

Getting Started

on Home Oxygen



THE
AUSTRALIAN
LUNG
FOUNDATION

*"When you can't breathe...
nothing else matters"™*

Acknowledgements

Contributors

Many thanks to the panel of experts who contributed to the content of this resource.

Tod Adams

*Thoracic Clinical Nurse Consultant,
Shoalhaven District Memorial Hospital, Nowra, NSW*

Heather Allan (Project Manager)

*Director – COPD National Program,
The Australian Lung Foundation, Brisbane, QLD*

Barry Blaikie

Patient Advocate, Perth, WA

Juliet Brown

The Australian Lung Foundation, Brisbane, QLD

Dr Paul Cafarella

Psychologist, Repatriation General Hospital, Adelaide, SA

Professor Alan Crockett PSM

University of Adelaide, Adelaide, SA

Andrea Fitzgerald

Oxygen Therapist, Austin Hospital, VIC

Dr Kerry Hancock

General Practitioner, Chandler Hill Surgery, Adelaide, SA

Judith Hart

Patient Advocate, Brisbane, QLD

David Hayne

Consultant Pharmacist, Melbourne, VIC

Jenny Hose

The Australian Lung Foundation, Brisbane, QLD

Christine Hunt

Patient Advocate and Carer, Rosebud, VIC

Reg Hunt

Patient Advocate, Rosebud, VIC

Professor Christine McDonald

Respiratory Physician, Austin Hospital, Melbourne, VIC

Vanessa McDonald

Clinical Nurse Consultant, John Hunter Hospital, Newcastle, NSW

Carol McVicar

*National Medical Marketing Manager, Air Liquide Healthcare,
Rosebery, NSW*

Rosemary Moore

Respiratory Physiotherapist, Melbourne, VIC

Katie O'Brien (Writer)

Communications consultant, Brisbane, QLD

Dianne Proctor*

Patient Advocate, Canberra, ACT

Caroline Polak Scowcroft

Patient Advocate and Carer, Canberra, ACT

John Serginson

Nurse Practitioner, Respiratory Caboolture Hospital, QLD

Jeffrey Sheldon

Patient Advocate, Brisbane, QLD

Peter Wark

*Associate Professor, Respiratory Physician, John Hunter Hospital,
Newcastle, NSW*

*Sadly, Dianne Proctor passed away in October 2009 and never saw this publication in print.

Publications

The following printed resources were reviewed and used as models to produce this patient guide:

Handbook for Home Oxygen Therapy, 2009

Produced by Medical Aids Subsidy Scheme, Queensland Health

All About Home Oxygen Therapy

Written by Associate Professor Christine McDonald for the Victorian Tuberculosis and Lung Association

My Home Oxygen

Produced by Department of Respiratory and Sleep Medicine, John Hunter Hospital

Better Living with Chronic Obstructive Pulmonary Disease: A Patient Guide, 2008

Produced collaboratively by The Australian Lung Foundation and Queensland Health

Website

The Canadian Lung Association website, www.lung.ca, was also reviewed and used as a reference tool for this resource.



Contents

A summary

The 12 things every home oxygen user should know ... i

Introduction iii

- Why oxygen is so important iii
- About this booklet iii

Who needs home oxygen therapy? 1

- Testing the oxygen levels in your blood 1
- Who may benefit from home oxygen therapy 1

How oxygen can help 2

- Oxygen may help you to live longer 2
- Oxygen and breathlessness 2
- Improvements in overall wellbeing 3
- Commonly asked questions 3
 - *Can I become physically addicted to oxygen?*
 - *Will my lungs get weaker if I use oxygen?*
 - *What might happen if I delay or avoid this treatment?*

How much oxygen is right for you? 4

- Your oxygen prescription 4
- Time spent on oxygen 5
- Commonly asked question 6
 - *If I feel my condition has worsened, or I feel I am no longer getting any benefits from home oxygen therapy, should I increase my flow rate?*

Oxygen equipment options explained 7

- Oxygen concentrators 7
- Medical oxygen cylinders 7
- How oxygen reaches your lungs 8
- Oxygen conserving devices 8

Oxygen equipment subsidies 9

- Equipment funding 9
- Purchasing oxygen equipment 10
- Commonly asked question 10
 - *Am I entitled to an electricity rebate?*

Using oxygen equipment 11

- Equipment safety 11
- Equipment care 12
- If irritation occurs 12
- Tips for using the equipment 13
- Commonly asked question 13
 - *What should I do if I have a bad cold and cannot breathe properly through my nose?*

Oxygen in everyday life 14

- Leaving home with oxygen 14
- Commonly asked questions 15
 - *Can I continue to drive while on supplemental oxygen?*
 - *What should I do if I run out of oxygen while I am out?*
- Maintaining the intimate side of life 16
- Introducing my family or a carer to oxygen 16
- Avoiding smoking and being around smokers 17
- Staying positive 17

Staying active with oxygen 18

- Using oxygen in the home 18
- Conserving energy 19
- Pulmonary rehabilitation 19
- Relieving breathlessness 20

Travelling with oxygen 21

- Are you fit to travel? 21
- Taking oxygen away with you 21
- Accommodation considerations 23
- Other suggestions 23

Where to turn for extra support 24

Our practical support tools

(available on-line at www.lungfoundation.com.au)

- Your oxygen prescription and goal setting
- Your power blackout action plan
- Your equipment checklists:
 - *Choosing a portable oxygen cylinder*
 - *Choosing a portable oxygen concentrator*
 - *Other considerations*
- Things to ask a supplier
- Information for buyers and sellers of portable oxygen equipment

