

Living with
Pulmonary
Fibrosis

How can oxygen therapy help?



Lung
Foundation
Australia



Centre of Research Excellence in
Pulmonary Fibrosis

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Why is oxygen so important?

Oxygen is essential for all your cells to function. When you breathe, you are helping to deliver oxygen to your body. Breathing is involuntary, which means you do it automatically, without thinking. Normally, your body regulates your breathing based on how much oxygen you need depending on what you are doing. In other words, it adapts to keep up with the demand.



Exertion or movement

When you perform daily activities like getting out of a chair, walking to the kitchen or doing the shopping



Cells need more oxygen

As soon as you start moving, your body decides that it needs more oxygen



Breathing changes to meet demand

You will start to breathe faster and deeper (the heart will also pump more blood)

What happens when your oxygen levels fall?

Your whole body is affected when oxygen levels fall, but the brain is one of the most sensitive organs to be affected. A lack of oxygen can make you feel irritable and make it difficult to make decisions or even concentrate on tasks.

Did you know?

Some people with Pulmonary Fibrosis (PF) have low oxygen levels. This happens when the body can't change breathing enough to increase your oxygen levels. Low oxygen levels can result if you have an issue with air moving in and out of your lungs, such as when scarring in the lungs reduces the number of alveoli, or air sacs, that normally work to absorb oxygen. **When this happens, your lungs may need some extra oxygen to help you stay active, alert and keep you moving.**

Oxygen therapy provides extra oxygen to your lungs

The normal air you breathe only has 21% oxygen. Oxygen therapy allows you to increase the amount of oxygen you breathe in. When you see your treating healthcare team, they will check to see if oxygen therapy could help you when you are resting, during exercise or both.

How often should you use oxygen therapy?

If you require oxygen therapy, your specialist doctor will give you an oxygen prescription, which will include how often you need to use oxygen therapy as well as how much oxygen you need.



Examples of oxygen prescriptions

- 24 hours at 2L/min
- 24 hours at 4L/min
- Night-time only at 2L/min
- During exercise/activity at 2L/min

Your doctor may also prescribe different oxygen settings for different activities, so your prescription may also look like this:

Activity	Duration	Flow rate/Setting	Mode*	Device
Exertion				
At rest				
Sleeping				

* Mode refers to a continuous flow or pulse (oxygen is only delivered on the 'in' breath).

Your prescription should also include some information on who to contact if your device is not working.

It is important that you follow the prescription your doctor gives you, just like you would follow the prescription for any other medication. You should use your oxygen as prescribed whether you are at home or out and about.

What do you need for oxygen therapy?

There are a few different ways you can receive oxygen therapy. Your treating healthcare team or oxygen provider will make sure you find a method that suits you. Here's a list of some of the key equipment you will need:

Oxygen source

There are three types of oxygen sources: home oxygen concentrators, portable oxygen concentrators or oxygen cylinders.

Oxygen concentrators

A concentrator is a machine that draws in air via a vent and filters out any unnecessary gases (especially nitrogen) leaving you with a higher oxygen concentration.

Home oxygen concentrators

- Larger device that plugs into an electrical socket in your home
- Has wheels so you can move it around the house, but you can't take it outside
- Can deliver 1-5 litres of oxygen per minute, while some of the larger concentrators can deliver up to 10 litres per minute.



Image supplied by Philips Sleep & Respiratory Care, Australia and New Zealand.



Portable oxygen concentrators

There are many different portable oxygen concentrators. Generally, they fall into two categories: wheeled on a trolley or those that are carried with a strap. Both run on a battery and are smaller than a home concentrator so you can take them with you when you go out.



Wheeled on a trolley

- Weighs 4–5kg
- Can deliver up to 2–3 litres of oxygen per minute with a continuous flow.



Carried with a strap around your shoulder or in a backpack

- Weighs 1–2kg
- Can deliver around 1 litre of oxygen per minute with a pulsed flow only.

Images supplied by Philips Sleep & Respiratory Care, Australia and New Zealand.



Talk to your treating healthcare team about which concentrator best suits you and your needs.



Oxygen cylinder

An oxygen cylinder contains compressed oxygen that weighs about 6.6kg when it is full (smaller oxygen cylinders may also be available and could be considered if your doctor thinks it is appropriate for you). A valve system (regulator) controls the pressure and flow of the oxygen coming out of the cylinder. When you use all the oxygen, you will need to have it refilled or replaced with a new cylinder.

A cylinder can supply up to 12 litres of oxygen per minute – how long it lasts depends on how much oxygen you use. For example, a medium-sized cylinder (called a C-size cylinder) will last about 2 hours if you are using 4 litres per minute or about 4 hours if you are using 2 litres per minute.

