

Module Five: Living With a Lung Disease



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Welcome

Welcome to Module Five of Lung Foundation Australia's C.O.P.E program.

C.O.P.E. stands for **COPD. Online. Patient. Education.**

This module is designed to guide you through the transition you will face now that you are living with COPD. This module offers information on how to manage depression, how to travel safely with COPD, how to manage legal issues, your support service options and the support available from Lung Foundation Australia.

This module aims to show you that while you may have been diagnosed with COPD, you can still lead a fulfilling and enjoyable life.

Please move through this module at your own pace by clicking through the 'Prev' and 'Next' buttons, located in the navigation bar.



Learning objectives

There are several factors that you may need to think about now that you are living with COPD. Remember, even though you have a lung disease, your life can still be as enjoyable as ever. This module will provide you with information on some of these areas.

Upon completion of this module, you should understand:

- Stress, anxiety and depression and what symptoms to look for;
- How to use various techniques to reduce stress;
- How you can continue intimacy and sexual activity;
- How you can travel safely by car or plane, and how to travel with oxygen;
- The legal issues you may face, including your rights at work and superannuation;
- The support services that are available to you; and
- The resources that Lung Foundation Australia can offer you.

Signs of stress

Research tells us that those with chronic disease who enjoy the best quality of life and fewest complications are those who understand their condition and are actively involved in managing their condition.

Stressors, such as illness, financial concerns or relationship difficulties, could cause:

- Your heart to beat faster.
- The muscles of your arms and legs to tremble or shake.
- Your breathing to change and increase the feeling of breathlessness.
- You to start sweating.

In response to stress, some people begin to avoid certain situations or activities. Avoidance can be a problem. Continuing to avoid situations or activities that make you feel anxious can reduce your activity level and social contacts. It can also increase your risk of developing anxiety and interfere with your ability to manage your condition.

If you avoid certain situations or activities due to feeling anxious or stressed, speak with your pulmonary rehabilitation facilitator or doctor about how you can gradually re-expose yourself to those situations or activities.

Links between anxiety, depression and COPD

Research indicates that there is a link between anxiety, depression and COPD. There are around three million Australians living with depression or anxiety. One in five women and one in eight men will experience depression at some time in their life. On average, one in four people will experience anxiety.

For people who live with COPD these figures can be higher due to factors such as the impact of living with the disease, uncertainty about the future or side-effects of their medicines.



Anxiety

Anxiety is more than just feeling stressed or worried. Stress and worry are normal reactions to situations where a person feels under pressure and usually pass once the stressful situation has passed, or the 'stressor' is removed.

However, for people experiencing anxiety, the stress and worry can be overwhelming, happen for no apparent reason or continue after the stressful event has passed. For a person experiencing anxiety, anxious feelings cannot be brought under control easily. Anxiety can be a serious condition that makes it hard for a person to cope with daily life. There are many types of anxiety and many people with anxiety experience symptoms of more than one type.

Signs of anxiety

While we all may experience some anxious feelings, anxiety has a disabling impact on the person's life. Anxiety can be expressed in different ways such as uncontrollable worry, intense fear (phobias or panic attacks), upsetting dreams or flashbacks of a traumatic event.

Watch the video below to learn more about the symptoms of anxiety.

COPD and anxiety

Evidence shows that anxiety and panic attacks are more common in people with COPD than in the general population.

The prevalence of one anxiety disorder in particular, panic disorder, is approximately 10 times greater in COPD than the population prevalence of 1.5 - 3.5%, and panic attacks are commonly experienced.

Living with COPD is one of many things - such as a family history of mental health conditions, stressful life events and personality factors - that may trigger anxiety. Feeling unable to breathe is a frightening experience and for some people may result in a panic attack. When a person is breathless, they worry they aren't getting enough air and this causes anxiety. Anxiety then makes the person breathe harder and faster and this worsens the feelings of breathlessness, resulting in panic.

The link between breathlessness, anxiety and panic attacks can also increase social isolation for a person with COPD. The uncertainty of coping, being able to climb stairs or walk a long distance may create anxiety and this results in avoidance of social situations where this might be required or unknown.

Medicines can also cause symptoms that increase anxiety. Over-use of reliever medicine can also add to the anxiety symptom of a racing heart.

In COPD, anxiety has been linked to greater disability, increased frequency of hospital admissions for acute exacerbations and breathlessness.

Depression

While we all feel sad, moody or low from time to time, some people experience these feelings intensely, for long periods of time (weeks, months or even years) and sometimes without any apparent reason. Depression is more than just a low mood – it's a serious condition that has an impact on both physical and mental health.

Depression affects how a person feels about themselves. A person may lose interest in work, hobbies and doing things he or she normally enjoys. Some people may lack energy, have difficulty sleeping or sleep more than usual, while some people feel anxious or irritable and find it hard to concentrate.

The good news is, just like a physical condition, depression is treatable and effective treatments are available.



Signs of depression

A person may be depressed if he or she has felt sad, down or miserable most of the time for more than two weeks and/or has lost interest or pleasure in usual activities, and has also experienced some of the signs and symptoms on the list below.

It's important to note that everyone experiences some of these symptoms from time to time and it may not necessarily mean a person is depressed. Equally, not every person who is experiencing depression will have all of these symptoms. The symptoms will not provide a diagnosis – for that you need to see a health professional – but they can be used as a guide.

Some common symptoms of depression include:

- Not going as much, loss of interest in enjoyable activities.
- Withdrawing from close family and friends.
- Being unable to concentrate and not getting things done at work or school.
- Feeling overwhelmed, indecisive and lacking in confidence.
- Increased alcohol and drug use.
- Loss or change of appetite and significant weight loss or gain.
- Trouble getting to sleep, staying asleep and being tired during the day.
- Feeling worthless, helpless and guilty.
- Increased irritability, frustration and moodiness.
- Feeling unhappy, sad or miserable most of the time.
- Thoughts such as, "I'm a failure", "Life's not worth living", "People would be better off without me".

COPD and depression

Being diagnosed with a progressive and incurable lung disease that can eventually make activities of daily living such as showering or making a cup of tea challenging can create feelings of nihilism and may lead to feelings of depression.

Both COPD and depression, if untreated, can impact greatly on a person's ability to keep active and enjoy life. Research has identified a relationship between severe COPD and depression. Prevalence of depression increases with the severity of COPD. It is important that people with severe COPD see their doctor, as those with depression have a higher likelihood of flare ups, frequent hospital readmission and worse survival.

