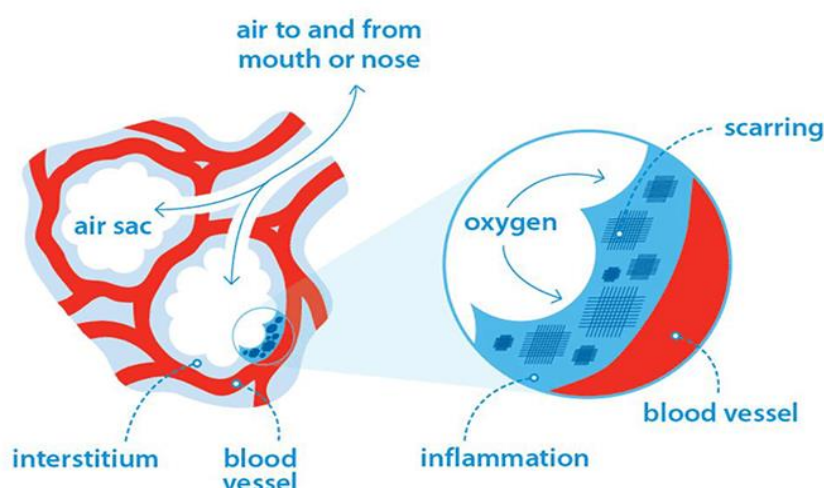


Interstitial Lung Disease associated with Connective Tissue Disease

Information for Patients

What is Interstitial Lung Disease?

Interstitial Lung Disease (ILD) is a term used to describe a number of diseases that cause **inflammation** and **scarring** (fibrosis) of the lungs. These changes affect how oxygen enters the bloodstream from the lungs, as well as the overall shape of the lungs. This combination means that the lungs **work less well** and you become breathless much more frequently.



Inflammation and scarring stops oxygen from reaching the blood

Why have I got ILD?

ILD can be associated with certain diseases where the body's **immune system** is overactive. This includes rheumatoid arthritis, systemic sclerosis, myositis and Sjögren's syndrome. The immune system, which is normally in place to fight infections, instead fights your own tissues, such as the joints and lungs in the case of ILD.

What are the symptoms?

The symptoms that you are most likely to experience from increased scarring of the lungs include:

- **Shortness of breath** (may be noticed initially after periods of physical activity).
- A regular dry **cough**.
- Tiredness.
- Reduced appetite and **weight loss**.

Some people also experience symptoms related to their connective tissue disease (CTD) (joint pain, changes to skin and rash) however, this is not always the case for everyone. Raynaud's phenomenon may be experienced, which is when cold temperatures can cause your fingers/toes to change colour.

For more information on symptoms you might experience with different diseases, visit www.versusarthritis.org

What is the Treatment?

The aim of treatment is not to cure ILD, but to stop it from getting worse and reduce the symptoms experienced.

Medications used to treat ILD will be the same as those used to treat your CTD. **Steroids** and **disease-modifying anti-rheumatic drugs** (azathioprine, mycophenolate) are commonly used to reduce inflammation in the lungs. Check out the versus arthritis website for more details on these medications.

Oxygen therapy is sometimes considered as a short term or long-term management plan.

What about Physical therapies?

Physical therapies can help you to improve your breathing and quality of life and your specialist team will refer you to Occupational therapists and Physiotherapists.

Occupational therapists (OT) are often very useful in people with CTD. They work to try and maintain your ability to go about your life as you normally would, either at work or at home.

Physiotherapists help you to keep mobile and maintain strength throughout your disease (so as you can function normally). This is through a combination of exercises and body movements designed to improve physical strength.

What is Pulmonary Rehabilitation?

Pulmonary rehabilitation is a series of courses that teach you the best way to deal with your symptoms and lead as least a restricting life as possible. Benefits of pulmonary rehabilitation include:

- **Learning more** about ILD.
- Promoting **physical activity**.
- Specific **breathing exercises** to help with breathlessness.
- **Psychological support**, involving a network of other individuals who also have ILD to provide support

What can I do?

Below is a list of suggestions to consider, to improve your symptoms and keeps your lungs healthy for as long as possible.

- If you are a **smoker**, consider quitting. Ask your GP for advice and support if you are finding it difficult.
- Aiming for an ideal **body weight**. NHS has a BMI calculator online at **www.nhs/live-well/healthyweight**
- **Exercise** as regularly as you are able to. Your CTD may limit the amount of physical activity you can engage in, and that's okay. Exercises such as swimming, walking, gentle cycling, aqua aerobics and yoga are generally better for your joints.
- Eat a well-balanced and nutritious **diet**.
- Get a good **sleep** each night.
- Keep up to date with your **vaccines** each year
- Try and avoid exposing yourself to any risks of a chest infection (cold weather, sick relatives etc).
- If you feel as though you are becoming sick with an **infection**, see your GP immediately.

Can surgery help me?

In all patients with severe disease, a lung transplant is always considered. In cases where a person is right for it, they are referred early to the transplant team. It is not always suitable for everyone and so it would be discussed thoroughly with you beforehand

How will living with it affect me?

ILD is a progressive disease, meaning it will worsen over time. This can happen slowly or quickly, and it is usually very difficult to tell which will happen to someone. For this reason, you will need follow up breathing tests every **4-6 months**. If there is any uncertainty with regards to the results of these tests, your specialist may want to repeat a **chest scan**.

Further information

Versus Arthritis (**www.versusarthritis.org**) – contains all the information you would need to know about specific connective tissue diseases and how to best manage the symptoms.

While there is no cure for ILD at the moment, improvements in the treatment for it relies on people that have it who are willing to be studied (in what's called a "**clinical trial**"). If you are someone who would be interested in signing up for something like this, speak to your Specialist.

Contact details:

Rheumatology Secretaries	01270 612238
Rheumatology Advice Line	01270 273631

Email: **rheumatology@mcht.nhs.uk**

This information is available in audio, Braille, large print and other languages. To request a copy, please ask a member of staff.