

Better Living with Chronic Obstructive Pulmonary Disease

A Patient Guide

Second Edition
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THE
AUSTRALIAN
LUNG
FOUNDATION



**Queensland
Government**

Queensland Health

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

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Your role in managing your chronic obstructive pulmonary disease

This chapter will help you to understand:

- The important role you have in managing your chronic obstructive pulmonary disease (COPD).
- How to develop and get the most from your management plan.
- How to work with your health care team.

What is the important role you have in managing your COPD?

Chronic conditions are becoming one of the greatest health challenges worldwide. For people living with a chronic condition, life can be a daily struggle.

Many people who are first diagnosed with COPD report feeling confused and worried. Others say that they are relieved to have an explanation for their breathlessness and other symptoms.

We do know that COPD can seriously affect every part of your life, particularly as the disease progresses. Simple activities you once took for granted, such as taking a walk or getting dressed can become increasingly difficult. Exacerbations or flare ups (when you have an acute worsening of your symptoms) can further affect your quality of life.

The good news, however, is that there is a lot you can do to slow down the worsening of your symptoms, improve your fitness and prevent flare ups.

Better Living with COPD is written to help guide you through the steps you can take to help yourself. Recent studies show that positive results can be achieved by people with chronic lung conditions, such as COPD, who are involved in managing their own condition. People have reported 'feeling less breathless', 'feeling more in control of things' and requiring fewer visits to the doctor or hospital.

Studies show that people involved in managing their COPD feel 'less breathless' and 'more in control'.

Effective management of COPD is based on a partnership between you, your carer and family, and your health care team. The following list is based on the Flinders Program, Flinders Human Behaviour and Research Unit, Flinders University, Adelaide, SA. You can take an active role in this partnership by:

- Knowing as much as you can about COPD, including your diagnosis and problems associated with your diagnosis.
- Being actively involved in decision making and the development of a management plan with your health care professional. This includes a written COPD Action Plan to help recognise when you are getting sick and what you can do about it. Developing a written COPD Action Plan is discussed in more detail in chapter 9.
- Developing and following a management plan agreed between you and your health care team that includes your medications as well as other important activities such as diet and exercise.
- Monitoring your symptoms and taking action to



reduce the impact of these symptoms. A sample symptom diary is discussed in more detail in chapter 9.

- Managing the impact that COPD has on your physical, emotional and social life.
- Adopting lifestyle behaviours that promote health, such as eating a healthy diet, getting regular exercise and quitting smoking if you are a smoker.
- Using support services that are made available to you.

How do you develop and get the most from your management plan?

When you have a chronic lung condition, you may experience difficulty managing all your treatments day after day. Support from your health care team, family and support groups can help you to stay motivated and look after yourself.

The following are some tips that others have used to help them set goals and stick to them.

- Set realistic goals that are important to you.
- Write your goals down and let your health care team, family and friends know what they are so they can support you to achieve them.
- Reward yourself when you have done well.
- Simplify your life as much as you can.
- Be kind to yourself.
- Seek support from family, friends and others.
- Locate your nearest support group by contacting The Australian Lung Foundation (phone: 1800 654 301). Others have found the support from others in a similar situation very helpful.
- Enrol in pulmonary rehabilitation and once, completed, maintain a regular exercise routine.
- Ask a family member or friend to participate in your exercise and walking program, or join a local exercise group such as Lungs in Action. The Australian Lung Foundation can give you the contact details of a group close to you.

COPD-X SELF-MANAGEMENT CHECKLIST

The following checklist is a useful tool to use when you develop a management plan with your health care team. Later chapters of this patient guide provide more detail about all of the important steps that might be included in your management plan.

- ➔ C: CONFIRM DIAGNOSIS
- ➔ O: OPTIMISE FUNCTION
- ➔ P: PREVENT DETERIORATION
- ➔ D: DEVELOP SUPPORT NETWORK AND SELF-MANAGEMENT PLAN
- ➔ X: MANAGE EXACERBATIONS

The guidelines that are used by health professionals in Australia to manage COPD are called the COPD-X Plan. COPD-X is a good memory tool to remember the things that need to be done to manage your COPD well. In this booklet we have provided you with a checklist using this same memory tool. It is different from the one your doctor uses, but essentially the important steps are the same. Using the same checklist or tool as your health care team can help you and your team communicate with each other better.

C: CONFIRM DIAGNOSIS

By now your doctor will have informed you that you have COPD.

To confirm your diagnosis and to assess the severity of your COPD it is important that you have a

breathing test performed (called spirometry). You should also have your spirometry checked regularly to monitor the progress of your COPD. You may do this at the GP's surgery, at a specialist appointment or in a lung function laboratory.

I have had a Spirometry breathing test

O: OPTIMISE FUNCTION

To improve your condition your doctor will prescribe treatments. These treatments may include inhaled medications (puffers), exercises or 'Pulmonary Rehabilitation' (see pages 27 and 40) and treatments for other common medical conditions that frequently complicate COPD eg. osteoporosis. It is very important that you use your medications correctly and as prescribed and actively participate in physical activity.