People with COPD are not only at high risk of depressive symptoms and mood disorders, but are at higher risk than people with other chronic conditions. People with COPD are more likely to report depressive symptoms than people with stroke, hypertension, diabetes, coronary heart disease, arthritis or cancer.



It is very important to know that both COPD and depression can be treated. Managing anxiety and depression can greatly improve people's wellbeing and quality of life as well as their COPD and their attitude towards it. People with anxiety and/or depression can find it difficult to take the first step in seeking help. They may need the support of family, friends and a health professional. Seeking proper treatment for COPD and anxiety and/or depression will slow the progress of the disease.

What are the treatments for anxiety and depression?

There is a range of effective treatments and health professionals who can help people on the road to recovery from anxiety or depression. There are also many things that people with anxiety, depression and COPD can do to help themselves to recover and stay well. The important thing is finding the right treatment and the right health professional that works for you.

Different types of anxiety or depression require different types of treatment. This may include physical exercise for preventing and treating mild anxiety and depression, through to psychological and medical treatment for more severe episodes. The treatment for anxiety and depression in someone with COPD involves a coordinated approach that monitors and treats the symptoms of anxiety, depression and COPD.

Smoking and anxiety and/or depression

Smoking is not only the most important risk factor in the development of COPD, but it also has a complex relationship with mental health.

There is evidence of higher occurrences of depression in smokers. There is also an element of shame associated with a smoking-related disease and some people may feel that they brought it on themselves, or that they deserve to have lung disease. While smoking is the main risk factor, not everyone who smokes gets COPD and no one deserves lung disease.

Numerous studies have concluded that depression and anxiety are risk factors for initiating tobacco smoking, often in adolescence or early adulthood.

Smoking rates amongst those with severe mental illnesses, such as major depression, are high.

People who are trying to abstain from smoking often increase their caffeine consumption and this increases agitation and symptoms of a racing heart, which can lead to anxiety and in some cases panic attacks.

Smokers with a history of depression and/or anxiety are more likely to experience worse nicotine withdrawal and have significantly more failed cessation attempts. A number of studies have found that smoking cessation itself may induce depressive symptoms in some individuals, particularly smokers with a history of depression leading to the suggestion that nicotine has an effect on mood.

Repeated, unsuccessful attempts to quit can result in feelings of worthlessness as a consequence and lead to depression.

Anxiety and depression related benefits of pulmonary rehabilitation



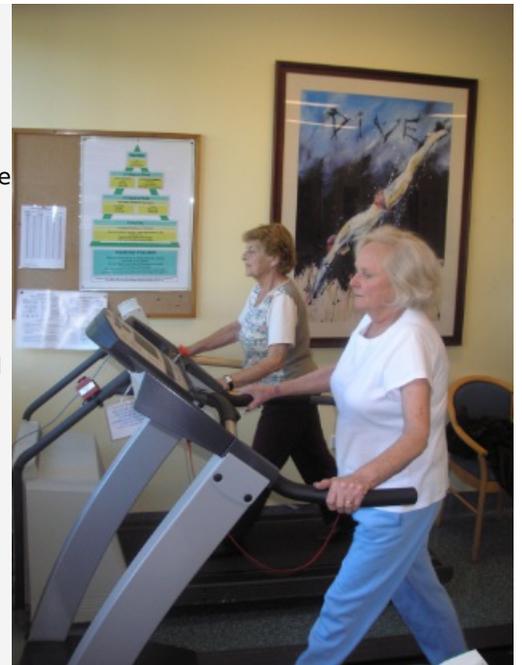
Growing evidence shows benefits of pulmonary rehabilitation (a 6-8 week program involving medically supervised exercise and education) for COPD patients who have depression and anxiety.

Pulmonary rehabilitation involves assessment of patient problems and goals, exercise training, education, nutritional intervention and psychosocial support with the aim of restoring the patient to the highest possible level of independent functioning.

Pulmonary rehabilitation has been shown to improve mood and decrease depression, assist with control of symptoms of anxiety and panic and removes social impediments.

For more information on pulmonary rehabilitation or to find out how to access a program contact Lung Foundation Australia or visit the website: www.lungfoundation.com.au.

[Click here to download the *Pulmonary Rehabilitation Fact Sheet*.](#)



Suggestions for how you can reduce stress

1. Establish a routine

Having a regular routine helps maintain balance in your life and increases your sense of control. In your routine, you should include activities you need to do as well as fun enjoyable activities that you can look forward to.

2. Eat well and drink plenty of water

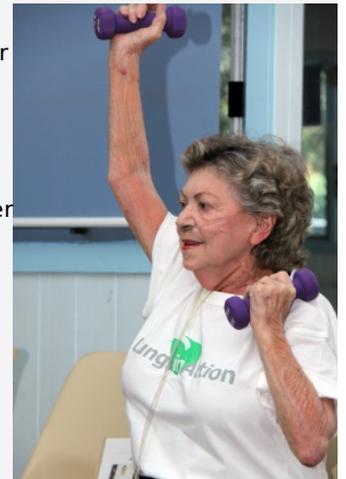
Your body will perform best when you eat well and drink plenty of water. However, if you have been advised to restrict fluids, you should follow this advice.



3. Exercise regularly

Talk with your pulmonary rehabilitation facilitator about the type, frequency and intensity of exercise that is right for you. Find out how to progress your exercise program as you improve, and plan regular exercise into your routine.

If you have completed a pulmonary rehabilitation program, see if there is a Lungs In Action program near you where you can continue to exercise (www.lungsinaction.com.au). If possible, exercise earlier in the day so as not to disturb your sleep.



4. Get plenty of sleep

Establish a regular bedtime. A warm bath, shower or milk drink before bed may improve your sleep. If you can't get to sleep after twenty minutes of being in bed, get out of bed and do a quiet activity until you feel tired.

5. Limit your use of alcohol and other drugs

Many people use drugs and alcohol to help manage their stress. For example, some people use alcohol and cigarettes to calm down and other people may use coffee, cola or energy drinks to get themselves going. However, drugs and alcohol can have harmful effects on people and can result in dependence.

6. Maintain your social network

People with chronic conditions who have few friends and don't get out much may have worse health outcomes. Getting out and catching up with friends is important and you should plan to do this regularly.



7. Join a local patient support group

Contact Lung Foundation Australia to find out about patient support groups near you (phone: 1800 654 301 or visit the website: www.lungfoundation.com.au). If a patient support group has not been established in your area, Lung Foundation Australia can help you to start one.

