

COPD AND ME

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Glossary of terms

ACBT: Active Cycle of Breathing Technique

COPD: Chronic obstructive pulmonary disease

Exacerbation: Flare up

HUFF: forced expiratory technique, used to remove phlegm from the lungs

NIV: Non invasive ventilation

SOB: Shortness of breath

FOREWORD

November 2018

Dear Patients and carers,

On behalf of COPD Support Ireland I am very pleased to release “ COPD and Me” a resource document for patients and their carers. COPD is a huge problem for patients and the Irish Health service. According to the National Healthcare Quality Reporting System there are approximately half a million people in Ireland with COPD. Worryingly only half of these have been formally diagnosed. In 2017 there were 17,500 acute hospital admissions because of COPD to Irish hospitals.

At an individual level you know the burden COPD places on patients and carers. Because smoking is the major factor in causing COPD many patients bear a degree of guilt about their diagnosis. Recent research, however, has highlighted the significant proportion of patients where other factors such as chronic asthma, air pollution, occupational exposures and family history played a predominant role. Irrespective of cause we need greater public awareness of COPD with ready access to Spirometry in the Community for accurate diagnosis and staging. With proper treatment and support we can do much to improve the quality of life for patients with COPD.

Patients with COPD experience “flare-ups, also called exacerbations of their underlying condition. Through education and support patients can **self manage** these in the community thereby reducing hospitalisations. Much of the modern treatment of COPD is focused on reducing these exacerbations. Pulmonary Rehabilitation has been proven to reduce exacerbations and improve quality of life for patients with COPD. A major aim of COPD Support Ireland is to see Pulmonary Rehabilitation available in a

timely fashion to all suitable patients. This should be supplemented with follow on exercise programmes in the community. Physical activity is crucial to maintenance of wellbeing for our patients. Our network of **Support Groups** can provide these exercise programmes as well as offering peer support to patients. Social isolation is a significant feature in COPD and active participation in a **Support Group** offers social interaction as well.

Many people have contributed to the production of this document and I wish to thank them sincerely. I warmly commend this booklet to you and expect it will enhance the care and self management of COPD.

A handwritten signature in black ink, appearing to read 'J. J. Gilmartin'.

Professor J J Gilmartin MD, FRCPI, FCCP
Chair COPD Support Ireland

1. What is COPD?

Chronic Obstructive Pulmonary Disease (COPD) is a common, treatable lung condition. A person with COPD will have persistent symptoms (for example cough and phlegm) and difficulty in breathing. As a chronic disease COPD will never go away but there are actions you can take to manage your COPD that will give you the best possible quality of life

COPD is an umbrella term for emphysema and bronchitis and is mainly due to exposure to harmful particles or gases that are inhaled, causing abnormalities to the airway and the gas exchange area within the lungs. Smoking is the greatest cause of these abnormalities. This means that the disease is largely preventable by never smoking and/or by avoiding long term exposure to harmful fumes, dust or gases in the environment or work place.

Following a diagnosis with COPD the focus of care, which will be guided by your healthcare team, will be to assist you in preventing exacerbations (flare ups) (Section

3). A Self-Management Plan developed between you and your healthcare team will guide you on the early steps to take if you feel you are getting a flare up.

The information in this booklet will assist you in caring for yourself if you have COPD, or if you are caring for someone with COPD.

2. Diagnosing COPD

The diagnosis of COPD is based on a combination of your medical history, an examination, an assessment of your symptoms and the results of a spirometry test which looks at the pattern of your breathing. You may have symptoms such as breathlessness and chronic cough, with or without phlegm, and a history of exposure to risk factors for the disease.

2.1 Risk Factors

Tobacco smoking is the main cause of COPD. Breathing in tobacco smoke irritates the lungs. They become inflamed and you may develop a cough. Other factors can also lead to the development of the disease including:

- exposure to indoor and outdoor air pollution
- inhaling dusts
- chemicals or
- exposure to fumes in the workplace over many years.

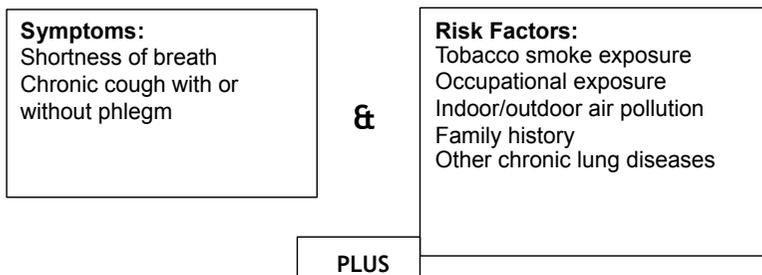
Some people who have never smoked develop COPD. This may be because of an existing illness, such as chronic asthma, and in others there can be a hereditary link called Alpha1 Antitrypsin, which can lead to the development of COPD.

2.2 Symptoms

- Chronic and progressive breathlessness is the most common symptom of COPD.
- Chronic cough with or without phlegm a lot of the time.
- You may find you have to slow down when doing normal daily activities such as shopping, showering, dressing or walking. For example, you may find that you need to stop and catch your breath half way up a flight of stairs or that you need to rest during a walk.

These symptoms often worsen over time, although they can vary from day to day. An exacerbation (flare up) happens when these symptoms worsen suddenly often as a result of an infection.

If you are over the age of 35 and you suspect you have the symptoms of COPD, with or without the risk factors, and/or there is a family history of COPD, go to your GP for an initial assessment and to arrange a spirometry test.



Spirometry Test is required to establish the diagnosis of COPD in conjunction with appropriate symptoms & risk factors (listed above)

2.3 Investigations

Detailed Medical History

Your GP will talk through the following with you:

- Past medical history and relevant family medical history.
- Smoking history or other risk factors.
- Onset of symptoms, history of exacerbations and/or previous hospital admissions for breathing problems.
- Other diseases including cardiac disease, osteoporosis, diabetes etc.
- Quality of life (QoL). You may be asked questions about how you are feeling and how you cope with certain activities. Your healthcare professional may use a questionnaire, which can be repeated when you are on treatment to check how you are getting on.
- An examination may also be done at this time, for example, blood pressure check, weight and chest sounds. These are important for general health and wellbeing.

Spirometry Test

Spirometry measures how much air you can blow out and how fast you blow the air out of your lungs after you have taken in a full deep breath. This test is used to confirm the diagnosis of COPD as well as how severe it is. It may be repeated at follow up visits to check how you are getting on. This breathing test takes about 20 minutes to complete.

Additional investigations

Other tests may be necessary for some patients or in some situations:

- Chest X-Ray and Computed Tomography (CT) of the chest.
- More detailed lung function tests in a Pulmonary Laboratory in the hospital.
- Pulse Oximetry which is a simple, non-invasive, painless way to check the amount of oxygen circulating in your blood.
- Arterial blood gas which is a special blood test done to help decide on treatment.

