Introduction

This booklet contains information for people who have recently been diagnosed with Chronic Obstructive Pulmonary Disease (COPD). It is also a useful guide for family members or friends who provide support to a loved one living with COPD. It has been designed to help you understand more about the condition of COPD and the treatment options available.

By being informed about your condition and taking steps to improve your health, you can reduce the impact COPD has on your life both now and in the future.

If you have any questions about your health or about COPD, it is important that you talk to your doctor or another member of your healthcare team.

See the back cover of this booklet for information on Lung Foundation Australia services and useful websites and organisations.

Lung Foundation Australia’s passionate and experienced Information and Support Team provides trusted advice, information and support to patients, carers and health professionals. Contact us via freecall 1800 654 301 to find out more.
Table of Contents

About COPD 6
Understanding COPD 7
Causes 8
Symptoms 8
Diagnosis 10
Treatment 11
Coping with a flare-up 17
Understanding COPD medicines 19
Oxygen therapy 23
Get to know your healthcare team 24
Useful websites 26
About Lung Foundation Australia 27
What is COPD?

Chronic Obstructive Pulmonary Disease (COPD) is a progressive lung condition that causes narrowing of the bronchial tubes in the lungs (sometimes called bronchi or airways), making it difficult to breathe. Sometimes air gets trapped in the lungs causing the feeling of breathlessness. When the condition occurs it is chronic (long-term) in nature, however it is important to remember that you are not alone and there are things you can do to help manage the symptoms and improve your overall quality of life.

COPD is an umbrella term for a group of lung conditions including:

- Emphysema
- Chronic bronchitis
- Chronic asthma

COPD in Australia

COPD is a common lung condition affecting both men and women. Around 1 in 7 Australians aged 40 years and over have some form of COPD² however around half of the people living with COPD symptoms do not know they have the condition³. Indigenous Australians are 2.5 times more likely to have COPD than non-Indigenous Australians⁴. Whilst COPD is not a contagious disease, it is the second leading cause of avoidable hospital admissions in Australia⁴.

Asthma-COPD Overlap

Around 20% of people with COPD also have asthma which is described as asthma-COPD overlap (also called asthma-COPD overlap syndrome, or ACOS)¹. Asthma-COPD overlap is not a disease on its own and may have several different causes. People with asthma-COPD overlap need different treatment from people with just asthma or COPD alone.
Understanding COPD

**What is emphysema?**
Emphysema is a condition in which air gets trapped inside the lungs making it harder to breathe in again. The main symptom of emphysema is breathlessness.

*Figure 1: Air trapped inside the air sacs (alveoli)*

**What is chronic bronchitis?**
Chronic bronchitis is a constant and long-lasting irritation and swelling of the airways. The main symptoms of chronic bronchitis are cough and increased secretions from the lungs such as mucus.

**Figure 2: Swelling and increased mucus production in the airways***

**What is chronic asthma?**
Asthma is a condition that affects the small airways. When you experience asthma symptoms the muscles in the airways tighten and the lining of the airways swell and produce sticky mucus. These changes cause the airways to become narrow, meaning there is less space for the air to flow in and out of your lungs.

Usually with asthma, medicines can reverse symptoms and open the airways. In chronic asthma, however, the medicines do not fully open the airways, meaning it is irreversible. This is categorised as COPD.

***Figure 3: Tightening of muscles and swelling of airways***

*Figure 1: Air trapped inside the air sacs (alveoli)*
**Figure 2: Swelling and increased mucus production in the airways***

COPD The Basics 7
Causes

There are many causes of COPD, which may include:

• **Smoking**: this includes if you currently smoke, have smoked in the past, or are exposed to passive smoking.

• **Environmental factors**: such as working or living in areas where there is dust, gas, chemical fumes, smoke or air pollution.

• **Genetic**: A small number of people have a form of emphysema caused by a protein disorder called alpha-1 antitrypsin deficiency (AATD). This is where the body finds it difficult to produce one of the proteins (Alpha-1) which protects the lungs.