8. Maintain interests and hobbies

Often people who have chronic conditions let go of interests and hobbies because they believe the effort outweighs the benefits. Participating in enjoyable activities can give life meaning and can help you maintain and enhance your skills and abilities.

9. Be aware of automatic or unhelpful thinking and self-talk

When life is busy or stressful, you may respond to events without stopping to consider your response. Before responding, stop and take some deep breaths, count to 10, or go for a short walk and consider whether you need to respond and how you will respond.

10. Planning and time management

People who plan how they will apply the skills they have learnt in pulmonary rehabilitation to their home or work life are more likely to use these skills in their daily lives. Effective time management is essential for maintaining your health, work, social and home life. Spread tasks, or parts of tasks, across several days, and build time into your schedule for unexpected events.

11. Communicate effectively

Effective communication includes both speaking and listening. Often when you feel under pressure, you can spend all your time speaking or thinking about what you want to say rather than listening. Take the time to listen to what is being said before responding. Assertive communication requires honest and direct discussion that describes the problem, the effect and the solution.

12. Practice relaxed breathing

When stressed, or experiencing strong emotions most people tend to breathe faster and shallower; this type of breathing can lead to a feeling of breathlessness and sometimes panic breathing. People who have COPD can minimise the risk of becoming breathless during times of stress or high emotion, by using the relaxed breathing techniques.

[Click here to download these suggestions in PDF format.](#)

Why is relaxation practice important?

Scheduling time to relax in your daily or weekly routine is important. Relaxation can be formal, such as guided relaxation practice, or informal, such as watching football or listening to music. Formal relaxation practice helps to:

- Increase your metabolism.
- Slow your heart beat.
- Relax your muscles.
- Slow your breathing.
- Lower your blood pressure.

If you are interested in finding out more about formal relaxation practice, ask your pulmonary rehabilitation co-ordinator for a tip sheet on relaxation. You can also find CDs in bookstores or in your local library or audio downloads on the internet that will guide you through different types of formal relaxation exercises.



Reducing the number of crisis events

- The chance of crisis events occurring due to ill health should be reduced if you use your medicines and inhalers appropriately, and remember to eat well and exercise regularly.
- The number of crisis events occurring due to injury, muscle strain or physical exhaustion should be reduced if you increase your exercise tolerance and practise your energy conservation skills.
- The number of crisis events occurring due to stress should be reduced if you practise your relaxation techniques and improve your communication and problem solving skills.



Managing crisis events

When a crisis event does occur, and you find yourself getting emotionally upset, you will need to decide what you can do to avoid the situation from becoming worse or how you can reduce the emotional impact of the event. The following strategies may help you manage crisis events:

- Become aware of your expectations. In the past, if a similar crisis event went from bad to worse, it doesn't mean that the current event will also go from bad to worse.
- Become aware of the language you are using and replace unhelpful thoughts with more helpful thoughts. For example, rather than thinking your weekend was a disaster, recognise that it rained on the weekend and, as a result, you were unable to do what you wanted to do.
- Protect yourself against becoming too stressed by developing a plan to deal with a difficult situation. You can mentally rehearse what you might do or say before a potentially challenging event occurs. You can also review how you managed after the event and create options for how you might handle a similar situation if it happens again.
- Don't forget to practice relaxation techniques and *use relaxed breathing*.
- Take time to do the things you enjoy.

Feelings of helplessness

The diagnosis of COPD may have a significant impact. Everyone with COPD feels helpless to some degree, particularly if experiencing recurring flare ups. However, it is important to remember that these feelings of helplessness are normal and remember that everything you can do to manage your condition helps.

Click here to download the COPD Depression and Anxiety fact sheet.

Intimacy and sexual activity

Many people who have chronic lung conditions, and their partners have concerns about the effect of sexual activity on their lungs. Sexual activity is not harmful to your lungs, and resuming intimacy and closeness with your partner can help to decrease feelings of loneliness and isolation.

Your lung disease does not directly affect your sexual ability. However, COPD can have an impact on your physical health, such as becoming more short of breath, and perhaps your emotional health, such as feeling anxious, depressed, or lonely. Physical and emotional factors can affect your sexual ability. The fear of becoming short of breath may lead to avoidance of sexual activity or an inability to maintain sexual arousal.

Medicines, such as bronchodilators and steroids that you take for your lung conditions, have not been documented to cause difficulties with sexual functions. Medicines for blood pressure, diuretics, and anti-depressants may affect sexual drive and function. If you experience difficulties that interfere with intimacy, talk with your GP or nurse about medicine effects or the need for increased oxygen during sexual activity.

It is possible to maintain and improve intimate relationships by reducing breathlessness, fatigue, fear and anxiety. Simple considerations include:



Planning for sexual activity

- Incorporate controlled breathing techniques and energy conservation strategies.
- Plan sexual activity when you feel at your best in the day.
- Cough and clear sputum prior to sexual activity.
- Use your reliever puffer before or during sexual activity.
- If you use home oxygen for activities, plan to use the same amount of oxygen during sexual activity.
- Be aware of your symptoms: breathlessness is normal during any demanding activity. If anxiety and fatigue develops, stop and rest briefly.

Pace yourself

- Take your time, be relaxed and ensure adequate rests before and during sexual relations.
- Avoid factors that will increase your fatigue, such as heavy meals, alcohol consumption, uncomfortable room temperature and emotional stress.
- Talk to your partner about positions that are more comfortable for you to avoid pressure on the chest and stomach, causing breathlessness.
- Use support from pillows and other furniture.
- Change positions if you become uncomfortable.
- Avoid perfumes, powders and hair sprays that may impact on breathlessness.
- Equally important and less fatiguing forms of intimacy include touch, affection, and physical closeness.

Communication

Communication is a very important part of creating and maintaining emotional intimacy and satisfying sexual relationships with partners. Avoiding talking about problems may lead to misunderstanding and increase strain in your relationship. It can help to:

- Put your fears on the table. Partners may be less concerned about things that worry us (such as appearance, shortness of breath or technique) than you think.
- Ask about and take time to listen to your partner's thoughts and feelings. It's possible they feel more fear or guilt than you do.
- Use "I" statements when discussing intimacy issues to reduce resistance and create more open communication.
- Be patient and kind with yourself and your partner as you communicate more and explore alternatives.