- 6 minute walk test – this indicates how far you can walk in 6 minutes and how walking for that time affects your oxygen levels, heart rate and other factors. Please be aware that not all these tests will be available in your GP practice, many of them are carried out in the hospital only.

3. Self-Management

Having a chronic condition like COPD can affect every aspect of your life and you may find that things you used to do can become more difficult. Self-management is about increasing your knowledge and skills in order to manage your COPD and feel more in control of things. Healthcare professionals can provide education, information and support to help you feel more confident in better managing your condition. A COPD Self-Management Plan can be developed with your healthcare professional. This will help you to manage your condition when you're well and to be aware of your symptoms and know what to do in the event of an exacerbation (flare up) of your COPD.

What can I do?

There is a lot you can do to manage your symptoms, prevent exacerbations (flare ups) and improve your fitness including:

- **Understanding COPD:** it is important to understand as much as you can about your COPD.
- **Role of medications and inhalers:** it is important to know about your medicines, how they work, how to take them. Make sure you are taking your inhalers correctly and that your inhaler technique is checked regularly. Always make sure you have enough of your medicines and never run out.
- **Smoking cessation:** if you smoke, stopping smoking is the most important thing you can do to improve your health. Stopping smoking will improve your cough and phlegm production. There are many supports available to help with smoking cessation (Section 4).

- **Emotional health:** take care of your feelings. Living with a long-term illness is not easy and can make people feel low and anxious. It is important to take care of your emotional health and there are supports available.
- **Avoiding exacerbations (flare ups):** recognise your symptoms, know what is usual for you. Monitor your symptoms and ensure you know when you may need to alter your medication or start treatment early for exacerbations. Know when and how to seek help. You can discuss this with your healthcare professional using a COPD Self-Management Plan to guide you.
- **Breathing exercises and chest clearance:** use controlled breathing techniques (Section 6.3) and chest clearance to help you get rid of phlegm and also help with relaxation techniques.
- **Exercise:** regular exercise is important – even a small amount of exercise is of benefit. Exercise contributes to improving your general feeling of wellbeing. It can also help you sleep better at night and it is very beneficial in strengthening the big muscle groups (Section 5).
- **Nutrition:** try to eat a well-balanced diet, eating little and often rather than having big meals. Try to maintain a healthy weight. Ensure you drink plenty of fluids, particularly during exacerbation (flare up). (Section 7)
- **Vaccinations:** It is important that you get the flu vaccine every year. (Section 6.8) and a pneumonia vaccination - your healthcare professional will tell you how often you need this.
- **Relaxation techniques:** relaxation techniques can help with breathlessness, feelings of anxiety or during times of exacerbations.
- **Rest:** ensure you get good sleep and plenty of rest particularly during times of exacerbations.
- **Equipment:** if using any medical equipment, for example nebulisers or oxygen, it is very important to ensure they are serviced regularly, and that masks and mouthpieces are cleaned and changed frequently.
- **Triggers:** know what it is that can trigger an exacerbation or flare-up and how to avoid these. For example, avoid smoky environments and pollutants like dust, smog, or foggy weather.
- **Bone health:** As we get older we are at risk of osteoporosis which is a weakening of the bone. A number of factors contribute to osteoporosis in

people with COPD but these can be monitored and there are many things you can do to improve and maintain bone health. Discuss exercise and vitamin supplements with your healthcare professional.

Many of these areas are discussed further in this booklet, but please ask your healthcare professional if you require further information.

4. Smoking Cessation

If you smoke, stopping is the most important thing you can do to help your lungs.

The 3 steps to successful quitting are:

1. Preparing to stop smoking
2. Stop smoking
3. Staying off cigarettes

Tips to help you stop smoking

- **Prepare to stop:** write down reasons for quitting and keep them close at hand.
- **Make a date to stop:** stick to it.
- **Support:** ask your family and friends for support.
- **Get help:** you are twice as likely to quit with help
 - Check out HSE quit resources (listed below). Choose the method that suits you best.
 - Ask your healthcare professional (GP/Nurse) for support: you may be given medication to help symptoms of nicotine withdrawal. This will increase your chances of quitting smoking.
- **Change your routine and plan ahead:** replace or change activities that you usually associate with smoking.
- **Think positively:** you may have withdrawal symptoms once you quit smoking. These are positive signs that your body is recovering from the harmful effects of smoking and will disappear once your body gets used to the change.
- **Learn to deal with cravings:** the 4 Ds:

- **Delay** at least 3 – 5 minutes and the urge will pass ○ **Drink** a glass of water or fruit juice ○ **Distract** yourself - move away from the situation ○ **Deep** breaths - breathe slowly and deeply
- **Save money:** treat yourself with the money that you would normally spend on tobacco.
- **Watch what you eat:** if you are worried about putting on weight - be aware of substituting other things for cigarettes for example, food or alcohol.
- **Be active:** regular activity is good for your health and helps you to manage stress.
- **Take one day at a time:** remember every day without smoking is good news for your health, your family and your pocket. If you slip up, all is not lost. Set a new date and start again.

What can I do?

- Stop smoking.
- Set a date to quit.
- Get help from others who have quit and from professional sources (see below)
- Stay away from places and people that make you want to smoke.
- Keep your hands busy, for example, hold a pen or pencil.
- When the craving is bad, chew gum or a toothpick. Snack on fruits or vegetables.
- Keep smoke, fumes and strong smells out of your home.
- If you start smoking again, don't despair. Try to stop again.



National Smokers' Quitline: 1800 201 203 www.quit.ie

- Freephone 1800 201 203
- Freetext QUIT to 50100
- Get started on www.QUIT.ie
- Find local HSE QUIT support groups on QUIT.ie or by calling the QUIT team.
- Tweet the QUIT team [@hseQUITteam](https://twitter.com/hseQUITteam)
- Join the Facebook page www.facebook.com/HSEquit
- Share your QUIT Story on the [QUIT Heroes App](#)
- Talk to your GP or Pharmacist who may advise on using nicotine replacement therapy or other medications to help you make that quit attempt successful

5. Exercise, COPD and Me



“I wouldn’t be able to exercise. It makes me too breathless. Wouldn’t exercise make this worse?”