Symptoms

The first symptoms of COPD can be subtle and may overlap with other lung and heart conditions. They may also be mistaken for signs of getting older, being overweight or unfit. COPD is a progressive lung condition with three stages:

1. **Mild COPD**

The first symptoms of COPD tend to come on slowly and can be very mild. In the early stages, you may not have symptoms all the time and you may find there is very little or no impact on your life or independence. You may cough up mucus in the mornings or feel more short of breath than usual if you walk quickly or exert yourself.

2. **Moderate COPD**

As COPD progresses, you may notice symptoms almost every day and find it harder to do your normal daily activities such as gardening, hanging out the washing, or carrying groceries without feeling short of breath. Other symptoms may include:

• A repetitive cough that doesn’t get better (this is due to a buildup of mucus in the airways)

• Increased mucus production, which is often thick, and white or brownish in colour

• Feeling tired

• More chest infections or taking a bit longer to recover from a cold or chest infection.
3. Severe COPD

In severe COPD, you will likely experience symptoms most of the time. You may:

• Find it hard to walk up stairs or across the room without feeling very short of breath
• Feel tired more of the time, despite resting
• Cough frequently and cough up a lot more mucus
• Feel frustrated with the constant need to clear your mucus from your airways
• Get chest infections frequently
• Take several weeks to recover from a cold or chest infection.

“I thought I was just getting older and suffering from the effects of years of smoking. I didn’t realise there was a name for what I have and that there was something I could do to feel better.”

Donna, lives with COPD
Diagnosis

While there is currently no cure for COPD, research shows that early diagnosis, combined with disease management programs at the early stage of the condition, can improve quality of life, slow progression, reduce mortality and keep people out of hospital.5

Diagnostic tests for COPD can include:

**Lung function tests (breathing tests)**

Spirometry is the most common breathing test used to confirm a diagnosis of COPD. The test involves blowing as long and hard as you can into a tube connected to a (spirometry) machine. The machine assesses how well your lungs work by measuring how much air you can inhale, how much you can exhale and how quickly you can exhale. The results will let your doctor know if you have COPD or another lung condition such as asthma.

FEV1 is the amount of air you can forcefully blow out of your lungs in one second. It is an important breathing test measure for airflow obstruction, such as from COPD.

Your doctor will compare your FEV1 with standards (called predicted values) for a person without lung conditions, who is of comparable age, gender and height. From this comparison your doctor will calculate a percentage. This is used to stage COPD as mild, moderate or severe.

Other tests may include:

**Chest X-ray:** takes pictures of the tissues in the lungs and surrounding organs.

**CT Chest:** takes more detailed pictures than an X-ray to look at the lungs and surrounding organs.

**Arterial blood gas analysis:** a blood test that measures how well your lungs bring oxygen into your blood and remove carbon dioxide.

**Laboratory tests:** these are not used to diagnose COPD, but may be used to rule out other conditions or to work out the cause of your symptoms.

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Figure 4: Spirometry is used to confirm a diagnosis of COPD
Treatment

Can COPD be cured?

Although the damage to your lungs cannot be reversed, early treatment is important to help improve how you feel. By taking the following steps you can improve your overall quality of life, slow the progression of symptoms, and keep your COPD well managed, including reducing the risk of flare-ups.

Quit smoking

Not all people with COPD have smoked, however, if you do smoke, quitting is the single most important thing you can do to improve your health and lung function. If you continue to smoke, your health and respiratory symptoms will worsen. The sooner you quit, the better your chances of living well and improving your lung function.