I understand my medications and what each is doing for me

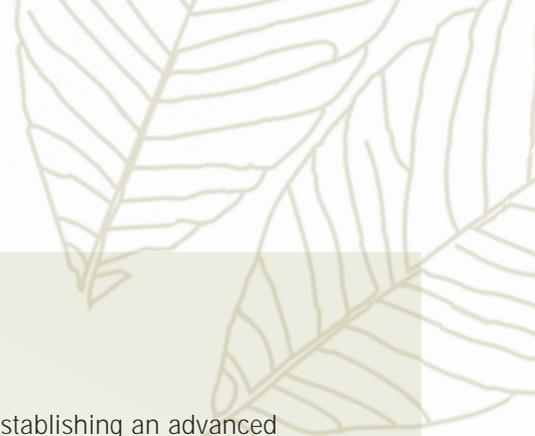
I have had my inhaler technique assessed (regularly) and learnt how and when to use my medications properly

I have been referred to a Pulmonary Rehabilitation group

I regularly exercise

I have discussed my other medical problems with my doctor and other members of the COPD team

I have had regular health checks with my doctor to monitor my signs and symptoms



P: PREVENT DETERIORATION

COPD is a progressive disease. However, there are a number of things you can do to prevent your COPD from getting worse. The most important of these is to stop smoking if you have not already done so. In addition to this you should ensure you get yearly vaccinations against the influenza 'flu' virus.

- I have successfully stopped smoking

If you are a current smoker:

- I have discussed stopping with a member of my COPD team
- I know how to start a quit plan
- I am aware of the medications that can help me stop smoking
- I have had my yearly flu vaccination
- I have had my pneumococcal vaccination

D: DEVELOP SUPPORT NETWORK AND SELF-MANAGEMENT PLAN

Self-management support involves education by health care staff to assist you in increasing your skills and confidence in managing your COPD. Members of the health care team including your specialist, GP, nurse, physiotherapist or pharmacist are there to help you become a good self-manager.

- I have developed supportive partnerships with my health care team
- My health care team and I have developed a written management plan to assist me in managing my health better

- I have discussed establishing an advanced health care directive with my doctor (for further information see chapter 21)

X: MANAGE EXACERBATIONS (FLARE UPS)

All people with COPD are at risk of exacerbations or flare ups of their condition. A very important goal of your COPD management is to prevent flare ups or if they do occur treat them early to prevent them from getting worse. A written COPD Action Plan can help you identify flare ups and provides you with instructions about how to manage them at an early stage of worsening illness.

- My doctor and I have developed a written COPD Action Plan
- I am aware of the signs and symptoms of a flare up
- I know how to increase my treatment during a flare up
- I have medication or prescriptions at home to start my Action Plan
- I know how long to increase my treatment during a flare up
- I know when to call for assistance (ambulance or hospital)

Using this checklist can help you and your health care team communicate about how you can achieve your goals.

How do you work with your health care team?

Your doctor looks after your health together with a range of other health care professionals, such as your nurse, pharmacist or physiotherapist. Good communication with all the members of your health care team will help you to look after your health. It is easy to get flustered or confused when talking to a doctor, especially if he or she uses words or terms that you are not familiar with. However, it is important that you understand exactly what they are saying. It is also important that your doctor understands what is important to you.

Your COPD may also change over time. As different symptoms occur, you will need to recognise these changes and talk to your health care team about adapting to these changes.

The following are some tips you might find useful when you are visiting your doctor.

- Make appointments with the same doctor, except in an urgent situation or when your normal doctor is not available.
- Make a list of questions and concerns before your visit. List these in order of priority.
- If you have many questions, ask for a longer appointment or schedule a second visit.
- Show your list to your doctor and decide together what you will discuss during this visit.
- Do not avoid asking questions because you are embarrassed or uncomfortable. Your doctor is there to help you.
- Bring a friend or family member for support.
- If you feel you do not fully understand what your doctor is saying, ask for further explanation.
- Ask your doctor to write answers down for you to refer to again.
- Find out the best way to contact your doctor in case you have additional questions or if you are concerned about symptoms or suspect a flare up.
- Let your doctor know if you have concerns over the costs of your treatment. They can help you find the best solution.

The Australian Lung Foundation has developed a helpful fact sheet called, "Talking to your doctor about COPD". It can be found at www.lungfoundation.com.au or call 1800 654 301.

In summary

Learning to live well with a chronic condition is possible. Coping with a chronic condition involves skills training, learning to manage a number of symptoms, and consciously assessing and making lifestyle changes. Experience has shown that those who develop a management plan with their health care team and follow it can live better with COPD.

The following chapters will provide all the details you need as you think through and develop a management plan, including:

- Stopping smoking and preventing a relapse (Chapter 6)
- Knowing your medication (Chapter 7)
- Using your inhalation devices (Chapter 8)
- Preventing and managing a flare up (Chapter 9)
- Introduction to pulmonary rehabilitation (Chapter 10)
- Exercise and physical activity (Chapter 11)
- Breathlessness, breathing control and energy conservation (Chapter 12)
- Airway clearance: Keeping your lungs clear (Chapter 13)
- Home oxygen therapy (Chapter 14)
- Healthy eating (Chapter 15)
- COPD and swallowing (Chapter 16)
- COPD and other related conditions (Chapter 17)
- Managing stress, anxiety and depression (Chapter 18)
- Intimacy and COPD (Chapter 19)
- Travel and COPD (Chapter 20)
- Legal Issues (Chapter 21)
- Community support services (Chapter 22)
- Frequently asked questions (Chapter 23)
- Resources and support available from The Australian Lung Foundation (Chapter 24)