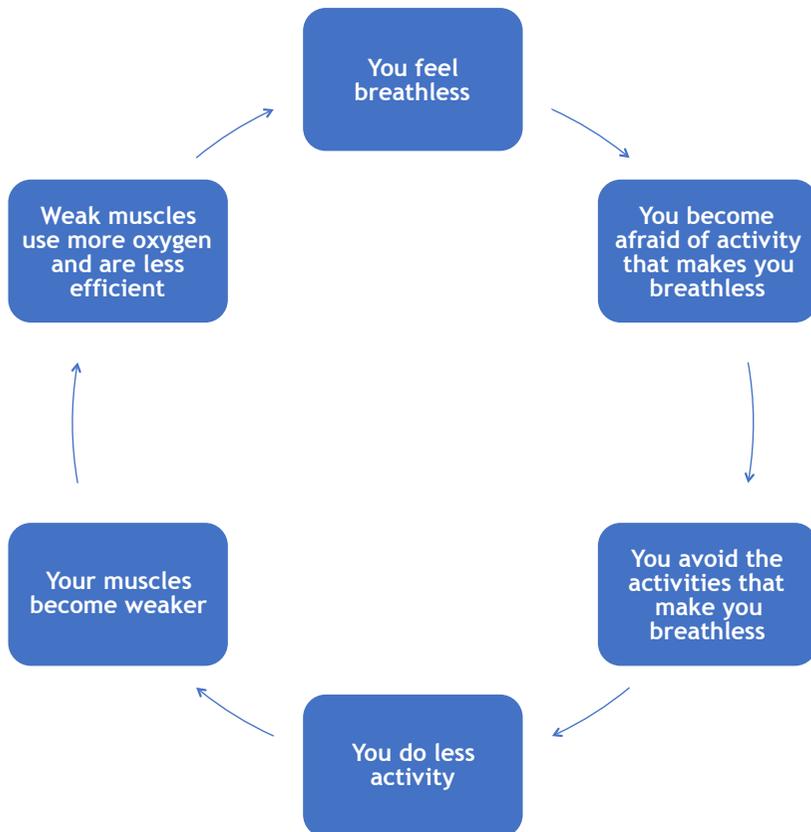
It’s very normal to feel this way if you’re short of breath with COPD. Exercise, done in a structured safe and controlled way, is one of the best things you can do to improve your breathlessness.

Many people with COPD find that being short of breath is the hardest part of their condition to deal with. Breathlessness causes people to do less and less activities. The less you do, the less you are able to do. This can lead to your muscles becoming weaker and eventually it can become difficult to do much at all

5.1 Cycle of inactivity



“How can I break this cycle and how can exercise help me and my lung condition?”



It may come as a surprise but breathlessness when you exercise is good for you. It is a normal response to physical activity. Breathlessness may occur more easily and more often when you have COPD but that does not mean that activity should be avoided.

Weaker muscles require more oxygen to work. Exercising regularly can make your muscles stronger so that they require less oxygen to do the same amount of work. If you avoid activity that makes you breathless then muscles tend to weaken and this can lead to more breathlessness.

Exercise cannot reverse COPD, but it can change how you control your breathlessness, improve fitness levels and improve your quality of life. It has a positive impact on both your physical and mental wellbeing.

It is important that you pace yourself, but the more you do the more that you will be able to do.

Tips for Safe Exercise

- Please consult your health care professional before starting any new exercise regime
- Do not exercise if you feel unwell
- Drink plenty of water throughout the day
- You should be able to talk whilst exercising
- Stop the exercise if you become too breathless

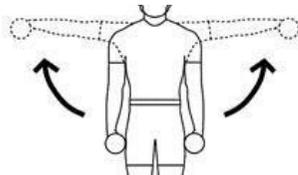
5.2 Home Exercises

Make some kind of exercise part of your daily routine. Walking for fitness is one of the best things that you can do but in times of poor weather it can be difficult to get out, so you will need to have a plan B.

Here are some exercises that can be easily done at home.

Arm Wings

- Stand or sit with hand weights or water bottles
- raise your arms out to each side to shoulder height and then lower
- repeat as often as you are comfortable.



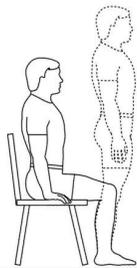
Step Ups

- Hold onto the rail and keep legs shoulder width apart
- step up onto the bottom step of the stairs
- step down again
- repeat as often as you are comfortable.



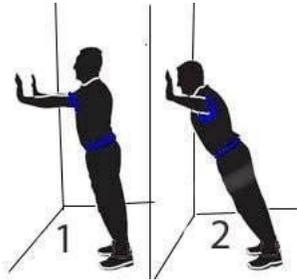
Sit to Stand Exercise

- Stand from a seated position
- Keep your feet shoulder width apart
- repeat as often as you feel comfortable.



Wall Press

- Stand in front of a wall and lift your arms up to shoulder height
- place your palms against the wall so that they are slightly wider than your shoulders
- lean your body forward but keep your back straight
- push off the wall until your arms are in an outstretched position with elbows slightly bent
- repeat as often as you are comfortable.



You can contact COPD Support Ireland to check out if there are exercise classes in your area with the local COPD Support Group.

Exercise has a similar shelf life to that of milk - if you don't keep it fresh it goes sour very quickly.

5.3 Pulmonary Rehabilitation



"It's provided me with the tools to help me live better with my condition"

Pulmonary rehabilitation (PR) is one of the most important things you can do to better manage your COPD. It is usually a 6 to 8 week group programme with two structured exercise sessions a week. You will work with a team of healthcare professionals who will help you to exercise safely and to manage your COPD better. The knowledge and skills you gain during the 6 to 8 weeks will help you to stay healthy and active long after you complete the programme.

The PR programme will cover different aspects of managing your COPD:

- airway clearance
- medications
- nutrition

- coping with breathlessness and relaxation techniques
- Oxygen treatment if needed
- pacing yourself, learn how to do everyday tasks with less shortness of breath and
- how to stay healthy and avoid COPD flare ups (exacerbations).

In addition, you will also meet people with COPD, who have many of the same experiences, questions and feelings that you do.

You may only be able to begin exercising at a slow pace. You will start at 30 seconds for each exercise. **This is okay.** If you require supplemental oxygen you can use it. Your oxygen level, heart rate and blood pressure will be monitored so you can exercise safely and effectively. You will be amazed at how much you can achieve through the classes.

What Can I do?

You should speak to your healthcare professional and ask to be referred to a local pulmonary rehabilitation programme. You will be assessed by the PR team prior to starting on a programme. These assessments will be completed again at the end of the programme.

It is important that everybody that is suitable for PR tries to attend a programme. It is also vitally important that you keep doing what you have learned so that you continue to get the benefits of regular exercise, either at home or at a local exercise class in your area.

5.4 Energy Conservation

Energy Conservation is changing the way you do activities to reduce the amount of energy needed. Success in energy conservation depends on how well you plan your day by keeping a balance of work, rest and play.

To conserve energy, follow the 4 P's:

- Prioritise
- Pacing
- Planning
- Posture

Prioritise

- Make a list of what you have to do
- Prioritise tasks into what you need to do, want to do and should do
- Eliminate any unnecessary tasks
- Decide if someone else can do some tasks for you
- Alternate between light and heavy tasks.

Pacing

- Work at a slow steady pace
- Allow plenty of time for rest and relaxation, at least 5 – 10 minutes every hour
- Use shortness of breath as a guide
- Space difficult and strenuous tasks evenly throughout the week.

Planning

- Modify activities to reduce the effort you need to do the job
- Sit rather than stand when possible
- Organise yourself, your home and your working environment
- Put items you frequently use in a convenient place
- Consider using a bag or basket to carry things
- Plan tasks around when help is available and when your energy levels are high.

