

Interstitial Lung Disease

Patient Information

Respiratory Service

Name:

Date of Birth:

NHS Number:

Date:

Issued by:

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Self-Management

Coming to terms with the diagnosis of a chronic progressive lung condition can be difficult and everybody copes with this differently. It may be particularly hard when you do not know what has caused your illness.

It is quite normal to experience various emotions, including feelings of: Shock as you may feel what is happening is not real. Denial; initially this protects you from being overwhelmed by the changes in your life. Anger is a normal emotional response, which may be directed at those close to you. Fear and anxiety as you may be scared about what is going to happen to you.

Feeling down sometimes is natural, but if you are feeling down most of the time, then you should consider seeking further support and advice.

Keep as active as possible.

You may be afraid of exercising as you become short of breath when you move and you may also feel too tired to exercise. However, keeping active can often give you more energy and lift your mood. Gradually building up the amount of activity you do will strengthen your muscles and keep your body active. As a result, this will make everyday activities less tiring and less demanding of your energy. This reverses the "cycle of inactivity" where the less you do, the less you are able to do.

Please remember what form of exercise/activity you do depends on your individual condition. You can always discuss this with your health care professional, who will advise you appropriately.

General advice on how to manage your condition and stay as healthy as you can

- Try to keep a positive attitude and be kind to yourself
- Take your medicines as prescribed
- Ask for help with smoking cessation if needed
- Avoid visiting anyone who is unwell with a cold, flu or chest infection

- Have your annual flu vaccination and check your pneumococcal vaccine (Pneumovax) is up to date - your GP can give you this information
- Drink plenty of fluids and eat a healthy balanced diet
- Consider eating smaller more frequent meals during the day. Many people find it easier to breathe when their stomach is not too full
- Observe how much sputum you normally have and its colour.

Coping With Breathlessness

Most people get breathless from time to time, particularly when exercising. Many people with a progressive lung condition can experience breathlessness easily. This breathlessness may be uncomfortable and can come on with very little or no exertion. Learning how to cope with this may help to reduce your anxiety.

Advice on how to manage your breathlessness may include:

- Breathing control techniques/exercises
- Different positions to help relieve your breathlessness
- Techniques to help conserve your energy and pace yourself
- Relaxation techniques
- Using a fan changes your feeling of breathlessness and is a very good method for combating it

What to do if you have an exacerbation/flare up of your condition

Sometimes you may have a rapid worsening of symptoms. This may be triggered by an infection or it may be a flare up of the inflammatory process. It is important to be aware of what are normal symptoms for you.

During a flare up, you may notice a change in your symptoms which may include:

- An increase in how breathless you are.
- Coughing up more sputum or the sputum being more sticky
- Change in colour of your sputum (clear to light or dark yellow, or green / light to dark yellow or green)

- An increase in how often you cough.

Action

- In these circumstances it is important to seek Advice
- Take your medication and inhalers, if used as prescribed
- Drink plenty of fluids
- If possible collect a sputum sample and hand to GP as soon as possible (if you cannot get to the surgery that day, keep the sample in the fridge overnight)
- Some colds get better without needing antibiotics, some don't. If in doubt seek a medical review.

Symptoms of Too Much Oxygen

It is very difficult to know whether you are getting enough oxygen, as it is not necessarily related to breathlessness. The correct flow rate of oxygen will be decided by the Home Oxygen Assessment Team or Doctor.

It is possible to get too much oxygen either if you have altered your flow rate or if you have (or starting with) a chest infection. If you suffer any of the following (when on oxygen) please contact the Home Oxygen Service or your GP straight away:

- Feeling drowsy, sleepy or muddled
- Develop a headache (especially in the mornings)
- Confusion or hallucinations

What Happens Next?

You will have been asked to sign a special consent form that allows the person prescribing your oxygen to share you details with the Fire Service and the Oxygen Supplier. You will also be asked to sign a Safety Declaration Form to confirm that you understand the issues of fire safety when using oxygen.

The oxygen Supplier for the North West is a company called Air Liquide. They will contact you to ask a few questions about your oxygen and arrange the delivery and installation. They will teach you and/or your carers how to use the oxygen equipment and make sure it is all set up and ready to use.

You will also receive a visit from the Community Fire Service to offer you a Home Safety Check, in addition to follow up care from the team that has prescribed your oxygen.

If you have any problems with your oxygen equipment, then contact Air Liquide on their helpline number 0808 143 9992 (24 hrs a day). Alternatively if you need to speak to your clinical team, use the following number (or your out of hours GP if they are closed).

Clinical Team Contact Details

Team: Wrightington, Wigan & Leigh Oxygen Service

Phone: 01942 482230

Home Oxygen Safety Leaflet

Patient Name:

NHS No.

Why do I need Home Oxygen?

Oxygen is only usually prescribed if you have been found to have low levels of oxygen in your blood. If your blood oxygen levels remain very low, over time it can cause your blood to thicken. This can put strain on your heart as it pushes the thickened blood around your body and can increase the risk of blood clot-related problems such as a Stroke or Heart Attack.