A summary

The 12 things every home oxygen user should know

- 1. Oxygen therapy can help.** Some people with lung diseases do not get enough oxygen into their blood. Low levels of blood oxygen mean that vital organs are being deprived of oxygen and this can cause damage over time. Doctors use tests to confirm if this is the case. Home oxygen therapy can help those with confirmed low blood oxygen by ensuring enough oxygen gets to vital organs. In some cases, home oxygen therapy can also make everyday life easier and more enjoyable.
- 2. Regular medical reviews are vital.** It is important to have your oxygen prescription checked by a respiratory specialist at least once a year. Or, if you feel your condition has changed, make an appointment to see your doctor earlier. *Do not adjust your oxygen flow rate on your own.*
- 3. Oxygen does not always relieve breathlessness.** There are many reasons why people have trouble breathing. Home oxygen therapy may relieve shortness of breath for some people, but for many it does not. Sometimes you need a combination of therapies to help relieve breathlessness. Ask your doctor or respiratory nurse to fully explain the benefits you can expect from oxygen.
- 4. Oxygen is not addictive.** Home oxygen therapy is not addictive and it will not weaken your lungs. You will get maximum benefit by using oxygen for the amount of time prescribed by your doctor.
- 5. There is a range of oxygen equipment available.** There are two main types of oxygen equipment used in Australia. The most common is the oxygen concentrator which filters nitrogen out of the air to deliver almost pure oxygen. Gas cylinders filled with oxygen are also widely used and come in a range of different sizes. The smaller cylinders are light enough to take with you when leaving the house and often go by the name *portable oxygen cylinders*.
- 6. Some oxygen equipment is funded.** Many home oxygen users will qualify for government funded equipment. However, qualifying rules are different in every state. If you need extra equipment, you can purchase or hire it direct from an oxygen supplier. Ask your doctor or a member of your healthcare team for help in working out the equipment that is best for you. A series of helpful practical support tools have been developed to support this booklet. They include equipment checklists and can be found on-line at www.lungfoundation.com.au

7. **Oxygen is safe to use but can make things burn more intensely.** Do not put yourself or your oxygen equipment near any sources of extreme heat, flames, or something that could cause a spark, including a lit cigarette. A study in the US has shown that smoking is by far the largest cause of serious burns in people using home oxygen.
8. **Continue on with everyday life.** Although it may take a while to get used to your oxygen equipment, try to continue with your normal routines as much as possible. Many people do not need to use their oxygen on trips outside the home. For those who do, feelings of self-consciousness about using oxygen equipment in public are usually short lived. Once your confidence improves, the benefits should start to outweigh any downsides.
9. **Avoid smoking and being around smokers.** Cigarette smoke is very damaging to the lungs. Quitting smoking is the single most effective thing you can do to help your condition. It is also important to avoid other people's cigarette smoke.
10. **Keeping active is good for your health.** Regular physical activity is very important for those with lung disease to help you perform activities of daily living more easily. Activity does not need to be strenuous. Good activities include walking the dog, an outing, or even just doing jobs around the house. A pulmonary rehabilitation program can also teach you how to exercise more easily. For information on a program near you, call The Australian Lung Foundation on 1 800 654 301.
11. **Travelling with oxygen equipment is possible and requires planning.** Some of the things to check before booking a trip are: how to correctly transport your equipment; whether you can use your portable oxygen during the journey; and how to arrange an oxygen supply at your destination. You may also need a letter from your doctor stating that you are fit to travel.
12. **Plan what to do in an emergency, such as a power blackout.** The most important thing to remember is to try to remain calm and not panic. Although losing power will be annoying, most oxygen users (even those on oxygen for 16 hours a day or more) are safe without their oxygen supply for many hours, if they rest. Call an ambulance if you are in need of urgent assistance.

Introduction

Why oxygen is so important?

Oxygen makes up 20% of the air we breathe and is an essential part of life. We take oxygen into our bodies each time we take a breath. The oxygen from the lungs is then dissolved into the blood and delivered to the body tissues and organs as the blood circulates.

In healthy people, the lungs keep the amount of oxygen in the blood stream at a normal level. But, if your lungs are damaged, they may not always deliver enough oxygen to the blood.

The body can tolerate low levels of oxygen for short periods of time, but low levels of oxygen for long periods of time can cause problems with your vital organs. Home oxygen therapy helps to return your blood oxygen levels to normal. This, in turn, reduces the damage happening to your body and can help you to live longer.

About this booklet

This booklet has been designed as a resource for Australians with a chronic lung condition, who have recently been prescribed home oxygen therapy, or may be prescribed it in the near future.

Inside you will find information about

- how home oxygen therapy works
- the equipment that is used
- practical tips others have found helpful
- the answers to some commonly asked questions.

The information in this booklet is largely aimed at adults with Chronic Obstructive Pulmonary Disease (COPD), as this is one of the most common adult lung diseases that can lead to the need for home oxygen therapy. People with other chronic lung conditions may also find this booklet helpful.

Additional information about COPD can be found in The Australian Lung Foundation's publication, *Better Living with Chronic Obstructive Pulmonary Disease: A Patient Guide*. This publication can be downloaded at www.lungfoundation.com.au or you can purchase a copy by calling 1800 654 301.

Who needs home oxygen therapy?

Testing the oxygen levels in your blood

Doctors use specific tests to see if the body is getting the oxygen it needs. The most common test is called an **arterial blood gas test (ABG)**. This test is performed by taking a sample of blood from an artery and using it to measure the amount of oxygen and carbon dioxide in your blood.

The oxygen level in your blood is measured as pressure. A healthy person usually has an oxygen level (or pressure level - PaO₂) above 85 millimetres of mercury (mmHg) at sea level. In people with lung disease the amount of oxygen in the blood is often lower. As long as the oxygen level is not too low (below 60 mmHg), the body can maintain normal function.

Another important measurement doctors look at is **blood oxygen saturation**. This is the amount of oxygen your blood is holding *at the moment* compared to how much it is *able* to hold. To explain this better, think of your blood as a sponge. When a sponge becomes full of water we call that 100% saturated, or at capacity. Even if you were to add extra water to this sponge, it could not absorb any more.

Ideally the blood should be at least 90% saturated with oxygen. When the blood is this saturated, it cannot hold much more oxygen.

Who may benefit from home oxygen therapy

If tests show that your blood oxygen saturation levels are adequate, then breathing in extra oxygen (through oxygen therapy) is not likely to benefit you, as your blood already has the correct amount of oxygen it needs.