Delivery equipment

Regardless of whether you use a concentrator or oxygen cylinder, you will need some equipment to get the oxygen from the source to you. Your treating healthcare team will talk to you about your options, but they include:

- Nasal prongs or an oxygen mask
- Oxygen tubing.

Oxygen is normally delivered through nasal prongs which are two small, soft curved plastic tubes that go into your nostrils and are attached to a lightweight plastic tubing. Nasal prongs allow you to eat and talk while receiving oxygen therapy. You may also be given oxygen by mask; however this is less common.



Image supplied by Air Liquide Healthcare

Portable oxygen devices

What is the difference between continuous and pulse flow?

Portable oxygen devices can either deliver a continuous flow of oxygen or a pulse flow of oxygen to fit in with your breathing pattern. Your treating healthcare team will discuss with you which of these is most suitable for you.

Continuous flow

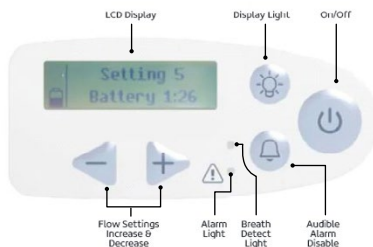
If your doctor has prescribed you continuous-flow portable oxygen, this can either be delivered by a cylinder or by a portable oxygen concentrator (there are a couple of different types that can deliver a continuous flow). The devices you can consider using will depend on your oxygen prescription. Make sure you speak to your treating healthcare team about which one suits you best.

Pulse flow

For portable oxygen concentrators, the amount of oxygen delivered in pulse flow is determined by the **setting number**. It is important to note that the setting number does not equal the amount of oxygen you receive in litres. There are several types of pulse-flow portable oxygen concentrators that you can discuss with your treating healthcare team. Please note that none of these concentrators will provide an oxygen flow rate above 1L/min.

On a portable concentrator, 'setting' does NOT equal 'litres'

Pulse-flow portable oxygen concentrators generally have settings 1 to 5, and each setting provides slightly more oxygen per breath. The exact amount of oxygen you receive at each setting depends on which machine you choose and how rapidly you are breathing.



If you choose an oxygen cylinder to deliver your pulse flow, you can also include an oxygen-conserving device, which only delivers oxygen when you breathe in, not when you breathe out. Using an oxygen-conserving device can help your cylinder last longer, which may reduce the costs associated with ordering and delivering new cylinders. However, these devices are not suitable for everyone, so make sure you talk to your treating healthcare team before you use one.



Image supplied by BOC Ltd, a Linde Company.

Deciding which portable oxygen device is for you

There are a few different portable oxygen devices on the market, all of which are slightly different. Your oxygen therapy device will become part of your daily life, so when you discuss them with your treating healthcare team, you might want to discuss some of the following points to make sure you choose the best option for you.

Remember, you need a prescription from your doctor to rent or buy oxygen equipment. Your doctor will let you know which oxygen device is appropriate for you.

- Do you need continuous or pulse flow?
- What flow rate do you require?
- Will you be able to carry a portable oxygen device, or is the trolley or walker the best option?
- How long are you usually out of the house?
- When you are out, are you normally close to a power supply, like in a café, or are you more likely to be going for a long walk?

The cost of portable oxygen devices

Portable oxygen concentrators can be expensive, so make sure you speak with your treating healthcare team to help you find an option that is within your means.

Some states and territories have government-assisted oxygen-supply programs. Access to this funding is based on specific criteria. Please speak to your treating healthcare team to see if you qualify.



Oxygen delivery devices for use outside the home

If your doctor prescribes oxygen for use outside the home, you can choose between a portable concentrator or a portable cylinder.

There is no right or wrong answer as to which one is best. The decision depends on you and your lifestyle and oxygen requirements. The table on the following page provides a comparison of portable oxygen devices. You can use this table to have a discussion with your treating healthcare team about which device is most suitable **before** you rent or purchase the equipment.