Posture

- Push or pull objects, rather than lifting
- Use with your legs, not your back
- Use your strongest, largest joints
- Minimise your arm movements
- Avoid bending, reaching or twisting.

What can I do?

- Follow the 4 P's
- Eliminate unnecessary tasks

- Remember that just because you can't manage to do all the activities you used to, it doesn't mean you can't live a full life.

6. Management & Treatment of COPD

6.1 COPD Medications

You may be prescribed several types of medicines to improve symptoms of breathlessness and help to prevent exacerbations (flare ups). Your healthcare professional (GP, Respiratory Nurse, Consultant) will decide with you which medications to use depending on how severe your COPD is, or what your everyday symptoms are.

Inhalers

Short Acting Inhaler: these can be used if you become short of breath occasionally or during activity as a reliever. They can be taken by inhaler, with a spacer device and more often during exacerbations or flare ups.

Long Acting Inhaler: these can be prescribed if you get breathless daily. They take longer to work but the effects last longer - between 12-24 hours. They can contain one drug or a combination of drugs depending on your symptoms.

Inhaled Steroids: steroid inhalers may be prescribed if you have more severe COPD or if you get a lot of exacerbations or flare-ups. They are usually combined with a long acting Inhaler. They may help to reduce inflammation and swelling in the airways or the lungs.

Types of inhaler devices



- There are many different types of inhalers available. Your healthcare professional will decide which one(s) are best for you in the management of your COPD. It is important to discuss how to use the inhaler correctly with your healthcare professional.
- Dry Powder Inhalers
- Meter Dose or gas/spray Inhalers
- Spacers attach to the meter dose and spray inhalers and help to deliver inhaled medication better into our airways
- Nebuliser (only if prescribed by your healthcare professional) - remember a spacer device is just as effective
- If you do not like your inhaler or you do not take it consistently discuss this with your healthcare professional.

Other Medicines for COPD

- **Oral medication:** Theophylline (Uniphylline) can be used to open the airways, but inhalers are first choice in stable COPD as they have fewer side effects.
- **Medicine to loosen your phlegm:** this usually comes in the form of a cough bottle or occasionally a tablet and helps to make the phlegm less sticky so it is easier to cough up. It needs to be taken regularly to be effective.
- **Steroid Tablets:** these may be prescribed if you are starting or have an exacerbation. They help to reduce the inflammation in the airways and help to reduce breathlessness. Take in the morning as prescribed as they can affect sleep.
- **Antibiotics:** These are usually prescribed if you have a chest infection or changes in your usual symptoms. To determine the correct antibiotic, a sample of

your phlegm may be sent to the laboratory to see what bacteria are causing your infection.

- **Long-term antibiotic:** occasionally long term antibiotics are prescribed for more severe COPD and if you continue to get frequent exacerbations or flareups despite taking all your treatment and making every effort to prevent them.
- **Oxygen:** this is considered a medicine and will only be prescribed if the oxygen in your blood is low. A special assessment must take place before it is prescribed.
- **Morphine based drugs:** are sometimes prescribed in very severe COPD to treat the symptoms of breathlessness. This needs careful consideration and assessment by your Doctor or healthcare professional.

What can I do?

There are several different types of inhalers and they come in different devices therefore it is important to:

- Familiarise yourself with your inhalers and make sure you can use them properly.
- Ask your healthcare professional or pharmacist to show you the correct technique.
- Use a Spacer device if you have a Meter Dose Inhaler (MDI) as it is much more effective than using the inhaler on its own - ask for one if you don't have one.
- If there are changes made to your inhalers, make sure you are happy you can use the new ones and ask if you should stop or continue the old ones.
- Be aware of the side effects of all your medication and tell your healthcare professional immediately if you develop any of these.
- Always bring a list of your medications with you to your appointments and your COPD Communication Card if you have one.
- There are very few side effects with inhalers but occasionally they can make you cough or you can get thrush in your mouth. If you develop any symptoms tell your doctor or healthcare professional - don't just stop taking them. Rinsing your mouth after using your inhalers will help prevent a sore mouth.
- When using a nebuliser, wash out the chamber of your nebuliser at the end of each use with warm water and washing liquid, rinse well and leave to air dry. Change the chamber as per manufacturer's advice and keep your machine clean.

- It is also important to wash your spacer as instructed and allow it to air dry.

6.2 COPD Communication Card

A COPD Communication Card given to you by your healthcare professional can be a guide to recognising and managing an exacerbation (flare up). This will contain all the information relevant to your COPD and an action plan for you to follow on a Good/Normal day, a Bad Day or if you are feeling Unwell or Very Unwell.

COPD Self-Management Plan - sample

<p>——</p> <p>You are able to carry out your usual activities... your phlegm is a normal colour and amount for you</p>	<p>Continue with your medications as prescribed and continue your day as normal</p> <p>keep as active as possible</p>
<p>——</p> <p>Your COPD may be bothering you e.g. More breath less than usual</p>	<p>Use chest clearance techniques use your reliever inhaler use breathing control exercises</p> <p>If no relief you may be unwell Move on to orange section for guidance</p>
<p>——</p> <p>——</p> <p>More wheezy, breathless, More phlegm-yellow or green</p>	<p>are your normal medications and inhalers not working</p> <p>are your reliever medications every few hours</p> <p>Contact your Doctor or Out of Hours service for advice</p> <p>Call your COPD Outreach team or COPD Support Ireland Adviceline for advice</p>

<p>_____</p> <p>If your reliever and rescue prescription are not helpful or you feel worse</p>	<p>If you are able to attend your Doctor then go to the hospital Emergency Department</p> <p>If you are short of breath at rest, have chest pain or confusion this is an emergency</p>
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6.3 Coping with Breathlessness

A common symptom of COPD is breathlessness. Breathlessness is feeling short of breath (SOB) or having trouble breathing. Many daily tasks can make you breathless such as walking, getting dressed, climbing stairs or doing jobs around the house. It may feel uncomfortable and being breathless can make you panic or feel frightened.

Taking control - What can I do?

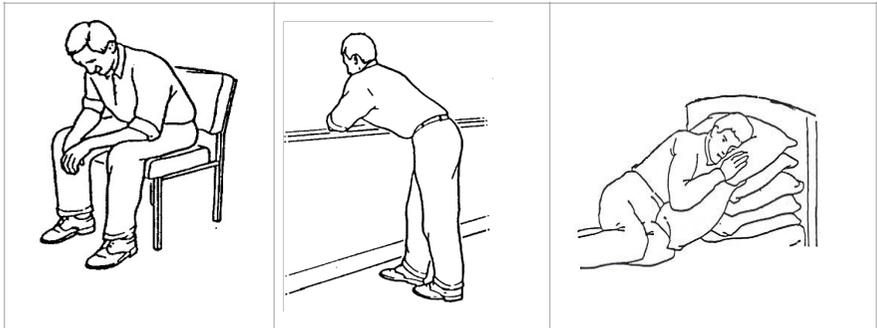
- **Do not hold your breath** this will make you feel more breathless.
- **Do not avoid** doing the things that make you breathless. When you learn how to control your breathing these feelings will not trouble you as much and you will be able to do more.
- **Do not panic** when you get breathless, your breathing will settle.