An oxygen pressure level above 60mmHg - is adequate for most normal functioning, as the blood is generally over 90% saturated with oxygen at this level of oxygen pressure.

Home oxygen therapy may be beneficial for people with oxygen pressure lower than 55-60 mmHg. At these levels, the blood is often not adequately saturated with oxygen. This condition is referred to as **hypoxemia**.



If tests show that your blood oxygen saturation levels are adequate, then breathing in extra oxygen (through oxygen therapy) is not likely to benefit you, as your blood already has the correct amount of oxygen it needs.

How oxygen can help

Oxygen may help you to live longer

One of the most common lung conditions in older adults is Chronic Obstructive Pulmonary Disease or COPD. This is a term used to cover conditions including emphysema and chronic bronchitis.

In the 1980s two large studies were performed in the UK and USA to explore the benefits of oxygen therapy on people with COPD who had low levels of oxygen in their blood.

The results showed that those who had very low levels of oxygen (PaO₂ less than 55-60 mmHg) benefitted from 16 hours of oxygen a day. This is why many people with COPD are prescribed oxygen for at least 16 hours per day.

There are other conditions which may cause low oxygen levels in the body, such as pulmonary fibrosis, cystic fibrosis, some cancers, pulmonary hypertension, heart failure, chronic asthma, obstructive sleep apnoea, and pulmonary embolism.

Home oxygen therapy may also be prescribed for people with low blood oxygen levels caused by these conditions, as it is expected they may benefit in a similar way to those with COPD.

Oxygen and breathlessness

Shortness of breath can be very distressing.

If you feel more short of breath during exertion, this is often due to an increase in your heart rate during exercise, not necessarily due to a low oxygen level in the blood.

To assess whether a fall in blood oxygen occurs during exercise, a measurement of the blood oxygen saturation may be taken using an **oximeter**. This device clips onto the earlobe or finger and gives a reading of the amount of oxygen in the blood.

Some people definitely benefit from oxygen during exertion, but many people become short of breath when they exercise, despite there being no fall in their oxygen levels.

If your blood oxygen levels are adequate then home oxygen therapy is unlikely to relieve your breathlessness.

There can be many other causes of shortness of breath besides a low oxygen level. Sometimes medications, exercise programs or learning special breathing techniques can help to relieve breathlessness. See *pulmonary rehabilitation* on page 19 and *relieving breathlessness* on page 20 for more information.



Improvements in overall wellbeing

If you have low blood oxygen levels, then home oxygen therapy *may* help you to feel more energetic, making everyday life easier. Some of the most common improvements oxygen users report include:

- Waking up feeling more refreshed in the morning
- Improved concentration
- Feeling less fatigued during the day

Not everyone notices all of these improvements. In fact, some people do not notice any day-to-day improvements. This is perfectly normal. Remember, oxygen therapy is still helping your body by getting oxygen to your vital organs.



Not everyone notices improvements but oxygen is still helping your body by getting oxygen to your vital organs.

Commonly asked questions

Can I become physically addicted to oxygen?

- **No.** Oxygen does not have any chemically addictive properties.

Will my lungs get weaker if I use oxygen?

- **No.** Oxygen therapy does not weaken the lungs.

What might happen if I delay or avoid this treatment?

- If you have been prescribed oxygen therapy, then the sooner you start it the better. Oxygen therapy is designed to increase your life expectancy by delivering more oxygen to your vital organs which may then help your body to function better.
- Reduced oxygen may cause the body to produce more red blood cells. Sometimes this thickens the blood (a condition called **polycythemia**) making it harder for the heart to pump the blood around the body. Oxygen therapy can help to reduce this strain on your heart, lowering your risk of heart failure.

How much oxygen is right for you?

Although many people are prescribed oxygen for at least 16 hours a day, not everyone needs to be on oxygen for such long periods of time. It is important to understand your prescription and follow it carefully.

Your oxygen prescription

Your prescription explains when you should use oxygen and the *flow rate* you should use.

When you should use oxygen

Your doctor will advise you about when to use your oxygen for maximum benefit.

Examples of common prescriptions include:

- use oxygen for at least 16 hours a day, and / or
- use oxygen while sleeping, and / or
- use oxygen when exercising or being more active

How much oxygen do I need?

Flow rate is the term used to describe the level of oxygen you receive from your oxygen equipment. Once you set your oxygen equipment to a flow rate, the correct amount of oxygen is then delivered to your body.

Flow rate is measured in litres per minute and is often written as LPM or L/M.

You may be prescribed one flow rate by your doctor, or different flow rates for different situations such as:

- a flow rate for normal awake hours
- a flow rate for when you are exercising or more active
- a flow rate for sleeping

My next review

It is important to have your prescription checked by your doctor 4 to 6 weeks after starting oxygen therapy. You then require a review at least once a year. If you feel your condition is changing, make an appointment with your doctor earlier.



It is important to have your prescription checked by your doctor 4 to 6 weeks after starting oxygen therapy.



If you feel your condition is changing, make an appointment with your doctor to discuss.

Time spent on oxygen

How long will you require this treatment?

Ask your doctor which category you are most likely to fall into:

- **I need oxygen temporarily, while I recover from an acute illness**
Sometimes blood oxygen levels can drop during a bout of sickness and then recover with treatment. In this case, you may only need oxygen for a little while, such as while you are in hospital, or for a month or so afterwards. Your doctor will test your blood oxygen levels to see how fast you are recovering.
- **Oxygen will be a permanent part of my life**
The amount of time you need to spend on oxygen will depend on when your blood oxygen levels drop below 90% saturation. If the oxygen levels in your blood are low all the time or they always seem to drop in certain situations (such as when you are sleeping and when you are more active), then it is most likely that oxygen will become a permanent part of your life. It is important, however, for your doctor to reassess your condition each year, to see if any changes need to be made to your treatment.

When do you require oxygen?

Your doctor will tell you how many hours you should use oxygen for each day for maximum benefit. Here are some different scenarios:

- **Oxygen only during activity (exertional oxygen)**
Some people's oxygen levels become low when they are more active and then return to normal when they are at rest. This is tested using an oximeter (see page 2).
- **Oxygen only while sleeping (nocturnal oxygen)**
Some people's blood oxygen levels drop when they are asleep.
- **Continuous, long term oxygen**
Some people have low blood oxygen levels all the time. In this case, oxygen may be prescribed for at least 16 hours a day.