	Portable concentrator		Portable cylinder
	Trolley	Strap	
What type of flow does it deliver?	Pulse or continuous flow.	Pulse flow.	Pulse or continuous flow.
How long does it last?	Approximately 1 hour with continuous flow or up to 3 hours on pulse flow. Some can last around 5 hours at a lower flow rate.	Depends on the flow rate. At maximum flow it can last around 2 hours, or around 4 hours at a lower flow rate.	Depends on the oxygen prescription (2L/min will last 4 hours in a C-size cylinder on continuous flow).
How much does it weigh?	Approximately 4-5kg.	Approximately 1-2kg.	Approximately 6.6kg when full.
How do you carry it with you?	On a trolley	With a strap over your shoulder or in a backpack.	In backpack, on a trolley or carried on a walker.
How can you refill it?	Charge the battery <ul style="list-style-type: none"> You can rent or buy additional batteries. 	Charge the battery <ul style="list-style-type: none"> You can rent or buy additional batteries. 	Change to a different cylinder (this may require you to change the gas regulator from one cylinder to another). Alternatively, you can take your cylinder to a refill centre or pay for delivery.
How much does it cost? <i>Note: in some states, oxygen equipment may be provided without cost by government schemes.</i>	\$5,000+ Option to rent.	\$4,000+ Option to rent.	Rental per cylinder and refill costs (plus a delivery charge if you cannot return it to a depot).
What is the maximum flow rate?	2L/min*	<1L/min*	Limited only by the regulator. It can do 1-4L/min (sometimes up to 6L/min), which covers most prescriptions.

*Your choice of machine is limited if your prescription is 2L/min or more.

Travelling with oxygen therapy

You can still travel if you need oxygen therapy, you just need to keep it in mind in your planning. Before you travel, it is important that you talk to your treating healthcare team. Together, you can make a plan that will best suit you and your needs.

Below are some tips to consider when travelling.



Travelling by car or caravan

- Make sure the oxygen cylinders or portable concentrator are secured in the backseat footwell
- If you have oxygen cylinders:
 - ensure you can see the regulator at all times, which tells you when you need to change over
 - plan to take enough oxygen to account for any unforeseen diversions or delays
 - plot your trip based on where you can swap or refill your cylinders
- If you have a portable concentrator, make sure it is plugged in using the car-charging kit and/or carry a spare battery
- Ensure no one smokes in the car.



Travelling on a cruise

- You will need to take a portable concentrator as you won't be able to take enough oxygen cylinders to last the whole trip
- Make sure the portable concentrator is suitable for your oxygen prescription
- Tell the cruise line that you have a portable oxygen concentrator and will need an uninterrupted power supply that fits with your concentrator plug or adapter
- Ensure the cruise line has oxygen supplies on board in case of an equipment malfunction
- You may need a medical clearance form signed by your doctor. Check with your cruise line company.



Travelling by plane

- Even if you don't usually use oxygen at sea level, you might need it when you fly, as the plane pressure is lower which means there is less oxygen available. Speak with your treating healthcare team before making any plans to travel by air.
 - You will require a medical clearance form signed by your doctor for international and some domestic flights. These vary depending on the airline, so ensure you contact them early.
 - Depending on the airline, you may have the option to:
 - Take your own portable concentrator or rent one for the trip. Make sure it is Federal Aviation Administration (FAA) approved.
 - Airlines do not let you use their power supply on board, so you need to ensure you have enough batteries to cover 1.5 x the travel time (for example, a four-hour flight will require enough oxygen supply for 6 hours).
- OR**
- Although rare, some airlines can provide you with oxygen cylinders on board. Some airlines provide this for free, while others may charge fees. It is important that you shop around when you are buying your flights as not all airlines are the same. Take care when booking with low-cost and code-shared airlines (where your ticket is with one airline but the plane is from another), ensure you know what your ticket will cover before you purchase the airfare.

Did you know? Insurance is essential if you want to travel

You **MUST** declare your lung disease as a pre-existing condition. This will mean your premium will be higher and you might need to do some research to find which insurance suits you best.

Hints and tips on integrating oxygen therapy into your life

Setting up an oxygen concentrator at home

The home oxygen concentrator is quite large, so you will need to find a good spot for it and leave it there. You can then use the oxygen tubing to create a circuit around your house that lets you access everywhere you need. When you are setting up your concentrator at home, there are some things you should consider:



Concentrator motors can be noisy - you probably don't want to keep it in a bedroom, but the hallway might be a good choice. Find a central area where there is good ventilation and you can reach key areas in your home.



Trip hazards - creating a circuit of tubing around your home can create trip hazards, particularly crossing doorways or at the top of stairs. When walking with tubing - hold the tubing up and away from your body to minimise the risk of tripping.

Be careful of open flames

Oxygen feeds fire, so if you are using oxygen therapy, you should be aware of any activities that include a flame:



Don't smoke or allow smoking inside your home, this includes e-cigarettes or vaping devices.



Try to avoid activities that involve an open flame or sparks, such as matches, candles, gas cookers or barbecues.

