

The Interstitial Lung Disease Clinic

Information for patients



Leeds Centre for
Respiratory Medicine

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Your doctor has referred you to the Specialist Interstitial Lung Disease Clinic at Leeds. This booklet gives you information about the clinic, some of the tests that may be needed and the treatment that may be offered. Please bring it with you to the Clinic each time.

The clinical team

You will be under the care of Dr Beirne, Dr Sutherland and Dr Boland who are Respiratory Consultants and specialists in this area. You may be seen by either of these consultants, one of the registrars or one of the Specialist Nurses at your clinic appointment.

If you need to get in touch with one of the doctors or nurses, their contact numbers are below.

Dr Beirne's, Dr Sutherland's
and Dr Boland's Secretary

0113 206 5113

ILD Specialist Nurses

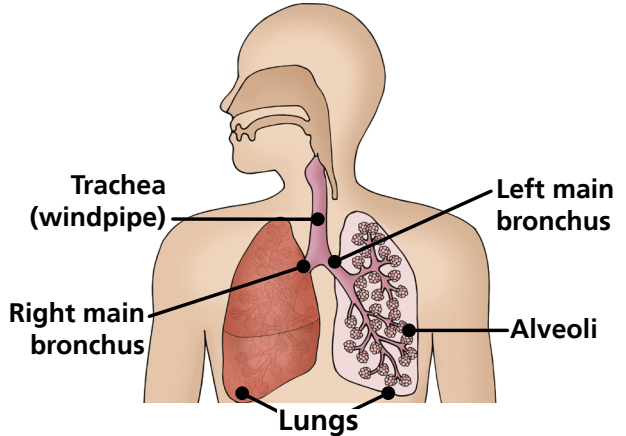
0113 206 7120

If you are from outside Leeds, you should also still be looked after by your local respiratory consultant.

What is Interstitial Lung Disease?

Interstitial Lung Disease (ILD) is a group of conditions that affect the delicate tissue of the lung (the lung interstitium). This includes the air sacs (the aveoli) and the surrounding supporting lung tissue.

There are over 200 different causes of ILD, some of which are relatively common but some are much rarer. These conditions can start with inflammation in the air sacs which can result in scarring (or fibrosis). This results in the lungs becoming stiffer.



The most common types of ILD are Idiopathic Pulmonary Fibrosis, Sarcoidosis, Hypersensitivity Pneumonitis and NSIP, which can be related to Rheumatoid Arthritis or Connective Tissue disease. Each requires different treatment, which is why sometimes it seems like it takes some time to come to a diagnosis.

The most common symptoms that patients have are breathlessness when walking or a dry cough. You may also experience weight-loss, fever and muscle aches depending on the type of ILD.

The clinic

The clinic takes place at the Chest Clinic in Martin Wing at the General Infirmary in Leeds. However, your first appointment may be by telephone.

When you visit the clinic, you will have a comprehensive assessment of your symptoms and medical history. We will go through your previous jobs and review your medication. You will be examined and most likely have further blood tests. You may have some breathing tests called spirometry and have your oxygen levels tested with a 'pulse oximeter' finger probe. You may then go on to have more in-depth breathing tests and a scan of your chest (a CT scan) if you have not had these already.

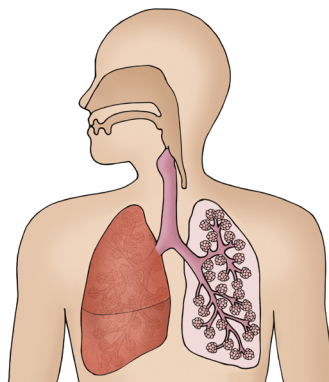
Please note: it is very unlikely you will receive treatment or a definitive diagnosis when we first speak with you.

Before a diagnosis can be reached, a team of doctors and nurses will review your test results to ensure there is agreement. This is called a Multidisciplinary Team meeting (an MDT - see page seven). Treatment options will be discussed and this will then be discussed with you at your next clinic appointment.

The ILD clinic can be very busy and it may take some time to be seen on the day. Please be prepared for this.

This is to ensure that all the patients attending the clinic are given the time they need to see the doctor or specialist nurse and ask questions, as many will have travelled some distance to attend. It may also seem like some patients are 'jumping the queue'. This will **not** be the case as some have tests on the day before being seen. If you have any questions, feel free to jot these down below in the notes section.

Notes and questions



The Specialist Interstitial Lung Disease Multidisciplinary Team (MDT) Meeting

Once you have had all the tests required, your case will be discussed at an MDT meeting. At that meeting, all of these tests will be reviewed, a provisional diagnosis made and options for treatment discussed. This will then be discussed with you.