Your doctor will tell you how many hours you should use oxygen for each day for maximum benefit.



Oxygen is a medication. Just as you would not adjust the dose of your tablets without consulting with your doctor you should not adjust your oxygen flow rate on your own.



Commonly asked question

If I feel my condition has worsened or I feel I am no longer getting any benefits from home oxygen therapy, should I increase my flow rate?

- **No.** If you notice any changes like these, you should talk to your doctor, especially if you have a high carbon dioxide level in your blood. Oxygen is a medication. Just as you would not adjust the dose of your tablets without consulting with your doctor you should not adjust your oxygen flow rate on your own.

There may be a number of reasons why you are noticing these changes, including:

- **You need your prescription reviewed.** Your oxygen flow rate may well need to be changed, but the only way to work this out is for your doctor to assess your blood oxygen level. *TIP: Every home oxygen user should have their prescription reviewed at least every 12 months.*
- **Your prescription is OK, but your lung condition has changed.** It is possible that your lung capacity is not as good as it used to be despite the oxygen therapy. This may be due to a number of factors, including the ageing process and the progression of your lung condition. A reduction in lung capacity can make breathing feel harder, even though your body is getting the oxygen it needs.

Oxygen equipment options explained

There are two main types of oxygen equipment used in Australia, oxygen concentrators and oxygen cylinders.

1. Oxygen concentrators

Home concentrator

- This is a machine about the size of a bedside table that concentrates oxygen by filtering the nitrogen out of the air.
- It is the most common source of oxygen delivery for people on long term oxygen.
- It has a long tube that allows you to move more freely around the house.
- It requires electricity to operate.



Home concentrator
Image supplied by Air Liquide Healthcare

Portable concentrator

- This is a smaller concentrator designed to be taken out of the home.
- Many are so light they can be carried in a bag or wheeled. They also contain their own power supply.
- These concentrators are fairly costly and normally require private funding. They are also available second hand. The Australian Lung Foundation has produced a short guide to buying /selling second hand portable oxygen concentrators. See p 24 (Practical Support Tools) or call 1 800 654 301 to get a copy.
- Most deliver oxygen in a **pulsed dose**, which means you receive oxygen when you breathe in, but not when you breathe out. This is done to make the machine lighter and also to preserve battery life.

2. Medical oxygen cylinders

Large freestanding or stationary cylinders

- These are occasionally provided as a back-up for people prescribed long term oxygen therapy, in case there is a problem with their concentrator or a lengthy power blackout.

Portable cylinders

- These are smaller cylinders that can be used when leaving the home. They can be wheeled, attached to a wheeled walker or wheelchair, or may be carried in a backpack.



Portable cylinder
and trolley

How oxygen reaches your lungs

Oxygen is usually delivered to your lungs through the nose or through a mask.

Through the nose

- The first and most common method is through soft nasal prongs (sometimes called **cannulae**) that are worn in the nostrils. The tubing normally stays in place by being placed over the ears and under the chin. These allow you to eat or drink while taking in the oxygen.



Cannulae

Through a mask

- Sometimes those who require a high flow of oxygen (greater than 5 litres per minute) are advised to use a mask. Others may be provided with nasal prongs for day time and a mask at night. Not all masks are suitable for you to use with an oxygen concentrator. Only use the type of oxygen mask and the flow rate that has been specified by your doctor.

Oxygen conserving devices (OCDs)

Pulsed dose OCDs

A pulsed dose OCD is a battery-operated device that is attached to your oxygen cylinder replacing your usual flow regulator. It gives a “pulsed dose” or burst of oxygen when you begin to breathe in and then nothing when you breathe out. This helps to deliver oxygen to you more efficiently from your cylinders and allows them to last up to five times longer, reducing the cost and inconvenience of more frequent refills. OCDs are not suitable for all people who use home oxygen and may not be suitable in all situations, eg when sleeping. It is important to check with your healthcare provider if, when and how it is safe for you to use an OCD.

Oxymizer™ Conserving Devices

The second type of OCD is a special type of nasal prong set called an Oxymizer™ with a reservoir contained within a facepiece or pendant (see photo). It fills with oxygen between breaths and gives a boost of oxygen when you breathe in. The oxygen flow for this device must be continuous not pulsed. The oxygen flow rate is set lower on the flow regulator, but your body gets the same amount of oxygen. It is important to ask your healthcare team what flow rate you should use with the Oxymizer™.



Oxymizer Pendant

The two types of OCDs cannot be used together.

Pulsed dose OCDs are not usually used with home concentrators although an Oxymizer pendant may be prescribed in a few specific cases.

Oxygen equipment subsidies

Equipment funding

Step 1: Your doctor will assess you (see page 1) to determine if you will benefit from oxygen therapy.

Step 2: Your doctor will write a prescription for your oxygen needs. This is usually in the form of an application to one of the subsidised programs.

The subsidy of home oxygen equipment varies widely from state to state, so the support you may be entitled to receive will depend on where you live.

There are a number of subsidy options that may be available to you. They include:

- **State government funding.** Each state uses different criteria to decide who is eligible to receive an oxygen equipment subsidy. In some states there is a central organisation that manages subsidies and in other states these subsidies are run through local health services or hospital boards.
- **Federal government funding.** The Department of Veterans' Affairs and the Commonwealth Department of Health and Ageing also provide funded oxygen equipment under certain conditions for war veterans and people in residential aged care facilities.
- **Private health insurance.** Some insurers provide subsidies on oxygen equipment.
- **Palliative care.** Some states fund oxygen equipment for patients who qualify under palliative care criteria.

In most cases, your healthcare team will help you work through your funding options and the equipment you may need. But, if this does not occur, ask for assistance from the doctor who prescribed your oxygen or your local community health service.

Step 3: If you do qualify for funding, ask about the equipment you will receive.