All intimacy should be for your enjoyment and fun. Laugh and talk about any difficulties either person is experiencing. Be prepared to try different ways to express affection. Tell each other what feels nice. Exploring sensuality and intimacy can open communication and strengthen your relationship.

Pulmonary rehabilitation programs usually provide opportunities to discuss issues related to sexual function, or you can individually discuss your concerns with your health care professional.

Driving safely

Many people with COPD continue to drive safely. The following are some considerations to ensure your safety and that of others.

- Talk to your doctor about your medical condition and any potential impact this may have on your ability to drive safely. They may provide a medical certificate stating your fitness to drive, or any conditions under which you can drive.
- Drivers who develop a permanent or long term medical condition that may negatively affect their ability to drive safely must report their condition to the Department of Transport as soon as it develops.
- COPD may adversely affect your ability to drive safely, and could result in a crash.
- Low oxygen levels or increased carbon dioxide levels may lead to poor judgement, drowsiness and reduced concentration.
- Driving ability may be affected by severe coughing fits which may lead to loss of consciousness.
- Oxygen therapy can enhance cognitive performance, longevity and wellbeing in those with chronic lung disease. If you have been prescribed long term oxygen you should clarify with your doctor about using oxygen while driving.
- Make sure the oxygen is secured in the car so that it doesn't pose an additional safety risk in case of a crash.
- Daytime sleepiness, sleep apnoea and other sleep disorders have the potential to impair driving performance, safety and risk of crashes. Consult your doctor and seek advice about precautions when driving.



How you can plan your travel to prevent health problems

Travel related health problems arise from a variety of factors related to your travel environment e.g. holiday destination, types of activities, food and water quality.

Travel related health problems can also arise when a pre-existing medical condition worsens during travel.

Fortunately most travel related problems can be prevented with careful advanced planning. Consult your doctor or travel medicine clinic so that a travel plan can be discussed in detail.

Consider the destination and how the following might affect your underlying health condition.

Countries/Regions visited

Air quality

Water and food quality

Planned activities are consistent with usual levels

Type of accommodation and facilities available

Altitude

Accessing health care

Any differences in electrical outlets and voltage

Season of travel: hot/cold/humidity

Check for any epidemics

Flexible tickets

Check in early

Arrive before darkness

Other suggestions

- Take medical documents (e.g. letters, scripts) with you/have your GP liaise ahead with major health centres. Map out phone numbers of medical services.
- Have travel insurance or access to health care.
- Some travel insurance providers have a telephone helplines to assist you in finding appropriate health care while you are travelling.
- Insurance can be difficult for those with chronic disease. Some countries have reciprocal health care with Australia. Refer to:
 - <http://medicareaustralia.gov.au/public/migrants/travelling/index.jsp>
 - <http://www.smarttraveller.gov.au/index.html>
- Take a plentiful supply of medicine and health equipment eg: relievers, puffers, oxygen tubing, masks, electrical adaptors, batteries.

General problems caused by commercial travel

- Dryness of air.
- Reduced mobility and potential DVT (blood clots) – those with chronic disease such as COPD would be advised to wear compression sockwear for long flights.
- Proximity to others and risk of infections.
- Long periods of travel disturb 24hr clock – sleep, eating, taking medicines.
- Stress of navigating busy airports, unknown roads.

Accommodation considerations

- Try to avoid places that cannot provide smoke free restaurants and accommodation.
- If you need portable oxygen, 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?

What do you need to know about air travel?

Although air travel is safe for the majority of people, people with COPD may be at risk due to the decrease in the concentration of oxygen in humidified air.

Some people with COPD 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.



Preparing for airline travel

- Visit your doctor several weeks or months before travel, to check if you will need oxygen during flight. If you do, check with your airline before you book your flight as not all airlines provide easy access to oxygen facilities.
- Learn what your oxygen needs will be while flying, and while in terminals. Airlines do not provide oxygen on the ground. Speak with your doctor and other health care team members about arrangements to supply oxygen for each part of the trip. Remember to bring enough batteries and power adaptors, masks, and tubes for use during your trip.
- Most airlines require a Travel Clearance Form (MEDIF form) or a letter from a doctor outlining your condition, approval for air travel, need for oxygen in-flight, specific information of oxygen flow rate. Bring enough copies for all flights.
- Make sure you have adequate supply of your usual medicines for the trip.
- Carry multiple copies of your prescriptions in case luggage is delayed, lost or stolen.
- If prescribed, carry relievers and puffers in your hand luggage.
- Oxygen policies and charges can vary depending on the airline. Make sure you check with the airlines about their requirements and available help for travellers with medical conditions.
- Travellers requiring CPAP may need a letter from the doctor for equipment to travel in cabin as extra hand luggage.
- Discuss risks and management of potential deep vein thrombosis (DVT or blood clots). This may occur as a result of reduced activity during prolonged travel.

What do you need to know about travelling with oxygen?

There are two important considerations:

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

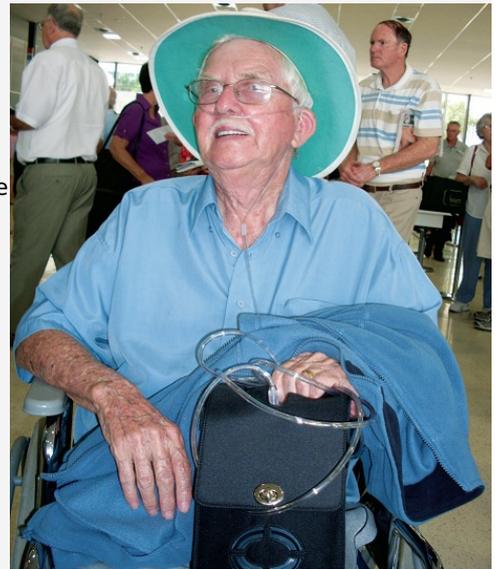
Using oxygen during your journey

Portable oxygen cylinders

- 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.
- 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.

Portable concentrators

- Some portable 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. Also you need to make sure you have the correct power adaptor for both the plane and your destination if travelling overseas.



Legal issues

When first diagnosed with any major illness, particularly one which is chronic and life altering like COPD, legal issues are often the last things you consider.

Unfortunately, neglecting your legal rights and options to protect you and your family too often make those daunting legal issues more complicated.

There are some simple steps you can take now to ensure you have access to any financial support you may need and also to ensure that in the future your family are taken care of even if you are unable to work or provide for them.

Your legal rights to accessing superannuation and insurance

All working Australians have a superannuation fund to which their employer must contribute amounts during the course of their working life. Some people also elect to contribute further to their superannuation personally.

