

- Make sure your mobile phone is charged.
- Check the battery supply in your stair lift.
- Have a torch with batteries ready in case of darkness.
- Never use candles or a naked flame near your oxygen.
- Have blankets ready in case your heating won't work.

## Physical activity and oxygen

If you become breathless when having a shower, doing housework or gardening, climbing stairs, walking or exercising, stop what you are doing. Turn up your oxygen flow for a short time until your breathing settles. When your breathing is under control again, turn down your oxygen flow to normal and finish what you were doing.

Remember to use the **STALL** breathing technique.

**S** = Stop what you are doing

**T** = Turn up your oxygen

**A** = Assume a comfortable position

**L** = Let your imagination take you to a safe place

**L** = Let your breathing return to normal

Contact us to order a **STALL** card for your wallet or purse. Our contact details are on the back page.

## Exercise

It is important to exercise every day even when you are on oxygen. Don't let a fear of breathlessness stop you from exercising. A lack of physical activity will affect your fitness and ability to exercise, and will cause you to become more out of shape and breathless.

Exercise, especially walking, is important for your wellbeing, bone health, mobility, mood and confidence. The **ILFA 2000 Steps a Day Challenge** and **ILFA Exercise DVD** are ideal exercise programmes for IPF patients. Phone or email us to request the exercise resources. Our contact details are on the back page.

You should expect to be more breathless when exercising. Everyone gets breathless with physical activity, even athletes. When exercising, turn up your oxygen flow to help your body cope with the increased energy demands. With time, exercise can improve your exercise tolerance and help regulate your breathing.

## Travel and holidays

You can still travel by car, bus, train, ferry and plane with oxygen but you need to plan everything so that you have a smooth journey and a good holiday.

Discuss your travel plans with your doctor or nurse at least six weeks before your trip. They will tell you if you are well enough to travel and will organise an oxygen prescription for travelling.

### Travel tips

- Tell your oxygen company, travel agent, insurance company and airline that you use medical oxygen. They can advise and help you with the necessary arrangements for travelling with oxygen.
- If you are going by car, always bring a spare portable oxygen cylinder in case of a traffic delay.
- When flying, book a seat near the toilets. Altitude can affect your oxygen levels and it will take more effort to move about the plane if you need to use the toilet. Remember to turn up your oxygen if you need to.
- When travelling by bus, coach, train or ferry, check if there are electrical sockets for you to plug in your oxygen equipment.

## Hotels

If you are staying in a hotel, let them know that you will be bringing your oxygen equipment and will need a larger room (called an access room). Ask for a room with a walk-in shower and plenty of space for moving around. Make sure there is a lift to your floor and tell staff that you will need help to take the equipment to your room.

## Life is for living!

Remember that oxygen has been prescribed for you because you need it.

Oxygen will help your breathlessness and improve your quality of life.

## Need more information?

Contact us to request some of our resources:

- the **ILFA 2000 Steps a Day** walking pack for lung fibrosis patients;
- the **ILFA Exercise DVD**
- a **STALL breathing technique card**
- a **Medical Alert Card** for patients on medical oxygen.

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**Irish Lung Fibrosis Association**

# Oxygen and Idiopathic Pulmonary Fibrosis

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## About this leaflet

This leaflet tells you about Idiopathic Pulmonary Fibrosis and how medical oxygen can help you to manage your breathlessness and improve your quality of life.

## What is Idiopathic Pulmonary Fibrosis (IPF)?

IPF is a progressive disease that causes scarring (fibrosis) and hardening of the lungs. The cause is unknown. Lung fibrosis makes it difficult for oxygen to move from the lungs into the blood. This results in low oxygen levels (also called low oxygen saturation or hypoxia) which causes IPF patients to develop breathlessness, cough, fatigue (tiredness) and low energy.

## Oxygen, energy and life

Oxygen makes up 21% of normal air. When we breathe in, air travels down the nose and throat to the lungs. Oxygen crosses from the tiny air sacs in the lungs (alveoli) into the blood supply. This oxygen-rich blood is then pumped around the body by the heart. Our bodies need oxygen to create energy so that our vital organs and muscles can work properly. We all need oxygen to survive.