- Most states will provide a subsidised home concentrator to those on long term oxygen. Some will also provide a back-up oxygen cylinder in case the concentrator fails or there is a lengthy power blackout or another form of emergency.
- Some states also provide a limited number of portable oxygen cylinders to use when outside the home.

Step 4: Ask for extra help if you need it.

The Australian Lung Foundation's Information and Support Centre may be able to provide some extra help, if you need it. The Centre can be reached on 1800 654 301.



Purchasing oxygen equipment

Many people have all of their home oxygen equipment needs met by a subsidised program. However, if you have been advised by your doctor or nurse that you will need *additional* equipment, you can rent or buy directly.

There are a number of companies in each state who supply home oxygen equipment. Each one will offer slightly different products at slightly different prices and service a slightly different geographic area.

If you are not receiving a subsidised home concentrator, you can purchase or hire one. They are considerably cheaper than portable concentrators.

The equipment most commonly purchased by individuals is portable oxygen. There are two portable oxygen options: oxygen stored in cylinders; or a portable oxygen concentrator.

It is important to check with your health professional before purchasing any equipment. You should test all equipment before purchasing.

The Australian Lung Foundation has produced three checklists to help you with the purchase of your equipment. These can be found at www.lungfoundation.com.au/LungInformation/EducationalMaterial. The first two checklists offer you things to consider when selecting portable oxygen equipment and the final checklist relates to selecting a supplier.

Commonly asked question

Am I entitled to an electricity rebate?

All home oxygen concentrators use power and will increase your electricity bills. Some states offer an electricity rebate to help compensate for this extra cost. To find out more, contact the government department that provides funded home oxygen equipment in your area or the doctor who prescribed your oxygen. Alternatively, call the electricity provider or The Australian Lung Foundation on 1800 654 301 for further information.

Using oxygen equipment

Equipment safety

Home oxygen therapy is very safe provided you follow some simple guidelines:

- Follow your prescription (that is your flow rate and hours of use per day).
- Use only the oxygen equipment recommended to you.
- Secure cylinders to prevent them falling.
- Report any problems with the oxygen equipment to the supplier as soon as they occur. Do not attempt to repair your oxygen equipment.
- Ask your oxygen supplier for instructions on how to use the equipment in the home. They should also provide information on how to safely transport the equipment.
- If you have been prescribed oxygen for 24 hours a day, you may need a back-up oxygen cylinder. Discuss with your doctor whether this is the case for you.
- Make sure you have smoke alarms in your house.

Things to AVOID

Oxygen can make things burn quickly, so it is best to keep your oxygen equipment at least three metres from any sources of heat, naked flames, or something that could cause a spark. Here are some examples:

- DO NOT smoke or allow others to smoke in your home or near your equipment.
- DO NOT put yourself or your equipment near matches, candles, gas appliances or open fires.
- DO NOT transport unsecured cylinders in a vehicle.

Things that are SAFE

It is safe to do most things while using your oxygen equipment. Some things commonly asked about include:

- IT IS SAFE to use oil heaters, air conditioners and electric blankets.
- IT IS SAFE to wear your oxygen equipment while taking a shower or bath, but remember that your concentrator is an electrical appliance and must not get wet.
- IT IS SAFE to wear your oxygen equipment while you exercise.



Home oxygen therapy is very safe provided you follow some simple guidelines.

Equipment care

Oxygen concentrator

Your concentrator's instruction manual will tell you what maintenance is needed. Make sure you understand exactly what is involved and ask your supplier for a demonstration if you have any concerns. Here are some additional reminders:

- Wash your filters regularly and replace them yearly.
- Your oxygen supplier is required to check your oxygen equipment on a regular basis. They may prefer to deliver newly tested equipment to your home and check your used equipment at their factory.

Care of accessories

- Oxygen accessories play a vital role in the comfort and delivery of your oxygen therapy.
- Always have a spare pair of nasal prongs and tubing available.
- Clean the ends of the nasal prongs at least weekly using soapy water and a soft cloth. You may need to do this more frequently if you have a lot of nasal secretions or an active infection.
- Replace your nasal prongs every four to six weeks. If they have become hard or brittle then replace them earlier.
- Oxygen tubing should be replaced if it becomes dirty, damaged or badly kinked.
- Accessories such as tubing and nasal prongs are available from your oxygen supplier.

If irritation occurs

Occasionally you may have some discomfort around the nostrils or behind the ears.

- Apply a water based lubricant or a sesame seed oil spray called Nozoil, to just inside the nostrils two to three times a day. These products are available from most pharmacies.
- DO NOT use petroleum jelly (eg. Vaseline) or petroleum based lubricants with nasal prongs, as they may be flammable and may irritate the lining of your nose. These products may also cause the nasal prongs to deteriorate.
- Some oxygen suppliers may have a different shaped nasal prong you could try.
- Ask your healthcare team if there is an alternative to nasal prongs that you could use during the day.
- If you are having trouble with rubbing behind the ears or on the cheeks, use soft foam pads (available from your oxygen supplier), or use cotton wool or gauze (available at a pharmacy) to wrap around the tubing.

Tips for using the equipment

- Concentrators need plenty of air circulating around them. Put them in a well ventilated spot, rather than a cupboard or confined space. If placing a concentrator near a window, make sure curtains do not stop the concentrator from drawing in the air it needs. If you place your concentrator in a bathroom make sure a window is open and that the concentrator cannot get wet.
- Concentrators should be located at least 15cm from the wall.
- You should plug your concentrator directly into a powerpoint. Do not use extension cords, double adapters or power boards.

Commonly asked question

What should I do if I have a bad cold and cannot breathe properly through my nose?

You can still use your nasal prongs, even when your nose is blocked. This is because the oxygen is actually drawn down from the back of your nose as you breathe in through your mouth. To reduce the unpleasant feeling of stuffiness, it is safe to use saline spray several times a day for a couple of days. This is just a short term treatment option. If you find the stuffiness continues or keeps coming back, then contact your doctor or respiratory nurse for advice.



You should plug your concentrator directly into a powerpoint. Do not use extension cords, double adapters or power boards.