You can access your superannuation before retirement age in the event of a serious illness like COPD. All superannuation funds also have a component of insurance which is there to help you in the event you are unable to work because of serious illness.

What is included in superannuation benefits?

- Contributions by your employer and you; and
- Insurance coverage for death and disablement.

All policies are different. Some funds will offer lump sum benefits in the event that you become totally and permanently disabled or partially and permanently disabled. Some funds will provide temporary cover if you are off work for only a short period of time by paying all or a percentage of your income whilst you are unable to work.

What can you access?

- Lump sum benefits
- Income protection and/or
- Death benefits

You should contact your superannuation fund to find out what benefits are available. You should critically analyse the information you are given by the superannuation fund manager or insurer. Because of the complexities involved and the different considerations that apply in your own different circumstances a one size fits all approach often means that some people will miss out on their entitlements.

Legal advice can help to ensure that the information you receive is correct and assists you with accessing all your entitlements.

The terms and conditions applying to these insurance components are sometimes straight forward but often more complex than they look.

You do not need to show fault on the part of anyone or that the cause of your illness was beyond your control. Generally the mere fact of having the illness and that it stops you from working is enough.

Benefits are generally available for people of working age. Different funds have different rules and you should carefully check your own circumstances and seek advice.

Coping with changes in the workplace

Many people with more severe COPD find that the symptoms affect their ability to attend work or their ability to undertake their work duties.

All employees are entitled to some measure of sick or unpaid leave in the event of a serious illness.

The sources of this entitlement are many and varied and can range from legislation through to written contracts of employment.

Whether you are an employee, an independent contractor or in business a serious illness should not be used by an employer or head contractor as an excuse to disadvantage you or treat you differently.

There are general protections available to you in the workplace in the event that you suffer an illness like COPD and need to access leave or have some reasonable adjustment undertaken to enable you to continue to work.

An employer cannot treat you unfairly or take adverse action against you merely because you have a chronic illness or are attempting to exercise a workplace right like taking sick leave. If an employer does take adverse action in these circumstances you are entitled to seek orders from a Court to restore the status quo as well as requesting that the employer be subject to a fine for breaching legislation.

Anti-discrimination laws across Australia recognise that people with illnesses are at a disadvantage and should be treated fairly. An employer must make reasonable adjustment in the workplace to assist you to conduct your work duties to the best of your ability having regard to the impacts of your illness.

Steps you can take to protect your assets for the benefit of your family

Wills

It is essential that your intentions regarding distribution of property as well as your wishes in relation to the continuation of treatment are known and documented.

A will is a document which identifies your intentions and provides instructions as to the distribution of your assets when you die.

Whenever your personal circumstances change you should review and if necessary update your will.

Depending on their relationship to you, family members will accrue rights under the will or in accordance with the law and sometimes those rights can conflict. Having a clear and up-to-date will is essential to avoid any conflict.

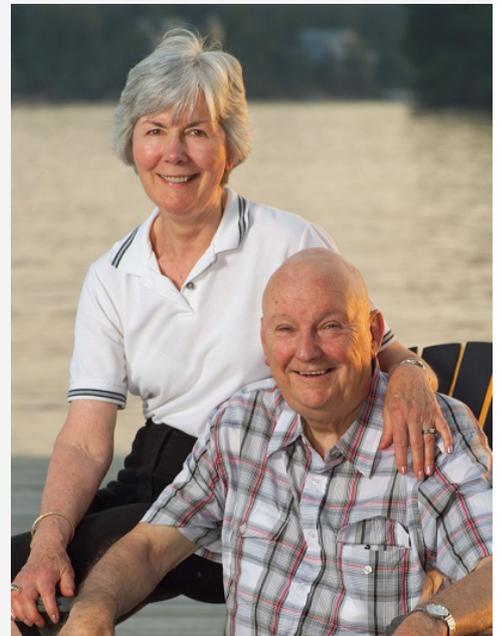
The way in which assets are passed via a will can impact on the beneficiary of those assets. Development of appropriate testamentary trusts will assist the beneficiaries to access those assets and assist with tax minimisation.

Testamentary discretionary trusts are particularly recommended if the beneficiary who will receive the assets:

- Has a disability.
- Is poor at handling his/her finances.
- Practices in a profession which has a high risk of litigation.
- Is in a high tax bracket.
- Has a history of bankruptcy.

In the event of conflict between beneficiaries or potential beneficiaries of an estate there are often significant emotions at play.

Good planning and open communication in the preparation of a will often avoids conflict or confusion.



How you can make sure your family and/or carers are aware of your wishes in relation to ongoing treatment

Enduring Powers of Attorney and Advanced Health Directives

For those living with COPD, it is important to plan ahead and to ensure your family members and/or carer is aware of your wishes in relation to ongoing treatment.

You have the ability to document an *Advanced Health Directive* or instructions for your loved ones as to your wishes in the event that you lose capacity to make decisions because of your illness or while undergoing treatment.

An Advanced Health Directive can look at issues including:

- What level and extent of treatment you wish to undergo.
- Who should have the power to make decisions on your behalf.
- Special medical conditions that your doctor or other medical staff should know about.
- Religious, spiritual or cultural beliefs that may affect treatment.
- Considerations in relation to resuscitation or the withholding or withdrawing of life sustaining measures.
- Your wishes in relation to the donation of organs in the event of your death.



In combination with an Enduring Power of Attorney, an Advanced Health Directive will ensure your wishes are met and maintained.

An Enduring Power of Attorney (called Enduring Guardianship in Tasmania) appoints a responsible and trusted person to make decisions on your behalf. This document remains in force even when you lose capacity to make decisions on your own.

Making sure you access all available financial support

There are many community based and Government organisations that will make financial and other support available to you in your time of need.

You do not have to accept adverse decisions that are made in relation to your entitlements to financial assistance or services. Often there is a process of review and appeal in relation to those decisions, particularly administrative decisions made by Government. The courts have a general power of review of those decisions to ensure that administrative decision makers exercise their powers in a just and fair manner.

As a member of a community organisation or other support service your membership terms and conditions may also enable you to review or appeal decisions made that are adverse to your interests.

You should seek legal advice about your rights in relation to any adverse decision.

Supportive care and end of life issues

Supportive Palliative and End-of-Life Care are fundamental stages that everyone diagnosed with a lung disease will face. It can be confusing to know what these different stages are, what they mean for you and when they might apply. We are individuals and every person's journey and lung disease is different, so your needs will also be different.