## Oxygen for IPF

If you have IPF and your blood oxygen levels are low, your doctor may prescribe medical oxygen to help ease your breathlessness and improve your energy levels. This extra source of oxygen will help you to carry on with your daily activities. Medical oxygen is also called supplemental oxygen, ambulatory oxygen or oxygen therapy.

Some IPF patients will need oxygen all the time or you may only need it when exercising or sleeping. Over time, the amount of oxygen you need may change. You should tell your doctor, nurse or physiotherapist if you are becoming more breathless, as your oxygen prescription may need to be reviewed.

### It is important to know that:

- Your oxygen prescription is as important as your medicine. Use your oxygen as prescribed by your doctor. Don't try to survive on a lower amount of oxygen.
- You will not become 'addicted' to oxygen. We all need oxygen to survive.
- Don't avoid leaving the house or going to social events because of your oxygen. Life is for living. There's no need to be embarrassed about using oxygen.
- Don't adjust your oxygen flow or how you use your oxygen based on the advice of other patients. The oxygen needs of IPF patients are very different to the oxygen needs of patients with other lung conditions. This is because of the type of damage caused by lung fibrosis.

## Oxygen companies

Your oxygen company can give you advice and answer any questions you may have about using oxygen or your medical equipment.

There are two oxygen supply companies in Ireland:

**Air Liquide Healthcare Ireland, Tel: 1850 240 202**

**BOC Healthcare, Tel: 1890 220 202**

## Oxygen equipment

Oxygen is delivered by either:

- nasal prongs (soft plastic tubes called cannulae) that are placed in your nose; or
- a face mask worn over your nose and mouth.

Home oxygen machines (also called concentrators) are plugged into the electricity supply in your home and make oxygen from the surrounding air. Your oxygen company will also provide you with oxygen cylinders and tanks to have as a back-up supply.

You will also get portable oxygen cylinders that let you leave the house and travel using oxygen.

Your oxygen company can advise you about the best equipment to suit your needs and make your life easier. For example, some oxygen machines have wheels, some have long-life batteries and some can be plugged into a power supply (electrical socket) when you are out.

## Portable oxygen supply

You are entitled to six portable oxygen cylinders every month from the Health Service Executive (HSE) under the Drug Payment Scheme or the Medical Card Scheme. If you need more than six cylinders to carry on with your normal routine, you should ask your doctor to increase your oxygen prescription. The HSE cannot refuse extra cylinders if your doctor prescribes them.

### Tips for oxygen

- Order new oxygen cylinders at least 3 days before you need a new cylinder.
- Make sure you have enough oxygen for long weekends.
- Check that your back-up oxygen cylinder is full and working properly.
- Contact your oxygen supply company if you have any problems with your oxygen.
- Do not use your oxygen near a naked flame or other source of heat.
- Get a smoke alarm for your home and check regularly that the batteries are working.

## Register as a Priority Support Customer with your electricity supplier

When you are prescribed oxygen, you should contact your electricity supplier as soon as possible to register as a 'Priority Support Customer'.

### The electricity companies in Ireland are:

- Electric Ireland Tel: 1850 372 372
- SSE Airtricity Tel: 1850 812 220
- Gas Networks Ireland Tel: 1850 200 694

If there is an unexpected power cut with loss of electricity and you are registered as a Priority Support Customer, the Electric Ireland Network will restore power to your area first.

If there are planned electricity cuts, the Electric Ireland Network will let you know the date and time of the cuts.

## What to do in case of a power cut

It is important to be prepared and know what to do in case there is a loss of electricity. You should talk to your family so they are prepared too and can help you. If there is a power cut, try not to panic as this could make your breathing worse.

### If there is a power cut:

1. Transfer from your home concentrator to your back-up oxygen cylinder.
2. Call the Electric Ireland Network customer care centre on **1850 372 999**. The sooner you contact them, the sooner they can respond.

If the power cut is going to last a long time, you may need to go with your oxygen concentrator to another house that still has an electricity supply or to a hospital that can give you oxygen.

### Always be prepared for power cuts

- Make sure you have enough oxygen at all times. Order your oxygen re-fills in advance. Don't leave this to the last minute.
- Know how to transfer to your emergency oxygen supply.
- Make a list with telephone numbers for your electricity supplier, oxygen company, doctor and GP co-op (for night-time and weekends).