Home concentrator
Image supplied by Air Liquide Healthcare

Oxygen in everyday life

Making the move to home oxygen not only means some changes for you, but can also mean changes for the loved ones around you. In this section we take a look at some of these changes and how others have managed the adjustment.

Leaving home with oxygen

Portable oxygen equipment is designed to allow you to continue using oxygen outside of the home.

Although it may take a while to get used to your oxygen equipment, try to get out of the house and back into your everyday routines as soon as possible.

It may also be possible to leave the home without oxygen equipment. Ask your doctor or respiratory nurse for some guidance.

Here are some tips to make outings low stress

- Don't be too ambitious about your outings until you gain confidence.**
- Mentally walk yourself through every aspect of your outing** so you can think through any potential problems before they arise. Think about where you are going to park the car, whether there are stairs to climb or a lift nearby, and if you can take your wheelchair or walker with you.
- Work out how long a portable cylinder may last for, so you know how many to take with you.** To do this, monitor your usage closely for a while. Take note of how many minutes a typical cylinder is lasting and then average out the results.
- Take a spare battery for your OCD if it is battery-run.**
- Toolkit.** If you are taking out more than one cylinder, take with you the correct tools you need to attach the flow regulator or the conserving device to the full cylinder and the tap handle to turn the cylinder on and off.
- Trial it at home.** Practise using your equipment and changing cylinders at home first.



If you are taking out more than one cylinder, take with you the correct tools you need to attach the flow regulator or the conserving device to the full cylinder and the tap handle to turn the cylinder on and off.

Commonly asked questions

Can I continue to drive while on supplemental oxygen?

If you have been prescribed long-term oxygen therapy and wish to drive, it is recommended that you discuss with your doctor whether it is necessary for you to use oxygen whilst driving or not. If you do use oxygen in the car, you will need to make sure that it is adequately secured.

What should I do if I run out of oxygen while I am out?

The most important thing to remember is not to panic. Most people can cope quite safely without supplemental oxygen for a period of time. Discuss with your doctor or respiratory nurse an action plan for situations where you suddenly do not have immediate access to your normal oxygen supply. Make sure your primary carer is aware of this plan.

A typical action plan may include these points:

- Try to remain calm.
- Have a list of important contact numbers that can be given to those coming to your aid.
- Conserve your energy. If you are on your own, call someone to help you home.
- If you are starting to feel breathless use any breathing control techniques which you have found to be helpful in the past.
- Call an ambulance if you are in need of urgent assistance.



If you run out of oxygen while you are out, don't panic. Most people can cope safely without their oxygen for a period of time if they don't exert themselves.



Maintaining the intimate side of life

Having a lung condition doesn't necessarily mean that you will lose interest in sex. Oxygen therapy may just require you to make a few adjustments to this part of your life.

Here are some tips others have found useful:

- Plan intimate times for when you feel your best. Some people feel better after their morning medications and some feel they breathe better in the afternoon.
- If you feel more energised with your oxygen on, then try using it during intimate times.
- Avoid having sex when you feel really tired, have just had a big meal, or have been drinking alcohol.
- There is no right or wrong way to fulfil the intimate side of your life. You just need to find something that works for you and your partner.
- Good physical fitness will help with your sexual performance, so keep as active as you can safely manage.
- You may need to ask to change your medication if your symptoms regularly affect your sexual activity.

Introducing my family or a carer to oxygen

If you are fortunate enough to have someone living at home or nearby to help with your care, it is important they understand how your oxygen therapy works. Here are some tips others have found helpful to achieve this:

- Encourage your family or carer to become as informed about your medical condition as you are. This may include coming along to your medical appointments, to gain a good understanding of your situation and to have any questions answered.
- Encourage your family or carer to become familiar with your oxygen equipment, including how to use it and reorder it.
- Encourage your family or carer to be involved in the planning of any outings.
- Encourage your family or carer to be aware of your emergency plan in case your equipment fails or there is a power blackout.
- Encourage your carer to seek support from groups such as Carers Australia (1800 242 636) or www.carersaustralia.com.au.
- Ensure your carer gets enough time to themselves.



If you have been prescribed portable oxygen equipment, the sooner you leave the house using it the sooner you will become used to it.

Avoiding smoking and being around smokers

If you are a smoker, home oxygen will not be able to help you.

Quitting smoking is the single most effective thing you can do to help your condition. It is not easy to quit, but it may be reassuring to know that most people diagnosed with severe COPD **do** succeed. For help call the QUIT line on 131 848 or speak to your doctor.

Staying positive

The main aim of home oxygen therapy is to try to improve your quality of life. Many people have reported feeling self-conscious about using oxygen equipment in public. Most of these people also found, however, that these feelings were short-lived. Once they gained some confidence, they found the benefits of oxygen therapy started to outweigh any downsides.

Here are some tips from oxygen users on ways to stay positive

- “Focus on what you can do with your oxygen equipment, rather than what you cannot.”
- “As your circumstances change, go with the flow, rather than looking back to how life used to be.”
- “If you are on oxygen more than 16 hours a day, concentrate on the time you have off oxygen each day and plan it carefully. Use the oxygen overnight so that you can have up to 8 hours during the day when you do not need to use it.”
- “Continue the everyday activities you enjoy as much as possible.”
- “If you have been prescribed portable oxygen equipment, the sooner you leave the house using it the sooner you will become used to it. Feeling self-conscious about your oxygen equipment is normal, but don’t let it get in the way of enjoying life.”
- “Use humour as a tool to cope with any reaction you get to your equipment. This is particularly effective with kids. Some people even dress up their cylinders.”
- “Join a support group and meet new people in the same situation as you.”

Staying active with oxygen

Staying active is good for those with lung disease. Here are some ways to help achieve this.

Using oxygen in the home

Many people find that oxygen therapy helps them to feel like being more active. Here are some tips for making your home oxygen concentrator as useful as possible:

- Home oxygen concentrators are heavy and many people find them difficult to move. Place your oxygen concentrator in a central position in your home so that it reaches the shower, bed and living area.
- If you enjoy being outdoors, talk to your supplier about attaching an extension length of tubing to your concentrator with a swivel connector. If easy for you to do so, you could also move the concentrator closer to an external doorway or window so your tubing reaches further outside.
- Use your oxygen in the shower and during other times of activity, such as when doing jobs around the house.

