over-the-counter from your community pharmacy or in most supermarkets. You should take 2 loperamide after the first episode of diarrhoea and 1 further dose after each episode of diarrhoea up to a maximum of 8 in a day. If loperamide is controlling your symptoms you should see your GP to have this added to your repeat prescription.

- **Sickness** - if you are experiencing sickness, make sure you are taking your medications as prescribed on time with food.

It is safe to take anti-sickness tablets with antifibrotics; please see your community pharmacist for advice.

- **Weight loss** - some people find that they lose weight while on antifibrotic medication. It is a good idea to weigh yourself weekly to keep an eye on this.

If you are losing weight and are worried about this please contact the ILD team. You can also see your GP who may consider referral to a community dietitian.

- **Sensitivity to sunlight and skin rash** - some patients treated with pirfenidone will experience sun sensitivity. It is recommended that you minimise exposure to sunlight. Wear a hat and clothing that protects your skin including face, arms and legs. Always use a broad spectrum (UVA-UVB) sunscreen with SPF50 or higher when you are outside, and reapply often throughout the day.

For mild skin rashes, apply an emollient and an oral antihistamine which can be purchased over-the-counter from your community pharmacy.

Uncommon side effects - if you have any of the side effects below stop taking your medication straight away and contact the ILD team:

- Yellowing of skin or eyes.
- Excessive itching.
- Unexplained bruising or bleeding.

Contact details

If you experience any of these side effects or need any further help or advice, you can contact the ILD team on the numbers below:

Symptom related queries: 0116 2563949 (directed to ILD Specialist Nursing Team)

Medication related queries: 0116 2502646 (directed to ILD Specialist Pharmacist Team)

If there is no answer, leave a message and someone will get back to you as soon as possible (except at the weekend/ bank holidays).

If you prefer to use email you can also contact the team on uhl.ild@nhs.net

Useful contacts

Action for Pulmonary Fibrosis Support Line: 01223 785725

Red Cross: 0344 871 11 11

Blue Badge: <https://www.leicester.gov.uk/transport-and-streets/parking-in-leicester/apply-for-a-blue-badge/>

Leicester	Northamptonshire	Kettering
Pulmonary Rehab 0116 258 3181	Restart Team 01604 544865	Rocket Team 01536 493558
O2 Team 0116 250 2968	O2 Team 01604 634700	O2 Team 01536 493300
LOROS 0116 231 3771	Cynthia Spencer House 01604 678030	Cransley Hospice 01536 493300
Patient group 07588 169494	Patient group 07743 272466	NASS Northamptonshire Adult Social Services Referrals online
Social Services 0116 305 0004	NASS Northamptonshire Adult Social Services Referrals online	

اگر آپ کو یہ معلومات کسی اور زبان میں درکار ہیں، تو براہ کرم مندرجہ ذیل نمبر پر ٹیلی فون کریں۔
على هذه المعلومات بلغة أخرى، الرجاء الاتصال على رقم الهاتف الذي يظهر في الأسفل
જો તમને અન્ય ભાષામાં આ માહિતી જોઈતી હોય, તો નીચે આપેલ નંબર પર કૃપા કરી ટેલિફોન કરો

ਜੇ ਤੁਸੀਂ ਇਹ ਜਾਣਕਾਰੀ ਕਿਸੇ ਹੋਰ ਭਾਸ਼ਾ ਵਿਚ ਚਾਹੁੰਦੇ ਹੋ, ਤਾਂ ਕਿਰਪਾ ਕਰਕੇ ਹੇਠਾਂ ਦਿੱਤੇ ਗਏ ਨੰਬਰ 'ਤੇ ਟੈਲੀਫੋਨ ਕਰੋ।
Aby uzyskać informacje w innym języku, proszę zadzwonić pod podany niżej numer telefonu

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