Do not feel guilty about having smoked. Most people say they would like to quit, and may have tried at least once. Some are successful the first time but others try many times before they finally give up for good. A quit plan can help you reflect on why you smoke and your motivations for quitting, and help you choose your preferred quit tools. These can include:

• Nicotine replacement therapy (NRT) products.
• Support options such coaching and/or counselling.
• Other strategies to help you plan for success, such as making changes to your daily routine to reduce the temptation to smoke.
Stay healthy and active

Studies have shown that people with chronic lung conditions use 25 – 50% more energy than people with normal lung function. This is mostly due to the changes in your lungs, increased work of breathing and using more energy to fight chest infections or flare-ups, which are more common in people with COPD. There are lots of things you can do to make sure you stay healthy and have energy to do the things you enjoy, including:

• Eat a healthy, nutritious diet
• Be physically active
• Get enough rest and good quality sleep
• Look after your wellbeing by enjoying friends, family and hobbies. Practising relaxation techniques can also help reduce feelings of stress or anxiety.

“I was suffering from shortness of breath and when I started trying to get fit, I couldn’t get around the block. Any minor incline was a challenge and set me off coughing. Since quitting, I’m running 30 to 40km a week and I don’t cough as much.”

Roy, lives with COPD
Your weight can have an impact on your energy levels, mobility and symptoms such as breathlessness. If you are underweight, your body has less nutrient stores. You may get tired more easily and your muscles, including your breathing muscles, can become weak. Being underweight can also increase your risk of getting infections.

If you are overweight, this can increase your breathlessness, making it hard for you to do daily activities like walking up stairs or carrying groceries. It also increases your risk of developing other health conditions such as high blood pressure, high cholesterol and type 2 diabetes.

The Australian Dietary Guidelines say that you should enjoy a wide variety of nutritious foods from these five groups every day:

- **Vegetables**: including different types and colours, and legumes/beans.
- **Fruit grain (cereal) foods**: mostly wholegrain and/or high cereal fiber varieties, such as breads, cereals, rice, pasta, noodles, polenta, couscous, oats, quinoa and barley.
- **Lean meats and poultry**: fish, eggs, tofu, nuts and seeds, and legumes/beans.
- **Dairy**: including milk, yoghurt, cheese and/or their alternatives, mostly reduced fat.

You should also drink plenty of water and limit intake of foods containing saturated fat, added salt, added sugars and alcohol.

It is important to get advice that is specific to you and your condition. An Accredited Practising Dietician (APD) can help you understand what your healthy weight range is. They can also help you set goals and develop healthy eating plans to ensure you are getting the right nutrition.
**Exercise**

If you get breathless during your normal daily activities you may start to avoid exercise, however, this can cause your muscles to get weak and you will lose fitness over time. COPD research has shown that regular exercise can help maintain your fitness, improve your wellbeing and reduce symptoms, such as breathlessness.

You should aim to exercise for at least 30 minutes, five times a week. It’s important to note that you do not have to do all 30 minutes at once. For some people this will be achievable whilst others will need to break the 30 minutes into smaller sessions. The activity you do should make you a little out of breath. It’s important to talk with a health professional, such as a physiotherapist, about what type of exercise would suit you.

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**Pulmonary Rehabilitation**

Pulmonary rehabilitation is an exercise and education program provided by specially trained health professionals. It teaches you the skills you need to exercise safely and manage your breathlessness. Research shows that pulmonary rehabilitation is one of the best things you can do to improve your breathing and wellbeing. It also reduces the frequency of COPD flare-ups and helps you stay well and out of hospital.

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**Lungs in Action**

After you finish pulmonary rehabilitation, it is important to continue exercising to help maintain your physical fitness and lung health. Lung Foundation Australia’s Lungs in Action program is a safe and fun community-based exercise class designed to help people with a chronic lung disease maintain the benefits achieved through pulmonary rehabilitation.
“Pulmonary rehabilitation made such a difference for me that my doctor took me off the waiting list for lung reduction surgery, and I am now back at work two days a week.”

John, lives with COPD
Ensure your vaccinations are up-to-date
Support your immune system and reduce the risk of flare-ups by having your vaccinations.