Looking after your oxygen device

If you have an oxygen concentrator or cylinder, there are some things you need to do regularly to make sure your equipment stays clean.



Clean the outside of your equipment

Every week, wipe down the outside of your device with a damp cloth and mild detergent and then use a dry towel to dry it off. If you have a concentrator, make sure it is unplugged from the wall before wiping it down.



Clean and replace your tubing

Replace your nasal prongs or mask every two to four weeks, and every time you get sick. Ensure these items remain clean. Make sure any equipment parts that touch your face don't come into contact with any other surfaces.

Replace your tubing every 2 months.



Clean the filter

Clean the air filter every week according to the manufacturer's instructions. These instructions will also tell you how often the air filter needs to be replaced.

Please note: this is not applicable for oxygen cylinders.



What if something goes wrong?

Contact your manufacturer if your machine has a fault or breaks down. If you have a concentrator, have it serviced by the manufacturer once a year.

Remember: each device is different, so make sure you follow the manufacturer's instructions.



Seamless charging with a portable oxygen concentrator

You will need to do some planning for when you move between your home concentrator and your portable concentrator when you are out and about. The tips on the following page should help ease this process.

The diagram shows an example of how you can use your portable oxygen concentrator when going about your everyday life, like going to meet friends in a café and doing some shopping on the way home. Note that this is just one example, not everyone will need to use their oxygen like this.



At home Use your home concentrator



Walking to the car Use the battery on your portable concentrator



In the car Plug your portable concentrator into the car charger



Travelling home Plug your portable concentrator into the car charger and then use the battery until you can connect back to your home concentrator



At a destination, like the supermarket Use the battery on your portable concentrator



At a destination, like a cafe Plug your portable concentrator into the mains power



Nostril dryness and bleeding

Some people find that their nostrils can get dry, crusted, and sometimes bleed when they are using oxygen therapy. Some tips on how you can manage this include:

- Use non-petroleum-based lubricants such as medical-grade sesame oil to keep your inner nostrils lubricated (talk to your pharmacist about which products are suitable for you)
- Talk to your treating healthcare team about the possibility of having short breaks from your oxygen therapy when you are at rest or using a humidifier at home.



Wearing oxygen in the shower

Some people with Pulmonary Fibrosis find that they feel quite breathless when they are in the shower. Regardless of whether you have a 24-hour prescription or not, you should consider using oxygen when you are showering. You may also want to consider sitting on a stool in the shower to help conserve your energy and make the task easier.

Ensure that only the oxygen tubing is in the wet area of the shower. To help prevent accidents with the water and electricity, do not bring the home or portable concentrator into the bathroom.

Some people find taking their time and having a shower in stages can also help. You might want to consider taking breaks after getting undressed, between getting out of the shower and drying off, before getting re-dressed and then leaving the bathroom.

Notes on your oxygen prescription

Which device(s) is recommended for me? _____

When should I use oxygen? _____

What flow rate is recommended for me? _____

Notes



Centre of Research Excellence in
Pulmonary Fibrosis

Funded in 2017 by the Australian National Health and Medical Research Council, the Centre of Research Excellence in Pulmonary Fibrosis (CRE-PF) aims to build research capacity in the area of Pulmonary Fibrosis. The CRE-PF enables a nationally coordinated, clinically focused research program to address the urgent need for more effective, personalised approaches to identify and better manage fibrotic lung disease, as well as to educate the public and train future generations of researchers in Pulmonary Fibrosis.

For more information on CRE-PF, visit cre-pf.org.au



As Australia's leading lung health charity, Lung Foundation Australia funds life-changing research and programs to reduce the prevalence of lung disease and improve support and care for all Australians. Lung Foundation Australia collaborates with the CRE-PF, working together to drive patient and clinician involvement in Pulmonary Fibrosis research and trials via the Pulmonary Fibrosis Australasian Clinical Trials (PACT) Network and the Australian Idiopathic Pulmonary Fibrosis (IPF) Registry.

For more information on PACT, visit pact.lungfoundation.com.au and for more on the IPF Registry, visit lungfoundation.com.au



FURTHER INFORMATION AND SUPPORT

Contact Lung Foundation Australia for more information, to access our support services and join our mailing list for regular updates and latest news.

Lung Foundation Australia Services

- Information and Support Team
- Lung disease information resources
- Education webinars
- Support groups
- Peer-to-peer connections
- Referral to pulmonary rehabilitation and Lungs in Action exercise programs
- E-newsletter

External Links

Pulmonary Fibrosis Foundation
www.pulmonaryfibrosis.org

Canadian Pulmonary Fibrosis Foundation
www.cpff.ca



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