Tips to avoid tripping on your concentrator tubing

- **Do not have more tubing than you need.** If you have an extra extension piece of tubing, only use it when you need it.
- **Swivels.** If you have two pieces of tubing connected, make sure you put a swivel piece in between them.
- **Remove kinks from the tubing.** Lie the tubing out in the sun and let it heat up. It will eventually lie flat and lose the memory of the twists and kinks.
- **Be mindful of the tubing.** This should become easier over time. Be particularly careful on stairs and in bathrooms and other small spaces.



Place your oxygen concentrator in a central position in your home so that the tubing reaches the shower, bed and living area.

Conserving energy

If you can reduce the energy you use up on everyday tasks, you should have more energy left for the things you really enjoy. Here are some effective ways to save energy:

- Use your oxygen in the shower.
- Sit on a chair or a stool while washing, shaving, or applying makeup.
- Use a rolling laundry basket to avoid carrying clothes and eliminate frequent bending over.
- Use the perma-press setting on your dryer to avoid ironing.
- When vacuuming or mopping, move slowly and inhale as you push the vacuum / mop head away from you and exhale as you pull it towards you. Take frequent breaks.
- Use a small mop for wiping up spills to save bending over. Use pick-up tongs to retrieve articles from the floor. Use a long handled dust pan to pick up sweepings.
- Use a high stool in the kitchen to allow you to sit down as much as possible and use a trolley to move things around.
- Know your limits.

Pulmonary rehabilitation

Pulmonary rehabilitation is an exercise and education program designed for those with a chronic lung condition. Those on oxygen therapy can benefit from pulmonary rehabilitation.

Most people who complete a pulmonary rehabilitation program feel they are able to do more and feel less breathless. Contact The Australian Lung Foundation on 1800 654 301 to find out if there is a program near you.





Relieving breathlessness

Even on supplemental oxygen, you may continue to experience breathlessness. Below are some tips you can try to control or reduce your breathlessness.

- **Medication.** Using your reliever or preventer medication can help to control your breathlessness. Have your inhaler technique checked by your doctor, pharmacist or respiratory nurse.
- **Pace yourself.** If you are noticing that you are getting more short of breath than normal, you may need to slow down to get your tasks done.
- **Relaxed breathing.** The body's normal reaction when breathless is to breathe faster and shallower. When you have damaged lungs it is better to keep your breathing slower and as relaxed as possible. Try to breathe out for longer than you breathe in to empty the lungs of stale air. This will help you to breathe in better. Pursed lip breathing may also help. Ask a member of your healthcare team to demonstrate this technique.
- **Recovery positions.** Find a comfortable position to stay in while you recover. Either stand with your arms supported by something like a rail or table (pictured), or sit with your arms rested on your knees. It is important to maintain good posture (straight back) so you don't put pressure on your lungs.
- **Stay calm.** It is important to learn some relaxation techniques. When you become nervous, your muscles tense up and this can make breathlessness worse. Talk to your healthcare team if you find that feelings of anxiety become more regular.
- **Massage.** Some people find massage helpful when recovering from an episode of breathlessness. Ask your carer to make calm stroking motions across your neck and back.

These options may not work for everyone, and some people may need to try a combination of things before they get any relief.

Travelling with oxygen

In most cases it is still possible to travel while on oxygen therapy; it just requires a little more forward planning. Before you book a trip, here are some points you might like to consider. Your oxygen prescriber or supplier may also be a good source of information.

Are you fit to travel?

- Some people with lung disease may require supplementary oxygen when travelling by air, even though they do not usually need it at home. Your doctor can arrange for a test (High Altitude Simulation Testing) to assess your oxygen requirements when travelling by air. Your doctor and your travel agent or airline will facilitate the paper work as long as they are notified well in advance. There is usually a cost associated with the paperwork.
- Talk to your GP before embarking on any travel. Air travel requires extra medical consideration, as the reduced air pressure in an aircraft affects your blood oxygen levels.
- Check with the travel provider about any requirements they have. In many cases, the company you are travelling with will require a letter from your doctor stating that you are medically fit to travel.
- Ask your doctor for a brief medical history you can take with you. This should include a list of your prescribed medications and your oxygen prescription. This will help if you lose your baggage or you require medical attention while away.

Taking oxygen away with you

There are two important considerations here:

- How do you safely transport your oxygen supply, whether you have a concentrator or portable cylinders?
- Can you use portable oxygen while in transit?

Transporting home concentrators

A home oxygen concentrator is transportable (although heavy), and can normally be taken away with you. It is important to talk to your supplier about how to transport it safely, but here are some general guidelines:

- Concentrators must be carried upright. They may be damaged if transported lying flat or on their side.



Check with the airline or travel provider to make sure they will allow your concentrator on board as luggage, and ask about the extra cost. It may be cheaper and easier to hire one and have it delivered to where you are staying.

- If travelling by car, put the concentrator in the boot if possible, or on the back seat restrained by a seatbelt.
- Check with the airline or travel provider to make sure they will allow your concentrator on board as luggage, and ask about the extra cost. It may be cheaper and easier to hire one and have it delivered to where you are staying.

Transporting portable cylinders

- Ask your supplier for instructions on how to safely transport your oxygen cylinders.
- Check with the airline or travel provider to ensure they will allow your cylinder/s on board as luggage.
- Alternatively, arrange to hire cylinders at your destination.
- Portable cylinders should not be taken overseas, as other countries may not be able to fill them.

Using oxygen during your journey

Here are questions you might like to ask your travel provider:

1. Can I use my own portable oxygen cylinders during my journey? If not, what special arrangements can you make for me? How much will this cost?