What is palliative care, and what is supportive care?

Palliative care does not necessarily mean 'end-of-life'. The past few years have seen the title change to include Supportive Care. The focus of Supportive and Palliative Care is to help you achieve and maintain the best quality of life you can for as long as you can; it makes sure your physical, practical, emotional and spiritual needs are being catered to; and it helps you to control symptoms that may arise during the course of your lung disease so you can feel some control in your situation.

It is advisable to access Supportive and Palliative care early on, as this has been found to have better outcomes for patients. Due to improved medicines to treat your lung disease and better relieve any side effects, some people receive Supportive and Palliative Care together with their treatments for several years in order to live for as long as possible with the highest quality of life within the limits of their lung disease.

Supportive and Palliative Care focuses on "symptom management", for example, managing your fatigue or breathlessness when the symptoms become worse and your medicines are not as effective or are no longer keeping your symptoms under control.

Supportive and Palliative Care services can initially be provided by your GP, specialist, nurse and allied health staff. You may be referred to a specialist palliative care team, if your lung disease progresses and as your needs become more complex. Supportive and Palliative care also offers support to families and caregivers in their adjustments to some of the lifestyle changes that they may have to face.

It is important to understand that just because a patient accesses supportive and palliative care services DOES NOT mean that they are near the end of their life. In fact, one reason patients choose not to access these services is because they think that by doing so they have accepted defeat or given up hope, and that death is near. In reality if you access supportive and palliative care services early it is proven to increase your quality of life, because it helps to reduce side effects and assists in managing the symptoms of your lung disease. Many people who have been referred to supportive and palliative care services wish they had been referred earlier because of how much the service has benefited them.

End-of-life care

At this stage you can choose where you would like to be at this time, taking into consideration where you would be most at ease, e.g. in your home, hospital or hospice. End-of-life care ensures you are as comfortable and as pain free as you can be. End-of-life treatments can include opiates (also used in the treatment of breathlessness) or respirators.

What treatments and life prolonging measures you receive at this time is your choice. You should discuss your wishes with your doctor, family and caregivers so they are aware and can ensure your wishes are adhered to when you can no longer communicate them. This is when your Advanced Healthcare Directive and Enduring guardian assist you and ensure your requests for medical care and intervention are followed.

For many reasons your doctor may not bring up end of life issues. Your doctor does not want to offend you or make you feel hopeless. Starting this conversation may be difficult, but it's important to discuss the topic as your health professional can assist you with your decision making, helping you to access legal advice and documents, and provide advice on services that are available to you. You may find it useful to have a list of questions to prompt you during your appointment and ensure all of your questions or concerns are answered. Remember that it is your right to choose or refuse treatments at any time.

Questions you can ask your health professional regarding supportive, palliative or end-of-life care

Some questions you might consider asking are:

- How can I remain as independent as possible?
- What treatments can I expect?
- Are there other treatments available that might help me and my lung disease?

- Will I receive conventional medical treatment if I have supportive care?
- Which health professionals will be a part of my supportive and palliative care team and who will coordinate my care?
- Do I have to pay for any supportive or palliative care services?
- Where will I receive supportive care?
- If I'm at home, what kind of help will be available?
- Can my family or carer access respite care or other assistance?
- Can I call the palliative care team at any time?
- How long do I need supportive care for?
- What will happen in the future to my body? How will I feel?
- I am worried about being unable to support my children financially and emotionally. What help is available?
- Can you help me talk to my family about what is happening to me?
- Are there any complementary therapies that might help?
- Can I get a second opinion about my need for supportive care?

How health professionals can provide symptom management

one

two

three

four

five

Patients often worry about how bad their symptoms like breathlessness and fatigue will get as their lung disease progresses. It's important to acknowledge that your symptoms will get worse, but if you have concerns you can speak with your doctor or health professional.

Click through the tabs to see some of the common symptom management techniques.

How can you use community support services?

- Be an active participant in your care.
- Learn about your lung condition and learn how to manage and adapt to it.
- Benefit from the knowledge and experience of other people who have lung conditions.
- Build your own support network to help manage your health.
- Plan ahead and use available services as you need them.

Where you can seek or access support services in the community

1. From your team of **health care professionals**.
2. From your local council.
3. From **Lung Foundation Australia** (phone: 1800 654 301), which may include:
 - Patient information resources.
 - Information on local pulmonary rehabilitation patient support groups and community exercise programs (maintenance).
4. From your local **Commonwealth Carelink Centre** (phone: 1800 052 222), which provides free information about local community aged care, disability and support services.
5. From the **Commonwealth Respite and Carelink Centre** (phone: 1800 059 059), which provides information and options about respite care and other support services for carers, such as:
 - Respite care in emergency and short term planned care situations.
 - Assistance in locating and booking residential respite.
 - Access to an emergency respite service 24 hours a day.

What is a patient support group?

A patient support group is a group of people who have common interests and needs. Lung Foundation Australia supports a network of support groups for people who have lung conditions, and their carers and family.



What do patient support groups do?

When you join a patient support group, you can expect to benefit from a range of possible activities from social support to special seminars to online support chat rooms.

How can you benefit from a patient support group?

Joining a patient support group allows you to:

- Discuss the information you have learnt from your doctor and other health care professionals, as sometimes the information is difficult to remember or confusing.
- Access new information on your lung condition.
- Share your experiences in a caring environment.
- Participate in pleasurable social activities.
- Change the way you think about your condition.
- Help your carer to understand your condition.

Have you ever experienced the satisfaction of helping someone else in distress? Sometimes, focusing our energy on helping others is the best therapy for overcoming our own troubled feelings.

There are people who need your support and friendship.

Who will attend the patient support group?

You will meet ordinary people, from all different working and ethnic backgrounds. They will share with you a common personal interest in managing their lung condition, whether they are a patient or a carer.

Group members will also have a wide variety of social and lifestyle interests.

Where and when do patient support groups meet?

Most groups have regular meetings that are held at a community or neighbourhood centre, or a meeting room at a local hospital. Venues with reasonable transport access are normally chosen.

How much does participating in a patient support group cost?

Membership of a patient support group normally involves a small annual fee and perhaps a gold coin at meetings to cover the costs of membership services, such as postage, photocopying and meetings. These fees are always kept to an absolute minimum.

How do you join a patient support group?

Lung Foundation Australia operates an Australia-wide network of affiliated patient support groups.