The MDT is made up of the respiratory consultants, the ILD nurse specialists, the radiologists (X-ray specialists) and the histopathologists (who look at biopsy samples if you have had one).

You will then be seen in clinic to receive the results of your tests and this discussion.

My diagnosis

After the MDT discussion, my diagnosis has been confirmed as:

.....

The plan for my treatment and review in clinic is:

.....

.....

.....

.....

.....

Troublesome symptoms

There are a number of symptoms you will be asked about. We will try to improve these if this is possible.

Cough

Cough is very common in ILD. For some people it is the worst part of the condition. In some, it may be caused by reflux (see below) but in others it may be helped with a number of different medications including a linctus with codeine in it and small doses of morphine syrup. Both of these are very good at damping down the cough. Your doctor or nurse specialist will discuss which may benefit you.

Breathlessness

This is also common in ILD. You will be given general advice about how to cope with breathlessness and we will discuss strategies and therapies which may help, for example oxygen or morphine. You may need an oxygen test to see if oxygen may help (see page 15).

Reflux

A lot of patients have symptoms of gastric reflux (GORD) which includes burning in the gullet, indigestion and wind. Reflux may not cause these symptoms (this is called silent reflux) but may simply cause a cough. There are various medications that may help and your doctor or nurse specialist will discuss this with you.

Unintentional Weight loss

Some patients with ILD can lose a lot of weight. If you have, we may suggest a review by a dietician to help to improve and monitor this or dietary supplements to help.

Other recommendations

Stopping smoking

You will be asked about whether you smoke. We would always recommend patients stop smoking and can give you help to achieve this - this includes e-cigarettes. See page 19.

Weight loss if overweight

In some circumstances, we will advise you that you need to lose weight in order to help with your breathing. This can be very difficult when you are troubled by breathlessness and we may recommend a review by a dietician.

Pulmonary Rehabilitation

Pulmonary Rehabilitation (Rehab) is important for anyone with a long lasting lung condition. It combines exercise (tailored to your level of breathlessness) and advice on lung health, to help you to manage your condition. A typical course lasts six to eight weeks, with two sessions a week. Taking part in this will lead to improvements on how far you can walk and your quality of life. You will also meet other people with similar conditions.

For more information, visit the British Lung Foundation website:

[*http://www.blf.org.uk/Page/Pulmonary-rehabilitation-PR*](http://www.blf.org.uk/Page/Pulmonary-rehabilitation-PR)

Antibiotics

We would recommend that if you develop a chest infection, that you promptly see you GP, who we would encourage to prescribe antibiotics as appropriate.

Tests / Investigations

The following pages will detail some of the tests you may have to reach an accurate diagnosis of your lung condition.

Blood Tests

You have probably had numerous blood tests before but it is likely you will require some more. Because there are many causes of ILD, we need to be sure that we diagnose the correct one.

The blood tests will include tests for various forms of arthritis, sensitivity to birds or animals, and other causes of lung inflammation. All of these things can cause ILD.

Lung function tests

You will probably have a breathing test at your clinic appointment at the Specialist ILD clinic. You may also need some more in-depth breathing tests. These tests will happen in the Lung Function Department in St. James's Hospital or the Leeds General Infirmary. These may happen on the same day as your follow up appointment.



The tests are performed by a physiologist. They will be able to explain what you need to do during these tests. You do not need any special preparation before these tests. If you normally take inhalers, you should take these as usual before coming to the test.

Pulmonary Function Lab. **0113 206 4759**

Bronchoscopy

You may need a bronchoscopic procedure as part of your investigations. There are two different types of this procedure and you will be informed by your doctor or Lung Nurse Specialist which one is required.



1) Bronchoscopy - your doctor will pass a long flexible telescope (thinner than a pencil) through your nose or mouth into the air passages in your lungs and will examine the airways. It is also likely that a biopsy will be taken.

2) Endobronchial Ultrasound (EBUS) - your doctor will perform the same test as a bronchoscopy (see above) but will also undertake an assessment of the lymph nodes using an ultrasound probe and will take biopsies from these nodes.

What happens during the test?

The test will be done under light sedation. This means that you will be given a relaxing injection to make you sleepy, but you will not lose consciousness. Your doctor will also spray a local anaesthetic in the back of your throat. This tastes bitter and makes your throat numb. A nurse will be with you during the test. The doctor will then perform the test as described above. The test will take between 15-45 minutes.

What do I need to do before the test?

The bronchoscopy team will tell you when to stop eating and drinking before the procedure. You should take your normal tablets, although if you take medication that thins the blood to help to prevent it from clotting, you may be asked to stop these before the test. If you are diabetic then you should be given advice about this by your doctor or Lung Nurse Specialist.