Use the following 3 steps to control your breathing:

STEP 1- Positions of ease

- These are positions that help you breathe more easily.
- They help to put your breathing muscles in a better position.
- They help you to relax your shoulders.

Sitting forward leaning	Standing forward leaning	Side lying
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STEP 2- Pursed-lip breathing

Breathe in slowly: it may help to count yourself, inhale for the count of 2, one, two.

Pucker or purse your lips: as if you are going to blow out a candle.

Breathe out: slowly and gently through your pursed lips while counting to four. It may help to count to yourself, exhale for one, two, three, four.



STEP 3- Reliever inhaler

Use a reliever inhaler if you have been prescribed one (for example: Salbutamol/Ventolin).



6.4 Airway Clearance

A common symptom of COPD can be excess production of mucous (phlegm) in the lungs, which can often be hard to clear. Excess build-up of phlegm in the lungs can lead to chest infections.

What can I do?

- There are number of airway clearance techniques, please ask your Physiotherapist for further advice on a technique which best suits you.

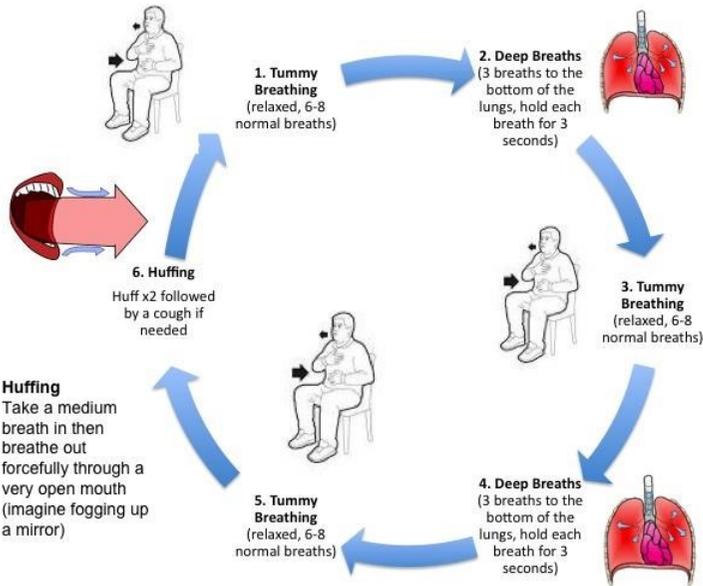
- The Active Cycle of Breathing Technique (ACBT) is a set of breathing exercises, which is used to help loosen and clear any phlegm you may have. (See below diagram)

It is good practice to clear your chest with these exercises every morning and evening if you suffer from excess build-up of phlegm. This might need to be increased to every 1-2 hours when you are feeling unwell and have lots of phlegm.

Repeat until your chest is clear and you no longer feel the “rattle” of phlegm.

Stop if you become tired or your chest feels wheezy or tight. Return to the exercises later when you are feeling better.

Sit comfortably and relax your shoulders.



6.5 What are exacerbations/flare ups?

Sometimes with COPD your usual symptoms might become worse or you may develop new symptoms. This can happen quite quickly or over the course of a few days. These episodes are called exacerbations or flare ups and are usually triggered by inflammation in the lungs, infection or irritants including: chest infection, flu, air pollution, smoke or seasonal allergens.

Often there is a pattern to how a flare up starts. You need to recognise what that looks and feels like for you, it might be that:

- There is an increase in the amount of phlegm you normally cough up.
- The colour of your phlegm is changing colour.
- You can't walk as far as you did the day before. For example, yesterday you could walk from your bed to the bathroom but today you need to rest half way.
- You feel you are getting a cold or flu.
- You can't lie down or sleep very well.

During an exacerbation or flare up:

- You may feel **more breathless** or feel you are not getting enough air in.
- Your cough is getting worse or you have developed a **new cough** – it can be dry or bringing up more phlegm.
- You might cough up more **phlegm** or the colour of your usual phlegm might change or become stickier.
- You may become **wheezy** or hear different noises when you are breathing.
- You might find it more **difficult to sleep** because you are short of breath or coughing more.
- You might feel **sleepier** during the day.
- Your ankles may become **swollen** or more swollen.
- You might develop a **temperature**.

More severe symptoms of exacerbations include:

- Chest pain.
- Blue lips or finger nails.
- Feeling confused or disorientated.
- Too breathless to talk.

What to do after an exacerbation:

- It can take a while to fully recover following an exacerbation or flare up and this can vary for each individual.
- For some people this recovery can be slow or can take up to six weeks. It is important that you continue to take all your medication as prescribed and follow your COPD Self-Management Plan

What can I do?

-
- Get your Flu vaccine yearly and the Pneumonia vaccine (Section 6.8).
- Quit smoking if you are a smoker and make your house a smoke free zone.
- Take all your medication including your inhalers as prescribed and check your inhaler technique regularly with your healthcare professional.
- Do your airway clearance as advised by your healthcare professional.
- Avoid crowded places during the cold and flu season.
- Avoid exposure to lung irritants such as smoke or sprays, aerosols and fumes.
- Wash your hands regularly and use hand sanitizers when you can't wash them.
- Drink enough water to stay hydrated and keep your phlegm from becoming thick or sticky.
- Take regular exercise, eat well and get a good night's sleep.
- Attend your clinic appointments.

6.6 Oxygen

Oxygen is used for some patients suffering from COPD. For some COPD can lead to low levels of oxygen in the blood. Tests for low blood oxygen levels include a fingertip probe, known as pulse oximetry, or a blood test taken from the artery in your wrist, called an ABG. If you have continually low levels of oxygen in your blood this can cause damage to organs such as the lungs and heart. To prevent this you may be prescribed home oxygen by your doctor.

There are different types of home Oxygen equipment and your healthcare professional will help you decide which type will be best for you. If you are prescribed Oxygen for use at home, called long term oxygen therapy or LTOT for short, you must use it for at least 15 hours per day a day as this will give you the most benefit.

The equipment is designed to allow you to move freely around your home. Oxygen can also be prescribed to assist you when you are out and about. This is called ambulatory oxygen therapy or AOT and should be used as advised by your healthcare professional.

Oxygen may be prescribed when you are discharged from hospital and then discontinued once you have recovered from your current exacerbation. It is important to have a follow up appointment with your doctor or nurse to check.

Home oxygen is a drug so it is important to use it as prescribed. Not using your oxygen can make you more unwell but so can using it incorrectly. It is especially important not to increase the flow rate as this can cause serious side effects and will not help your COPD.

If you are prescribed home oxygen by your doctor it is important to remember the following safety tips.