To find out about patient support groups in your area, contact Lung Foundation Australia (phone: 1800 654 301, or website: www.lungfoundation.com.au).

If there is no support group in your area Lung Foundation Australia will help you set one up.

What are your transport options?

Options for transport will depend on what transport is available in your local area. Your local council and community health centre will be able to provide details of the transportation services within your community.

Options may include:

- Disability parking permits (for more information, see your GP or occupational therapist).
- A taxi subsidy scheme with half price taxi fares (for more information, see your GP).
- An ambulance service at reduced cost for transport to and from medical appointments (for more information, talk with your local ambulance service).
- A Home and Community Care Program (for more information, talk with your local community health centre or social work department).
- A Patient Transit Scheme that provides financial help for travel and accommodation expenses for people from rural, regional and remote areas in some parts of Australia when travelling to the closest specialist treatment centre. Patients should make arrangements with a means test clerk, social worker or welfare officer at their local hospital before travelling.

Other helpful support services in the community

1. The Department of Veterans' Affairs

The **Department of Veterans' Affairs** can provide financial, medical, transport and homecare assistance for those people who have served in the armed services. The assistance available includes the following options:

- **Gold Card.** Veterans who have served for their country and who are deemed suitable for this benefit are eligible for a full range of health care services.
- **White Card.** Veterans who have served for their country are eligible for compensation related to their service in the forces. Australian veterans are eligible for Veterans' Home Care; however, British or other overseas veterans are not eligible for Veterans' Home Care.
- **Orange Card.** Eligible veterans can access the range of pharmaceutical items available under the Repatriation Pharmaceutical Benefits Scheme.

For more information contact Veterans' Home Care (phone: 1300 550 450).

2. The Home and Community Care Program

The **Home and Community Care Program** provides government funding for the frail aged and young disabled people, and includes the following services:

- Medical Aids Subsidy Scheme.
- Meals on Wheels.
- Community Agencies (for example, Queensland Health Primary and Community Health Services, Blue Care™, Spiritus and Ozcare).
- Palliative Care Services.
- Home Assist Secure (Queensland Government Department of Housing).
- Aged Care Assessment Service.
- Community Aged Care Packages.
- Day or Respite Care.

3. The National Smoking Quitline

The **National Smoking Quitline** (phone: 137 848) provides assistance if you wish to quit smoking.

4. Will Preparation Do-It-Yourself Kits

Will Preparation Do-It Yourself Kits are available for purchase if you wish to prepare a will. Alternatively, speak to a solicitor or a Public Trustee in your state.

5. Counselling and information services

Counselling and information services, such as:

- Lifeline (phone: 131 114)
- Centacare (located in your capital city)
- Suicide Call Back Service (phone: 1300 659 467)
- Beyond Blue Info Line (phone: 1300 22 4636)
- The Shed OnLine (www.theshedonline.org.au)
- Carer's Australia (phone: 1800 242 636).

6. Financial support services

Financial support services such as:

- Centrelink Financial Services 13 23 00;
- Financial Counselling Service 1800 007 007.

7. Legal and advocacy support services

Contact the Legal Aid service and Public Trustee Office within your State or Territory.

8. Relationship support services

Relationships Australia 1300 364 277 and Mensline 1300 78 99 78.

9. Accommodation support services

Contact the Department of Housing within your State or Territory for information and referral to appropriate agencies including Homelessness Information services. If your issues are related to a private rental property you may wish to contact your local Tenant Advice and Advocacy Service - refer to your local phone directory for your nearest service contact details.

Resources and support available from Lung Foundation Australia

Lung Foundation Australia is here to help. We are a national charity providing information and support to those affected by lung disease. The following are some of the resources developed for those with Chronic Obstructive Pulmonary Disease (COPD).

All these resources can be found on our website www.lungfoundation.com.au or can be ordered by calling 1800 654 301.



Resources

To download these resources, click on each title.

Better Living with COPD - A Patient Guide

This resource has been developed to support people with COPD to better understand their condition and the steps they can take to better manage COPD.

Breathe Easier - Your Guide to COPD

This fact sheet outlines in simple language the most important facts you need know about COPD.

Save your Breath: Information for People Recently Diagnosed with COPD

This resource has been developed for those people who have recently been told by their doctor that they have COPD. It will help you to understand more about COPD and what to expect when living with this condition.

Home Oxygen

This resource has been developed for those people with a chronic lung condition, who have recently been prescribed home oxygen therapy, or may be prescribed it in the near future.

Talking with your Doctor about COPD

This fact sheet gives some tips about how to get the most out of your appointments with your doctor.

COPD Action Plan

Take a copy of a COPD Action Plan with you to your doctor and fill it out together.

Fitness to Fly

Many patients living with lung disease have an increasing yearn to travel and this article will help you to understand the possible risks of air travel and whether you are "fit to fly".

Pulmonary Rehabilitation Factsheet

This fact sheet outlines the benefits of pulmonary rehabilitation and answers frequently asked questions.

LungNet News

Published on a quarterly basis, this is a free newsletter which provides useful articles on lung health and a wide range of information on lung disease.

Obstructive Sleep Apnoea

This resource has been developed for people who suffer from Obstructive Sleep Apnoea and answers frequently asked questions.

Educational flyers

Related to the lungs, lung health and respiratory disease.

Patient Support

In addition to the wide range of educational material available to those with lung disease, Lung Foundation Australia provides a range of support services. For further information on how to access this support, please call our Information and Support Centre on 1 800 654 301.

Information and Support Centre - Free-call 1800 654 301

The Information and Support Centre can help you to find out more about chronic lung disease and the help that is available to you. The Centre can be contacted during office hours on weekdays on free-call 1800 654 301 or enquiries@lungfoundation.com.au.

Patient Support Groups

Located in all States and Territories, Patient Support Groups meet regularly to provide a welcoming, informal environment for those with a lung condition, their families and/or carers. Lung Foundation Australia maintains a list of groups in each state and territory and can link patients up with a group nearby, or, if there is no existing group provide help to start one.

Pulmonary Rehabilitation Programs

Lung Foundation Australia maintains a list of contacts for programs in each state and territory, including contact details, any required referral and dates and times of classes.

Education Days

Held annually in each State, LungNet Education Days provide an opportunity for patients to hear first-hand from health professionals about the latest developments in lung health.