Both tests are generally very safe, and many hundreds are performed at St James's Hospital each year. There can however be rare complications and very occasionally a patient may die as a result of the test. Nationally, the chance of this happening is thought to be about about one time in three thousand patients. Your doctor will be able to discuss the possible risks with you and answer any questions before starting the test and will ask you to sign a consent form.

What happens after the test?

Following the test you will be taken to a recovery room where a nurse will look after you for about one hour during which time you will not be allowed to eat or drink. You may occasionally cough up small amounts of blood after the test. Sometimes you may need an X-ray following the test.

You can go home the same day provided there is someone to pick you up and stay with you overnight. You should not drive a car, operate machinery or drink alcohol for 24 hours. If there is no one to stay with you overnight then we will arrange for you to stay in hospital overnight and go home the following morning. Do not sign any legal documents for 24 hours after sedation.

When will I find out the result?

You will not be told the results on the day of the test. Your doctor will discuss the findings and any biopsy results when they next see you in clinic.

***You will have your test at St James's Hospital,
David Beevers Unit:***

Tel: **0113 206 6653**

CT chest scan

A CT chest scan is a type of x-ray that takes pictures of your lungs. The CT scanners are in Jubilee Wing at Leeds General Infirmary (LGI), Lincoln Wing at St James's Hospital (called the Celia Craven CT Scanner) and Bexley Wing at St James's Hospital. Your appointment letter will tell you where to go for your scan.



The person carrying out the scan is called a radiographer. They will explain the test and answer any questions that you have. You may have a cannula (small plastic tube) inserted into your veins before getting onto the scanner. You will also be asked whether you have ever had an allergic reaction to X-ray dye (also called contrast), and you should discuss this with the radiographer if you are worried.

You will then be asked to lie on a flat couch which will then move you through a large doughnut shaped machine that takes the pictures. You may need an injection during the scan. Once you are on the couch, the test only takes about 5 minutes. You will not get the result straight away, as the scan has to be reviewed by a specialist doctor. Your doctor will discuss the result of the scan with you the next time you are seen in outpatient clinic.

CT telephone numbers

St James's Hospital **0113 206 5232**

LGI **0113 392 5621**

Lung biopsy - only in a very few patients!

After the MDT discussion outlined on page seven, in some cases, a recommendation to have a surgical lung biopsy may be made. This happens quite rarely if a diagnosis cannot be made (less than 10% of cases).

If a lung biopsy is recommended, you will be referred to a thoracic surgeon who will explain the procedure in their clinic. Generally it is a 'key-hole' or minimally invasive procedure. You can discuss any concerns you have with the surgeon at that time. You will be required to have a short admission to hospital and a general anaesthetic (you will be put to sleep for the procedure). The surgeon will perform the procedure and you may need a chest tube to be left in the chest whilst you are in hospital overnight.

You will not get the results whilst you are in hospital but it will be examined by a specialist pathologist (histopathologist) under the microscope and will then be discussed at an MDT meeting.

Oxygen Treatment

Some patients with ILD will deteriorate despite treatment and require oxygen. This will be discussed with you when or if you need it.

You will be referred to your local oxygen assessment service. Part of the assessment may involve a blood test to measure your blood oxygen level and a walking test to see if your oxygen levels drop when you are walking.

There are several ways in which oxygen can be of benefit:

1. Short-burst Oxygen

Short-burst oxygen is used in some circumstances for short periods of time following exertion, to help with some of the feelings of breathlessness.

2. Ambulatory Oxygen

Some ILD patients with severe disease get quite breathless when they are walking around and their oxygen level can drop at the same time. If this is the case, oxygen may help with some of these symptoms if used on exertion.

3. Long-term Oxygen

If your oxygen level is low even when you are sitting at rest, long-term oxygen, which is used for at least 16 hours a day, may be needed to prevent extra strain on your heart.

All of these oxygen therapies are assessed by our specialist nurses, to see who would benefit and what equipment would be most beneficial.

Research Trials

Most causes of ILD are relatively rare and there are always trials of treatment to find new ways of treating them. In Leeds, we usually have 2 or 3 trials on going looking at new medication for ILD. You may be asked if you would like to participate in them and we encourage you to ask if you are interested.

Participation in drug trials can be time consuming and isn't for everyone. Whether you participate or not will not affect your treatment in clinic at all. These drug trials are purely voluntary.

If you would like more information, Dr Beirne, Dr Boland or Dr Sutherland can provide you with it, if you fit the criteria for the studies that are currently underway.

Lung Transplant

For only a small number of people, lung transplant may be an option. There are only about 150-180 lung transplants performed in the whole UK each year for other lung conditions as well as pulmonary fibrosis. There are a number of factors that need to be considered before referral for lung transplant which include your general health and your age, both of which can influence the likelihood of a successful outcome. If this is something that you wish to discuss, feel free to raise it with your doctor.