- **Influenza**: A yearly influenza vaccine has been shown to reduce risk of death and hospital admissions.
- **Pneumonia**: It’s important to remember that no matter how healthy and active you are, your risk of getting pneumococcal pneumonia increases with age. This is because the immune system naturally weakens as we get older, making it harder for our bodies to fight off infections and diseases. Talk with your doctor about the best way to protect yourself against pneumococcal pneumonia.

Access emotional support
Everyone experiences COPD differently. Initially your COPD may not have much impact on your life or emotions, however as it progresses, it is important to access support. You may also experience changes in your mood or feel anxious. It can be difficult to know if you feel down because of your physical health or if you have symptoms of depression and/or anxiety. Your doctor or another member of your health care team can help you work through these feelings.

There are also a number of community organisations that specialise in providing confidential help and support. See the back of this booklet for more information or contact Lung Foundation Australia.
COPD flare-ups are serious!

If you notice symptoms of a flare-up see your doctor as soon as possible. Getting treatment early will reduce the severity of your flare-up and may prevent the need to go to hospital.
Flare-ups can cause permanent damage to your lungs and make your COPD worse. Reduce your risk of a flare-up by:

- Taking your COPD medicines as instructed by your doctor.
- Supporting your immune system with influenza and pneumococcal pneumonia vaccinations.
- Staying away from people (including babies) who have colds, flu, sinus infections and/or sore throats.
- Avoiding things that can make your symptoms worse such as fumes, dust or cold or very humid air.

Our COPD Action Plan helps you recognise when your symptoms change. It also provides you with actions to take to reduce the severity and length of symptoms. Talk to your doctor about making a COPD Action Plan at your next appointment.

“I believe in doing what I can and being honest with myself about my condition. Planning is a big part of my everyday living. I do this to make sure I conserve energy and can make each day count”

Ian, lives with COPD
There are a number of medicines that people with COPD can take to improve their breathing. Some work by helping to open up the airways, while others relax the muscles around the airways to make breathing easier. COPD medicines are most commonly taken using an inhaler device (sometimes called a *puffer*) to deliver the medicine directly into the lungs.

There are three main categories of COPD medicines:

1. **Reliever medicines**

Reliever medicines should be used when you feel short of breath suddenly. These medicines are called short-acting bronchodilators (pronounced *bronk-oh-dye-lay-tors*) and work by relaxing the muscles around the airways. This helps open the airways to allow air in and out of the lungs easily. This can reduce the feeling of shortness of breath.

Reliever medicines are effective within minutes of inhalation and last for several hours.

If you are using your reliever inhaler more often than prescribed, talk to your doctor. This may mean that your COPD medicines and management plan need to be reviewed.

### Relievers

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<tr>
<td>Ventolin® MDI</td>
<td>Bricanyl® Turbuhaler®</td>
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<td>Asmol® MDI</td>
<td>Atrovent® MDI</td>
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<td>#Airomir™ MDI</td>
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Always make sure you carry your reliever inhaler with you when you leave the house in case you suddenly feel short of breath.
2. Maintenance medicines

Maintenance medicines are long-acting bronchodilators. Like reliever medicines, they work to open the airways by relaxing the muscles around them. Maintenance medicines usually take longer than relievers to start working, however their effects last longer - 12 to 24 hours depending on the medicine.

There are two types of bronchodilators:

1. Long-acting muscarinic antagonists (LAMA)
2. Long-acting beta2-agonists (LABA)

You can be prescribed one type of long-acting bronchodilator alone, or may receive a combination of two types, such as Ultibro® (glycopyrronium bromide/indacaterol), Anoro® (umeclidinium/vilanterol) Spiolto® (tiotropium and olodaterol) and Brimica® (aclidinium and eformoterol).

COPD medicines containing corticosteroids

Some inhalers contain corticosteroids in addition to bronchodilators.

Corticosteroids work by reducing inflammation, and help to make your airways less sensitive to irritants that can cause swelling and mucus production. These medicines include Symbicort® (budesonide and eformoterol), DuoResp® (budesonide and eformoterol), Seretide® (fluticasone and salmeterol), Cipla Inhaler® (fluticasone and salmeterol), Breo® (fluticasone furoate/vilanterol) and Trelegy® (fluticasone/umeclidium/eformoterol).