- Look after your equipment and follow the instructions provided by your oxygen supplier.
- Do not expose your oxygen to naked flames or other heat sources.
- Do not smoke near oxygen equipment.
- Store oxygen equipment safely, your oxygen supplier will provide advice.
- If you are not using your oxygen, turn it off. Be especially careful not to leave oxygen tubing, with oxygen flowing through it, on beds, soft furnishings or even your lap.
- Ensure you have working smoke alarms and a fire extinguisher in your home.

6.7 Non-Invasive Ventilation (NIV)

Some people with COPD may find breathing extremely difficult as the lungs and the chest muscles work harder and harder for each breath. When we inhale we breathe in oxygen, this is used by all the cells in our body to make energy. This process creates Carbon Dioxide (CO₂) gas which is carried in the blood to the lungs where we exhale it into the air. If your lungs and chest muscles are overworked they become less efficient at taking oxygen in and breathing out carbon dioxide.

Signs of this include feeling tired and sleepy and sometimes a bit confused. To assist with your breathing and give your lungs some relief your Respiratory Team may prescribe a BiPAP® machine.

BiPAP® machines provide relief to overworked lungs and chest muscles by supplying air to the lungs at a higher pressure as you breathe in. This helps to keep the airways open reducing the amount of energy it takes to breathe and ensures a steady supply of oxygen to the body. When you breathe out the machine drops its pressure so that you can breathe out easily. These 2 different levels of pressure will be prescribed by your doctor to suit your own personal needs and adjusted if required.

BiPAP® is usually used at night time but can be used during the day if needed. Getting used to BiPAP® can be difficult and you may experience some or all of the following side effects.

- Dry, blocked, irritated nose.
- Discomfort.
- Claustrophobia.

It is important to discuss these problems with your doctor or nurse. They will help you manage these problems allowing you to continue your treatment.

6.8 Vaccines

People with COPD are more at risk of catching the flu and pneumonia, both of which can be very serious and affect your breathing. You can protect yourself from both of these diseases by getting vaccinated. This is when small quantities of inactivated organisms which cause the flu or pneumonia are injected into the body. This does not cause the flu or pneumonia but encourages your body's immune system to produce antibodies, allowing it to fight off infection.

The Influenza (Flu) vaccine

The flu is a highly infectious disease, so you need to have your flu vaccine every year - September or October time is best. Remember it will take 10-14 days for the vaccine to start protecting you against the flu.

You might experience some side effects such as soreness and redness at the injection site. These usually go away in a day or so.

The Pneumococcal (Pneumovax) vaccine

This protects against infections such as pneumonia, caused by a group of bacteria called Pneumococcal bacteria. Like the flu vaccine this vaccine encourages your immune system to make antibodies. Unlike the flu vaccine you do not need to get it every year. All those over 65 regardless of any underlying disease need one dose of vaccine. Under the age of 65, most adults in risk groups which includes COPD, require one dose of vaccine and another after they reach the age of 65 but there needs to be 5 years between the two vaccinations. You can talk to your healthcare professional.

7. Nutrition: COPD, Nutrition and Me



Why does nutrition matter when I have COPD?

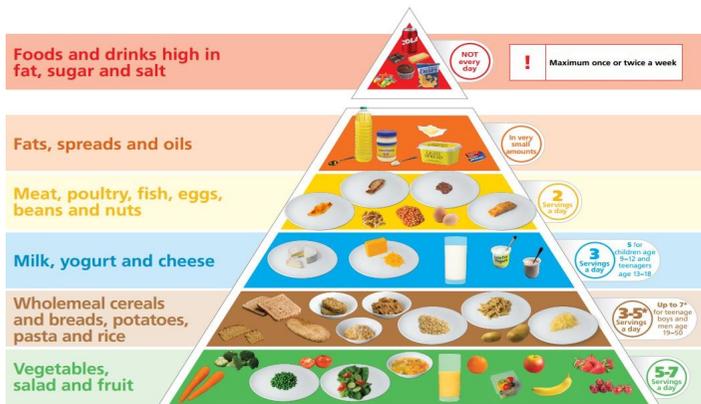
Nutrition plays an important role in the management of COPD. It won't cure COPD but the right nutrition can help you feel better, make your body stronger and support your body to fight infections.

Good nutrition can:

- Provide the energy your body needs to breathe.
- Promote a strong immune system to help you prevent and fight infections.
- Help you reach a healthy weight.

What can I do?

Basing your daily intake around the food pyramid is a good way to ensure you are getting the nutrients your body needs. Variety is important as different food groups contain different nutrients.



- **Vegetables, salad and fruit** contain antioxidants, which fight harmful free radicals and can help maintain your immune system.
- **Cereals, breads, potatoes, pasta and rice** provide valuable energy to our bodies.
- **Milk, yoghurt and cheese** products contain calcium, which is essential for healthy bones. This is especially important if you take steroids as they increase bone loss.
- **Meat, poultry, fish, eggs, beans and nuts** contain protein which is important to build and maintain muscle.
- **Fats, spreads and oils** are high in energy and provide vitamins, such as vitamin D which we need to absorb calcium.
- **Confectionary for example: cakes, crisps, fizzy drinks** provide very little nutrition other than sugar, fat and empty calories.

I've lost weight without trying, what can I do?

Many people with COPD can experience a poor appetite. It is very common to feel full more quickly and be put off by certain foods. When you have COPD your body needs extra energy just to breathe and even more energy to fight an infection. This means you might lose weight without trying. Losing lots of weight quickly without trying can put your body at risk of malnutrition and can make you feel weaker and more fatigued.

If you have lost more than 3kg or half a stone in the last 6 months you should discuss this with your doctor who may refer you to your local dietician. If you are unable to get all the nutrition you need through food and drinks, oral nutritional supplements may be useful.

Here are some tips which may help a poor appetite:

- **Eat little and often:** choose smaller meals and snacks.
- **Try to eat something**, no matter how small, at every mealtime.
- **Avoid drinking** for a half hour before and during meals as this can make you feel fuller more quickly.
- Try to **eat a protein food** twice daily e.g. cheese, meat, chicken, fish, eggs, beans, pulses or nuts.
- **Fruit and vegetables** can be filling and low in calories, when your appetite is poor don't fill up on these foods too much.
- Add **extra butter, cream or cheese** to foods, this increases the calories but not portion size.
- Try to have a **pint of full fat milk each day** - milk is great by itself or used to make a white coffee, hot chocolate or other milky drink.
- If the energy it takes to prepare food and drink makes you short of breath choose items that are **quick and easy to prepare** such as ready meals, tinned and frozen foods.
- If you **smoke try to avoid it** just before meal times as this can reduce your appetite even more.

What if I'm trying to lose weight?

You may find it's more difficult to manage your weight when you have COPD. If you are very overweight your heart and lungs have to work harder to supply oxygen to the body, which can limit your ability to carry out everyday activities.

It can be more difficult to manage your weight for lots of reasons. You may be less active than you used to be. Some medications may affect your weight also. Steroids are important medications in managing COPD. They decrease inflammation in the

airways, making breathing easier, but they can also increase your appetite, making it more difficult to watch your weight.