- Many airlines do not allow you to take your own portable oxygen cylinders on board. Instead you may need to hire an aircraft approved oxygen cylinder or arrange in-flight oxygen through the airline. These arrangements can take time.
- If you are using the airline's own in-flight oxygen equipment, they may not allow you to take it off the plane. So, if you have a stop-over on your journey, you will probably need to arrange a different oxygen supply for the time you spend on the ground in between flights. Direct routes are easier for this reason.

2. Can I use my own portable concentrator during my journey?

- Some portable oxygen concentrators are easy to use on board planes and other modes of transport and can then be used during stop-overs as well. It is wise, however, to check that the company you are travelling with will allow your concentrator on board.
- You may need to book a seat near an appropriate power source so the concentrator batteries can continue to charge in transit. This is especially important for long journeys where the concentrator may need to operate for many hours.

Accommodation considerations

- Try to avoid places that cannot provide smoke free restaurants and accommodation.
- Check that your accommodation provider will allow oxygen cylinders to be delivered and stored on their premises.
- Check access to the room. Do you need to climb flights of stairs to get there, or is there a lift?

Other suggestions

- Take your medication with you as hand luggage.
- Avoid destinations with high humidity, extreme temperatures (hot or cold), high pollution and higher elevation, as each of these factors may make it harder for you to breathe.
- If travelling overseas, find out:
 - What electrical outlets they use
 - What medical facilities are available on each leg of your journey
 - What costs your private health insurance will cover if you need medical attention
 - If you do not have private health insurance or travel insurance, check whether you need to pay the full price of any medical attention you may require. A few countries offer Australian tourists subsidised healthcare.



Check that your accommodation provider will allow oxygen cylinders to be delivered and stored on their premises.

Where to turn for extra support

Starting home oxygen therapy is not always easy. If you need more information or some extra support there are organisations that can help.

Practical Support Tools

The Australian Lung Foundation has developed a series of Practical Support Tools. These can be downloaded from www.lungfoundation.com.au and include:

- Your oxygen prescription and goal setting
- Your power blackout action plan
- Your equipment checklists
 - Choosing a portable oxygen cylinder*
 - Choosing a portable oxygen concentrator*
 - Other considerations*
- Things to ask a supplier
- Information for buyers and sellers of portable oxygen equipment

The Australian Lung Foundation

The Australian Lung Foundation is here to help. Call the Information and Support Centre on 1800 654 301 or log on to www.lungfoundation.com.au

Our services include providing:

- A wide range of patient information on lung disease, including a comprehensive handbook called *Better Living with Chronic Obstructive Pulmonary Disease: A Patient Guide*.
- Information on pulmonary rehabilitation classes around Australia and *Lungs in Action* community exercise programs.
- Information on how to join a patient support group.
- Lung Care Nurse available to provide advice by calling 1800 654 301



Commonwealth Respite and Carelink Centres

Phone 1800 052 222 to find the centre closest to you.

Commonwealth Respite and Carelink Centres provide a single point of contact for information on the community, aged and disability services that are available near you. They can also provide information on your local carer support and respite care services.

Carers Australia

Phone 1800 242 636 or log on to www.carersaustralia.com.au

Carers are those who provide unpaid care and support to family members and friends who have a disability, chronic condition, terminal illness or who are frail. Carers Australia is a network of carers' associations in each state and territory. The purpose of these state associations is to improve the lives of carers. Together they provide important services like counselling, advice, advocacy, education and training.

www.seniors.gov.au

This is a government website designed to show you the range of government and non-government information and services aimed at Australians over 50.

Free phone support

These phone services provide immediate health advice 24 hours a day, 7 days a week. If you call from a home phone, the call will either be free or charged at the cost of a local call. Calls from mobiles will be charged at a higher rate.

- HEALTHDIRECT AUSTRALIA: 1800 022 222 (ACT, NSW, NT, TAS, SA, WA)
- 13 HEALTH: 13 43 25 84 (QLD)
- NURSE-ON-CALL: 1300 60 60 24 (VIC)

Your medical data form

Use our template to record your most important medical details.
Please photocopy this page and keep a copy with you at all times.

Personal details

<input type="checkbox"/> Name
<input type="checkbox"/> Address
<input type="checkbox"/> Phone number

Emergency contacts

<input type="checkbox"/> Carer's name	Ph
<input type="checkbox"/> GP's name	Ph
<input type="checkbox"/> Respiratory specialist name	Ph

Medical condition(s)

Current medication(s)	AM	PM	As needed
	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Known allergies

--

Your oxygen prescription

<input type="radio"/> I need to use oxygen for a minimum of 16 hours a day
<input type="radio"/> I need to use oxygen while sleeping
<input type="radio"/> I need to use oxygen when exercising or being more active

How much oxygen do I need?

litres per minute during normal awake hours
litres per minute when I am exercising or more active
litres per minute when I am sleeping

Record any other prescribed flow rates here:

litres per minute when I am

My next review is

--

This resource is one of a series produced by The Australian Lung Foundation to provide information on lung disease, its treatment and related issues.

The information published by the Lung Foundation is designed to be used as a guide only, is not intended or implied to be a substitute for professional medical treatment and is presented for the sole purpose of disseminating information to reduce lung disease.

Please consult your healthcare professional if you have further questions relating to the information contained in this booklet.

If you would like to support The Australian Lung Foundation in its important work, please call 1 800 654 301 for details on how you can make a donation.

All donations over \$2 are tax deductible.



*"When you can't breathe...
nothing else matters"™*

The Australian Lung Foundation
Toll Free: 1800 654 301
Address: 44 Brookes Street, Bowen Hills Qld 4006
Postal address: PO Box 847, Lutwyche Qld 4030
www.lungfoundation.com.au

Financial support for The Australian Lung Foundation COPD National Program is provided in the form of unrestricted educational grants from Foundation Partners:



Funding is also received from Supporting Partner Nycomed Pty Ltd.

ISBN 978-0-646-54334-5

© Copyright 2010

The Australian Lung Foundation supports and encourages the dissemination and exchange of information. However, the material in this booklet is protected by copyright. The Australian Lung Foundation has no objection to this material being reproduced, or being made available on line or electronically, provided that The Australian Lung Foundation is recognised as the owner and that the material remains unaltered.

November 2010