A successful lung transplant is not always 'miracle cure'. The average life expectancy after lung transplant is about 50% after five years and is influenced by a number of issues, including the characteristics of the donor lungs. There is a window of opportunity for lung transplantation where your lung disease is sufficiently advanced to make it in your interests but not so advanced that you are not physically able to go through such a big operation.

For more information please see the NHS choices website:

www.nhs.uk/Conditions/Lung-transplant/Pages/Introduction.aspx

Palliative Care

Unfortunately, patients with ILD can deteriorate despite treatment and in some cases, there is no treatment available for their condition. In this circumstance we start to talk about 'palliative care'. This is care aimed at improving troublesome symptoms such as breathlessness and also to see if there is anything we can do to improve quality of life. Even if your lung disease is not getting worse, we may recommend a referral to palliative care because of their expertise in controlling troublesome symptoms.

We will try to speak openly and honestly in the clinic about your lung condition. There is often uncertainty about how it will progress and that it may get worse. This can be difficult to talk about both for you and your family.

Pulmonary Fibrosis Support Group

Most lung diseases that are classified as ILD are rare. It is often helpful for patients to meet other people with the same or similar conditions, to share experiences and learn how other people manage their condition. A support group has been set up and is encouraging patients, their relatives and carers to attend. For more information, please ask the doctors or nurses about the next meeting.

A commonly asked question

I've been referred by another hospital specialist from outside Leeds; do I still keep seeing them?

Many people who come to the Specialist Interstitial Lung Disease clinic come from areas outside Leeds. We encourage your local respiratory doctor to continue to see you whilst you come to Leeds so that you have a contact in your local hospital should you need it. The letters from your clinic visits will be copied to them as well as you.

Useful Numbers and websites

Dr Beirne's, Dr Sutherland's and Dr Boland's Secretary **0113 206 5113**

ILD Specialist Nurses **0113 206 7120**

Stop Smoking Support Sessions - Leeds area

Web: www.leedscommunityhealthcare.nhs.uk/our_services_az/stop_smoking_service/ Tel: **0800 169 4219.**

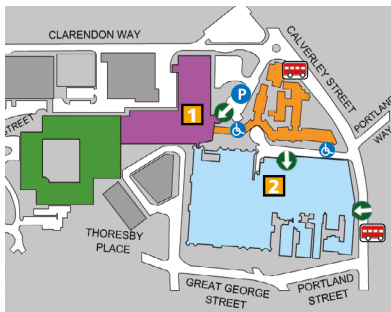
NHS Choices - Smoking Cessation for outside the Leeds area

Web: <http://www.nhs.uk/service-search/stop-smoking-services/locationsearch/1846> - just type in the location you are looking for in the search section.

British Lung Foundation www.blf.org.uk

Action on Pulmonary Fibrosis www.actionpulmonaryfibrosis.org

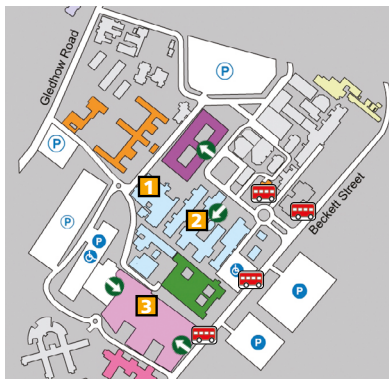
Hospital site plans



Leeds General Infirmary

- 1 Jubilee Wing - Radiology
- 2 MartinWing - Leeds Chest Clinic

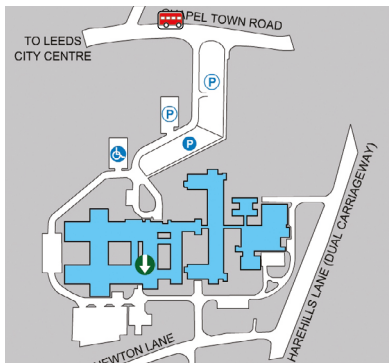
- Entrances
- Visitor parking
- Disabled parking
- Bus stops



St James's University Hospital

- 1 David Beevers Unit
- 2 Lincoln Wing - Celia Craven CT Scanner
- 3 Bexley Wing - Follow up Clinic, Radiology Department and PET Scanner

- Entrances
- Visitor parking
- Disabled parking
- Staff parking
- Bus stops



Chapel Allerton Hospital

- Entrances
- Visitor parking
- Disabled parking
- Staff parking
- Bus stops

What did you think of your care? Visit bit.ly/nhsleedsfft
 Your views matter