Using oxygen for 16 hours a day or more can prevent this thickening and reduce the risk of a blood clot.

You may still be prescribed portable oxygen if your blood levels only drop when you are exerting yourself (and oxygen is found to improve your activity levels). This will only be prescribed by an oxygen specialist after an exercise test when your condition is stable.

It is important to remember that oxygen is not an effective way to help with breathlessness and the reason for using it is to prevent problems with your blood, not your breathing.

Oxygen is a prescribed medication and is only given if it is clinically needed AND that it is used safely. Oxygen may well therefore be stopped (and removed) if your condition improves or there are any safety concerns identified.

Please inform the supplier of your home insurance that you now have oxygen in your home; this should not cost you more money.

Please read the important safety information inside this leaflet alongside the oxygen suppliers' handbook that you will get on delivery of your oxygen.

DO'S

- Use your oxygen as you have been advised to following your assessment. Do not alter your flow rate. Do not allow children or anyone unfamiliar with the equipment to tamper with it.

Why? Patients can feel worse if they have **MORE** than the prescribed rate. More is not necessarily better. If you feel drowsy, muddled or if you are experiencing a lot of headaches, please contact us. Tampering with the equipment can cause damage.

- You must switch your oxygen off when you are not using it, even for short periods of time.

Why? Surrounding materials, including your clothing, will become 'soaked' in oxygen if left running on furniture and will ignite if in contact with a heat source or spark.

- Ensure your cylinder is kept upright and is not banged or knocked over.

Why? If your cylinder falls over, either the cylinder or the valve and flow regulator (at the top of the cylinder) may be damaged, causing problems with your flow rate and the potential for leak, possibly leading to a fire.

- Do use your oxygen in a well-ventilated room

Why? There is less risk of the air becoming too oxygen rich and therefore less risk of a fire.

- Do keep the oxygen mask clean, by wiping with a damp cloth
- Do attend all of your oxygen assessment appointments.

Why? Oxygen will only be prescribed as long as it is safe to do so. Without a regular review and updated oxygen assessment, it may not be safe to continue the oxygen prescription and will therefore be removed.

DON'TS

- Do not smoke or allow anyone else to smoke in the same room as the oxygen. This includes the use of 'Electronic' Cigarettes
- Do not light candles or oil burners whilst using your oxygen
- Do not cook whilst using your oxygen, or sit near heat source in the kitchen (this includes microwave ovens)
- Do not store your oxygen in a warm place and do not sit close to the fire when using your oxygen (or run tubing close to your fire).

Why? Naked flames & other heat sources **WILL** cause oxygen to ignite. You risk severe burns or an explosion if you smoke whilst using oxygen. Always turn oxygen off when cooking.

- Do not let others use your oxygen.

Why? Oxygen is a prescribed drug to be used only by the person it has been prescribed for. Also, to do so increases risk of infection.

- Do not allow the plastic oxygen tubing or the cylinder to come into contact with any source of heat. If you have long oxygen tubing, please make sure it doesn't get tangled; check your tubing for signs of damage. Keep the tubing tidy.

Why? The tubing may melt, causing the oxygen to leak out, you will not get the correct amount and the risk of fire will be increased. Keeping the tubing tidy prevents trips and slips.

- Do not use any oil or paraffin based creams/ointments (such as Vaseline or E45 cream) on your nose, face or hands.

Why? Oxygen can react with these creams/ointments to cause skin irritation. Also they are flammable and will increase your risk of harm in the event of a fire. Consult your pharmacist for further advice.

Contact Details

Contact	Name	Telephone
GP Practice		
Community Respiratory Team		
Pharmacy		
Out of Hours Service		
Respiratory Consultant		

Local Pharmacy - Your local pharmacies offer a wide range of services, including information and general advice on symptom relief medicines, as well as a prescription collection and delivery service.

Please use this space to write notes/reminders.

Comments, Compliments or Complaints

The Patient Relations/Patient Advice and Liaison Service (PALS) Department provides confidential on the spot advice, information and support to patients, relatives, friends and carers.

Contact Us

Tel: 01942 822376 (Monday to Friday 9am to 4pm)

The Patient Relations/PALS Manager
Wrightington, Wigan and Leigh NHS Foundation Trust
Royal Albert Edward Infirmary
Wigan Lane
Wigan WN1 2NN

Ask 3 Questions

Become more involved in decisions about your healthcare. You may be asked to make choices about your treatment. To begin with, try to make sure you get the answers to three key questions:

1. What are my options?
2. What are the pros and cons of each option for me?
3. How do I get support to help me make a decision that is right for me?



How We Use Your Information

For details on how we collect, use and store the information we hold about you, please take a look at our “how we use your information” leaflet which can be found on the Trust website: https://www.wwl.nhs.uk/patient_information/leaflets

This leaflet is also available in audio, large print, braille and other languages upon request. For more information please ask in department/ward.

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