This kind of combined medicine is usually prescribed for people with moderate to severe COPD who have had two or more flare-ups over the previous year.

Inhaled corticosteroids on their own are not used for people with COPD. They are used to treat asthma, and for those people that have both asthma and COPD. After using inhaled corticosteroids, it is important to rinse the mouth to avoid possible side effects.

You only have to use one inhaler to take two medicines. Combined medicines can also reduce the risk of flare-ups.
To get the most benefit out of these medicines, you should take them each day, as instructed by your doctor. Used daily, they will help to reduce your COPD symptoms in the long term.
3. Flare-up medicines

These medicines are for short-term use when you are experiencing a flare up. If taken early, they can reduce the severity and duration of a flare-up. Your doctor will tell you what medicines to take when your symptoms worsen and will write instructions in your COPD Action Plan.

Antibiotics

Antibiotics will not help manage COPD on a day-to-day basis. They are prescribed if you have a flare-up due to infection. If the colour, amount and/or texture of your mucus (phlegm) changes, this can mean you have an infection. If you are prescribed antibiotic tablets by your doctor, make sure you take the tablets for as long as instructed, even if you start to feel better.

Oral steroids

Steroid tablets can be prescribed for a short period of time to help treat symptoms of a flare-up such as wheeze or breathlessness. Your doctor will normally prescribe a course for 5 – 10 days. It is also important that you take them at the time of day as instructed by your doctor. Do not stop taking steroid tablets suddenly without consulting a doctor.

Take your medicine as instructed

The medicines prescribed by your doctor are tailored to you and your symptoms. It is important to take your medicines as instructed even when you feel well. Do not be tempted to decide when and how much medicine you will take. This will reduce the effectiveness of your medicine and could make your COPD worse.

“Now that I am on the right medicine I am coping more with household jobs, and enjoying life with my family and friends. There are still limitations, but I don’t feel as restricted.”

Gaye, lives with COPD
Learn how your medicines work. This will help you to understand why and when you need to take them. Ask your doctor, nurse or pharmacist:

• What your medicine is for
• How the medicine works
• How to take the medicine
• When the best time to take it is
• How long the dose is effective
• What the possible side-effects of the medicine are and how you can avoid or reduce them
• Whether the medicine will cause problems with any other medicine you are taking
• To include all your medicines in your COPD Action Plan.

Up to 90% of people with COPD do not know how to use their inhaler device correctly. It is important for a trained health professional (such as your doctor, nurse or pharmacist) to show you how to use your inhaler and assist you to get the technique right. Correct use of your inhaler device is important and will ensure you get the most benefit from your medicine.

Oxygen therapy

In severe stage COPD your oxygen levels can be low and home oxygen may be prescribed by your doctor or specialist. While oxygen therapy can help to reduce the damage to your vital organs, it is not prescribed to stop breathlessness. Some patients may need continuous oxygen while others may only require oxygen during physical activity like walking or exercising. While oxygen therapy may relieve breathlessness in some people, in many cases it does not.
Get to know your healthcare team

As well as your doctor, there other health professionals who can help you manage your COPD - this is your healthcare team. A respiratory nurse, pharmacist, physiotherapist or dietician may be part of your healthcare team.

You may choose to ask one or more of your family or friends to also be part of your healthcare team. They can assist by attending appointments with you or helping you monitor your symptoms.

Regular visits with your healthcare team are important

Having regular contact with your healthcare team will help you to stay in control of your COPD symptoms. You should go to your appointments even if you are feeling well.

You can talk to your healthcare team about:

• Changes in your symptoms, or flare-ups
• Your medicines, including any side effects
• Other conditions you may have and their impact on your health and wellbeing
• Strategies to self-manage your COPD
• Environmental risk factors you may have recently been exposed to such as smoking, dust or fumes.
Tips for appointments with your healthcare team

It is important that you understand the information your healthcare team gives you during appointments. It is also equally important that they understand your personal needs and what is important to you.