Lungs in Action

Lungs in Action is Lung Foundation Australia's community based exercise program. Visit the website to find a program near you: www.lungsinaction.com.au

How you can support Lung Foundation Australia

Lung Foundation Australia receives no on-going Government funding to support our core activities and therefore we rely on financial sponsorship and support from individuals, businesses and industry, donations and bequests, as well as our own fundraising events and initiatives.

Here are some ways you can help support Lung Foundation Australia:

Become a financial member

For information on how to become a financial member, please [click here](#).

Make a donation

A donation to the Lung Foundation will assist us to achieve our vision and goals. All donations over \$2 are tax deductible.

[Click here to donate to Lung Foundation Australia](#).

Make a bequest

A very positive and personal commitment by you, which will help us to maintain and expand our lung health programs.

[Click here for more information on making a bequest](#).

Hold a fundraiser

If you would like to hold a fundraiser on behalf of the Lung Foundation, please let us know.

We have lots of tips and tricks to help you along the way, which you can find [here](#).

FAQs - What is Lungs in Action?

Lungs in Action is a community-based exercise class designed specifically for those with COPD or other chronic respiratory conditions.

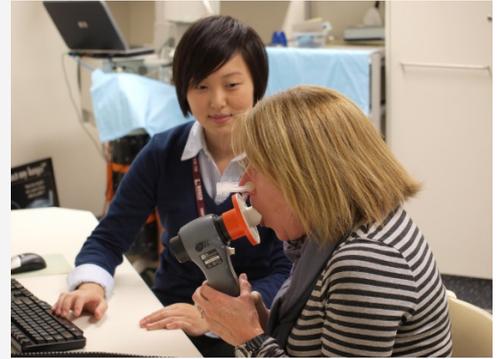
This video will introduce you to this pulmonary rehabilitation program so you can better understand what to expect at these classes, as well as how these classes can help you.

For more information on Lungs in Action, call Lung Foundation Australia at 1800 654 301, or *visit the website*.

FAQs - What tests can be done to assess my lungs?

There are many tests that can be done to find out if your health problem is related to your lungs.

These tests, and what they are used for, are as follows:



Respiratory function tests

Respiratory function tests are breathing tests to find out how your lung function compares with people who are like you but who do not have lung conditions.

Spirometry, gas transfer tests and lung volume measurements may all be done as part of a complete test of pulmonary function or each measurement may be done alone.



Lung function screening tests

These screening tests use a simple hand-held device that will quickly determine whether you are at risk of COPD and therefore would benefit from having a full spirometry test done.



These devices (Piko-6 and COPD-6) are used by some general practitioners and pharmacists.

Chest x-ray

A chest x-ray takes a picture of your lungs and will show the lungs as well as the heart and several major blood vessels. Chest x-rays are useful if other conditions, such as pneumonia or lung tumours, are suspected.



FAQs - What other tests may be useful?

A computed tomography (CT) scan

This scan can take many small specialised pictures of the lungs. Although a CT scan is not routinely performed, it can provide more detail than a chest x-ray.

An arterial blood gases (ABGs) test

This is a blood test that measures how efficient your lungs are at bringing oxygen into the blood and removing carbon dioxide from the blood. As an ABGs test requires an injection into an artery, this test can be more painful than a standard blood test.

An oximetry test

This test is a way of indirectly measuring oxygen levels in your blood. This test is not painful and is commonly used to measure oxygen saturation, which indicates how much of the oxygen in your body is in red blood cells.

However, as this test can be less reliable than ABGs, ABGs will be used when a more accurate measure of oxygen levels is required, such as when deciding whether supplemental oxygen is required.

A sputum test

A sputum test is used to find out what type of infection is in your sputum and which antibiotics would be most effective against that infection.

Exercise tests

Exercise tests done to assess your heart, lungs and muscles. Exercise testing will usually be performed as a walking test or on an exercise bike.

These tests can be done in an exercise laboratory, a gymnasium or on a walking track. In the laboratory, you will usually be asked to breathe through a mouthpiece connected to a machine.

This machine measures how much effort it takes you to exercise. You may also be connected to heart and oxygen monitors.

FAQs - What are clinical trials?

Clinical trials are research studies that test new and potentially better ways of improving peoples' health. They are an important process to assess whether promising approaches to prevention, diagnosis and treatment are possible, safe, and effective in humans. Some trials also look at ways of enhancing a person's quality of life.

Clinical trials are the final stages of a long and careful process that often starts many years earlier. Trials are the link between scientific discoveries made in the laboratory and making new treatments available for people with lung disease.

How to find a clinical trial

Talk to your doctor if you would like to take part in a clinical trial. Your doctor may be involved in a suitable trial, know of one being done elsewhere, or if not, may be able to help you find one.

If you hear of, or read about a clinical trial, for your chronic lung disease ask your doctor for more information. Keep in mind that clinical trials are not run at every treatment centre, so you might have to travel to a different location, including interstate, to take part in one.

Is a trial suitable for you?

Your doctor may suggest you enter a clinical trial. This would be only after you have been carefully assessed and the trial is believed to be suitable for you. If the trial is not suitable, you will be offered the best treatment available.

If you want to consider taking part, your doctor must explain the trial to you and make sure you understand it completely. Your treating doctor should answer any questions you have about the trial. If you're unsure, ask your doctor about someone else you can talk to about the trial.

You can also seek a second opinion about the trial and other options. You should only agree to participate in a trial when you understand all you need to know about it.

Informed decision-making

Informed decision-making is required by law and is an essential part of being in a clinical trial. It means you should only be enrolled in a clinical trial after you understand the trial fully and have given your consent in writing.

You should be given a full explanation of the treatment proposed for you in the trial. Then you can discuss this with your doctor or nurse. Having all this information should enable you to decide whether you wish to participate in the trial.

If you choose to participate, you will be asked to sign an informed consent form before entering the trial. A copy of this form will be given to you for your records. This is a standard part of every clinical trial.

Conclusion

This module aimed to show you that while you may have been diagnosed with COPD, you can still lead a fulfilling and enjoyable life. There are several areas that will require your attention as you transition to living with a lung disease. This module aimed to provide you with useful information to assist you.

You should now understand:

- Stress, anxiety and depression and what symptoms to look for;
- How to use various techniques to reduce stress;
- How you can continue intimacy and sexual activity;
- How you can travel safely by car or plane, and how to travel with oxygen;
- The legal issues you may face, including your rights at work and superannuation;
- The support services that are available to you; and
- The resources that Lung Foundation Australia can offer you.

You can revisit this module at any time by selecting Module Five from the dashboard.