Here are some tips to help you lose weight or reduce weight gain

- Write down or reflect on why you want to lose weight, this helps motivation.
- Don't skip meals; you're less likely to overeat if you have regular meals.
- Keep a diary; keep track of what you eat and drink, your weight or physical activity.
- Keep foods on the top shelf of the food pyramid to a treat, rather than every day.
- Fill up on fruit and vegetables: they're low in calories and high in important nutrients.
- Watch your portion sizes: most of us eat too much.

If you would like support to lose weight you should discuss this with your doctor who may refer you to your local dietician.

Other issues which may affect your nutrition

Dry mouth

You may find your mouth feels very dry. Oxygen treatment, some inhalers and breathing through your mouth can all cause a dry mouth. Having a dry mouth can make food less appealing and make it more difficult to chew and swallow food. Your sense of taste may change also. Here are a few tips which may help:

- Make sure you are drinking enough fluids - try sipping throughout the day and while eating.
- Suck on sugar free hard-boiled sweets or chewing gum.
- Suck on ice cubes or frozen fruit pieces.
- Choose softer, moist foods, such as stews, soups and casseroles.
- After using inhalers try rinsing your mouth out with water.
- Avoid alcohol, alcohol-based mouthwashes, caffeine and smoking as these can all make a dry mouth worse.
- Talk to your pharmacist about artificial saliva options.

Bloating and trapped wind

Many people who are breathless gulp air when eating which can cause bloating. If this is something you experience it may help to:

- Eat smaller meals more often.
- Ensure you are sitting upright at mealtimes in a relaxed environment.
- Take your time, smaller bites and try not to eat on the move.
- Try not to have too many fizzy drinks or chew chewing gum.
- Peppermint tea or peppermint cordial may help with bloating and trapped wind.

Reflux

When you have COPD you are more likely to develop oesophageal reflux. It is caused by acid from the stomach leaking up into the food pipe, oesophagus, causing you pain.

If you are very overweight losing weight has been shown to help to reduce reflux. Avoiding lying down too soon after eating may also help your reflux.

Some people, not everyone, find that reducing the following may also help with symptoms:

- Alcohol
- High fat foods
- Carbonated beverages such as fizzy drinks
- Coffee and high caffeine drinks
- Citrus fruit/ juices
- Spicy foods
- Eating late at night.

It's important to only exclude food and drink which have an impact on your symptoms.

Constipation

Many people with COPD will experience constipation at one time or another. This can result in you feeling sluggish, uncomfortable and can reduce your appetite. It

is important to discuss this with your healthcare professional. If this is something you experience it may help to:

- Stay hydrated and aim for at least 6 - 8 cups of fluid per day, drinks such as water, tea, coffee, milk and juice all count.
- Choose the brown wholemeal options wherever possible such as bread, cereals, pasta or rice.
- Add seeds or bran to foods to add extra fibre.

What can I do?

- Eating a variety of foods in the portions that suit you best is a good place to start.
- Ask your healthcare professional to refer you to a dietician if you are concerned about any of the issues covered in this booklet or require further advice.

8: Mental health and wellbeing

COPD and my mental wellbeing

Many people with COPD enjoy a good quality of life. The more you understand your condition and are actively involved in managing it, then the better your quality of life will be. Managing your COPD means that you need to **manage your mental wellbeing as well as your physical symptoms**. Some people may experience problematic levels of stress, anxiety and depression. For example, some patients don't want to go out because they feel worried that they will get breathless and start coughing, and that people will stare at them. This type of belief can stop you doing the things in life you enjoy and can stop you from keeping well. It is important that you are able to recognise when you feel stressed, anxious or depressed so that you know you will be in control so that you can manage your own mental wellbeing.

Anxiety and Stress

Stress can be present in our lives when we feel that we cannot meet the demands that are placed on us. Living with COPD can place lots of different types of

demands on you. For example, when symptoms feel worse or we feel alone, we might not feel able to cope and then feel anxious. Anxiety is more than just feeling stressed or worried; it can have a disabling effect on your life. Stress and anxiety can negatively affect our body and some common physical symptoms to watch out for are:

- 1) shortness of breath
- 2) tiredness
- 3) sleep problems
- 4) headaches
- 5) muscle tension
- 6) racing heart
- 7) hot and cold flushes

Stress and anxiety also have emotional effects: people can feel

- 1) Fear and worry
- 2) Panic
- 3) Tense and nervous
- 4) Distressed

These physical symptoms and emotions can influence each other. For example, 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. This cycle shows how our thoughts about symptoms can cause emotions, which can cause behaviours that can make it hard to keep well.

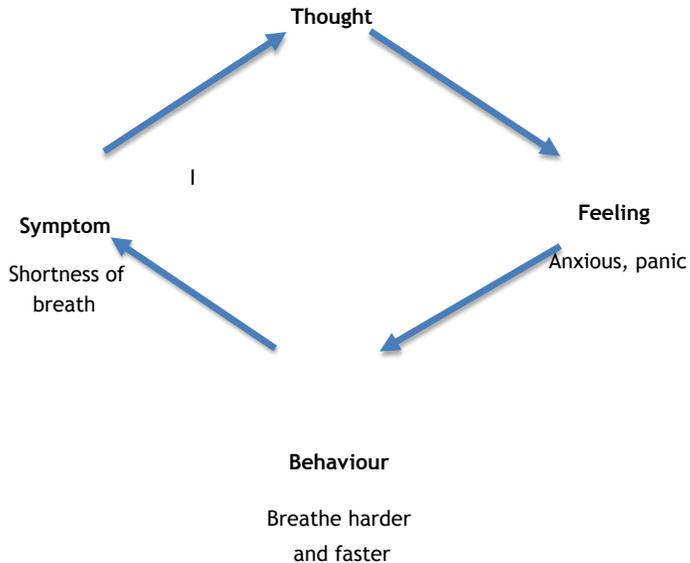


Figure 1. Cycle of thoughts, feelings, behaviours and symptoms.

Depression

COPD has a significant impact on your life and it is normal to feel sad and helpless at times, especially during exacerbations. The ongoing stresses can make you feel depressed. Although we all feel sad at times in life, depression is where the strong emotional effects last for a couple of weeks; common signs include:

- 1) withdrawing from other people
- 2) lack of enjoyment in activities you used to enjoy
- 3) feeling sad and worthless nearly all of the time
- 4) feeling irritable, frustrated and moody nearly all of the time
- 5) feeling guilty and helpless nearly all of the time
- 6) finding it hard to concentrate
- 7) changes in eating (either too much or too little)
- 8) changes in sleeping (either too much or too little)
- 9) decreased interest in sex and intimacy