The following tips can help you get the most out of your appointments with your doctor and other members of your healthcare team:

• Keep a symptom diary to help you monitor your symptoms over time. Discuss any change in symptoms at your next appointment.
• Use a notebook to keep track of the information you discuss with your healthcare team. Take it with you to all appointments.
• Before your appointment make a list of questions and concerns in your notebook. List them in order of priority. If you have a number of questions you may need to make a longer appointment or schedule a second visit.
• Show your list to your healthcare professional at the beginning of your appointment and decide together what you will discuss during this visit.
• Take a friend or family member to your appointments for support.
• Ask your health professional to write information in your notebook for you to refer to again.
• If you don’t understand something, ask your healthcare professional to repeat the information or to explain it in a different way. Do not avoid asking questions because you are afraid or embarrassed. Your healthcare team is there to help you.
• Ask about the best way to contact your healthcare team in case you have medical questions, or if you suspect a flare-up.
• Let your healthcare team know if you are worried about the cost of your health treatments. They can help you find the best solution.
Useful Websites

COPD Online Patient Education
cope.lungfoundation.com.au

C.O.P.E. is a free and easy to use and interactive program designed by Lung Foundation Australia to help you self-manage your COPD. It connects you with downloadable resources, videos and links to information that may be of interest to you.

Community Organisations

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<th>Organisation</th>
<th>Website/Phone</th>
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<tr>
<td>Advanced Care Planning</td>
<td>advancecareplanning.org.au 1300 208 582</td>
</tr>
<tr>
<td>Beyond Blue</td>
<td>beyondblue.org.au 1300 224 636</td>
</tr>
<tr>
<td>Carer Gateway</td>
<td>carergateway.gov.au 1800 422 737</td>
</tr>
<tr>
<td>Carers Australia</td>
<td>carersaustralia.com.au 1800 242 636</td>
</tr>
<tr>
<td>Department of Human Services</td>
<td>humanservices.gov.au</td>
</tr>
<tr>
<td>Dieticians Association of Australia</td>
<td>daa.asn.au 1800 812 942</td>
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<tr>
<td>Lifeline Australia</td>
<td>Lifeline.org.au 13 11 14</td>
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<tr>
<td>My Aged Care</td>
<td>myagedcare.gov.au 1800 200 422</td>
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<tr>
<td>Quitline</td>
<td>quitnow.gov.au 137 848</td>
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<tr>
<td>The Department of Health</td>
<td>health.gov.au 1800 020 103</td>
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Lung Foundation Australia is the only national first point of call working to support anyone living with a lung disease. Every day we work to support patients and caregivers through funding research and offering programs, services and evidence-based lung health information.

Our mission is to improve lung health and reduce the impact of lung disease for all Australians by:

• Driving community awareness about lung health.
• Funding world class, life-changing research.
• Advocating for people with a lung condition to receive the level of care and treatment they deserve.
• Providing information and support for patients.
• Facilitating best-practice training and education for health professionals.

We understand that being diagnosed with a lung condition can have an enormous impact on you and your family. We want you to know that you are not alone and that we are here to support you to live well with your lung disease.

You can contact Lung Foundation Australia for more information and to access our support services including:

• Information and support line
• Lung disease information and resources
• Education seminars and webinars
• Lung cancer support nurse
• Respiratory nurse
• Peer-to-peer connections
• Referral to pulmonary rehabilitation
• Lungs in Action exercise programs
• Newsletter

For more information about the services listed, please call 1800 654 301 or email enquiries@lungfoundation.com.au
The COPD National Program receives sponsorship funding from a number of industry partners. Industry partners have no direct or indirect influence over the content of COPD educational resources. Lung Foundation Australia maintains complete editorial and design control over all educational resources as well as all other program materials and promotions.

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