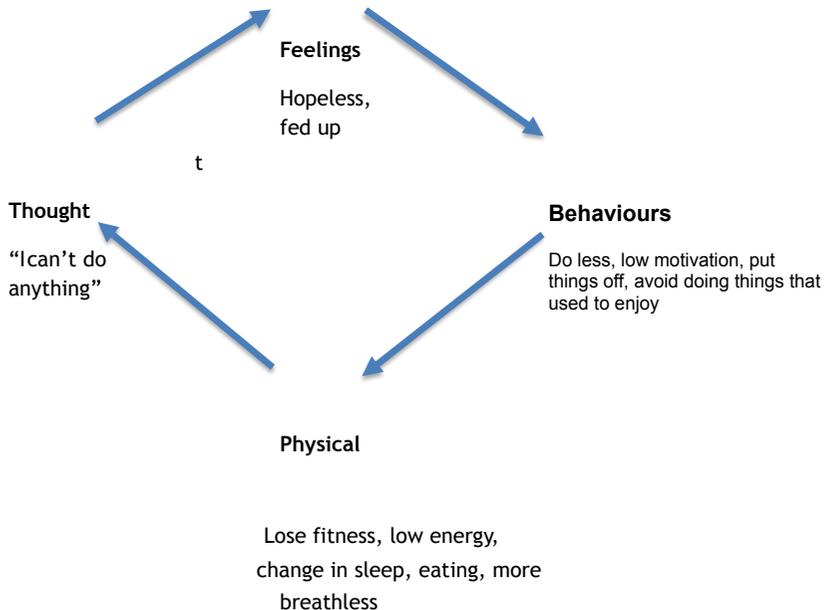
10)increased use of alcohol and cigarettes

Depression affects how you think and feel about yourself. Our thoughts influence our feelings, which influence our behaviours.

Thinking that you cannot do anything can make you feel hopeless, fed-up and sad. These feelings then make you do less, which means you end up feeling more tired, being more breathless, and having less energy. Feeling more tired and more breathless can make you feel like you can't do anything.....and so the cycle starts again.

It is important to understand the connection between thoughts, feelings, behaviours and physical sensations. For example, feeling embarrassed to be with other people might make you withdraw from being with others; but this can make you socially isolated, which reduces your social support, can impact on your ability to selfmanage the disease, and can make you feel depressed.

The important thing to remember is that **your thoughts, feelings and behaviours can be changed.**



Managing mood

Managing your mood is as important as managing your physical symptoms of COPD. Untreated depression and anxiety can result in more frequent and longer hospital stays when your symptoms flare up and reduce your quality of life.

Managing your mood helps you keep well, keep active and enjoy life.

There are plenty of effective things we can do to help manage stress, anxiety and depression.

- 1) **Talk to your GP or consultant.** A General Practitioner (GP) is a good first step to discuss your concerns. It can be difficult to discuss your feelings with others, but your GP can:
 - a. make a diagnosis after your check up
 - b. discuss available treatments
 - c. refer you to a mental health specialist for psychological treatment
 - d. provide brief counselling or, in some cases, psychological therapies
 - e. prescribe medication

You can plan with your GP about how best you can manage your emotional well-being.

- 2) **Talk to a mental health professional** such as a clinical psychologist. Psychological therapies not only help with recovery, but can also help prevent a recurrence of stress, anxiety or depression. These therapies help build skills in coping with stressful life circumstances and managing your emotions.
 - For example, cognitive behaviour therapy (CBT) is an effective treatment for people with stress, anxiety and depression. It teaches you how to evaluate your thinking and coping about common difficulties and helps you to change these. The cycles of distress can be broken.
- 3) **Medication** can help manage symptoms of anxiety and depression. Medication in combination with psychological therapies can be very beneficial.

Tips to keep you well

As you are different to other people with COPD, the things that help keep you well will be different to those that keep other people well. Everybody has good and bad days. The following is a list of tips and suggestions that can help maintain your mental wellbeing and keep you well.

- 1) Routine:** Having a regular routine helps maintain balance and increases your sense of control. In your routine, you should have a healthy balance of activities you need to do as well as fun activities that you want to do and can look forward to. Taking part in enjoyable activities can give you a sense of meaning and can help you maintain and enhance your skills and abilities. These don't need to be energetic, expensive or adventurous. Examples might be phoning or visiting a friend, going to the cinema, painting, cooking, doing an evening class, taking a walk every day
- 2) Be active:** Physical activity is good for people with COPD. Plan regular activity (e.g., walking, cycling) into your routine to keep your fitness level up. Make a plan for how you can build up your activity level gradually and pace yourself in working towards your goals. Talk with your doctor about the type, frequency and intensity of exercise that is right for you. You may be able to join a Pulmonary Rehabilitation Programme at your local hospital. Getting out of breath during activity is normal. It helps the heart and lungs become healthier and fitter. There are numerous benefits of being physically active. If possible, exercise earlier in the day so as not to disturb your sleep.
- 3) Eat and drink well:** Eat healthily and include a wide variety of nutritious foods. Don't use alcohol or cigarettes to manage stress.
- 4) Sleep well:** have a regular bedtime and routine before going to sleep. Frequently not sleeping well can make us feel exhausted, irritable, stressed and depressed.
- 5) Be social:** get out regularly to catch up with friends and family. If you cannot get out, ask them to call round or to phone to chat. Get help, support and encouragement from family and friends. Don't be afraid to ask for help from a

family member, friend or professional. Accepting help from others strengthens your ability to cope. Get involved in social activities. Consider joining a patient support group. **6) Be mindful and aware of your automatic and unhelpful thinking.** When you feel stressed or anxious, you may respond to thoughts too quickly. Take some time and ask yourself if there are other ways in which you can think about a situation. You can break a harmful cycle of thoughts, feelings and behaviours. Think about what you can do to manage the situation to keep you well. When you are 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.

- 7) Focus on things you can control.** When you are not doing as well as you would like at a particular behaviour, avoid focusing on the things you cannot control as this can lead to feelings of hopelessness. Instead, focus on what can be changed and change them. This can foster positive feelings of hope and persistence at the task.
- 8) Relax:** plan time in the day for you to relax. Relaxation can be formal (e.g., deep breathing, muscle relaxation) or informal (watch TV, listen to music, reading)
- 9) Have goals:** A goal is something that we aim for that gives us a sense of focus and keeps us motivated. It is important that it is personally meaningful to you. It could be something like visiting a friend/neighbour, going to a social event, doing the gardening, or walking to the shops. The goal should be achievable and enjoyable.

Break the big goals into smaller steps. They are easier to complete and it's easier to see your progress. These provide a gradual sense of accomplishment that can motivate you to continue. Pace yourself in achieving the goal: it will take time, you need to go at your pace, and remember you are not competing with others. Expect good and bad days, and after a bad day, it is important try again. Working towards a goal and achieving it helps build confidence and makes us feel better.

- 10) Write things down.** Keeping a diary or simply writing down a thought can greatly help to cope with problems. Write things down to help show you how you think about your situation. It allows you to organize your thoughts and to look at

the situation as an outsider. You can re- write it, come back to it later or simply throw it away when you're finished.

11) Knowledge: learn about your COPD, stress, anxiety and depression. Being aware of signs and symptoms helps you understand what is happening

12) Visit GP: Visit your doctor regularly to review your COPD and mental health. They can work with you to ensure you stay well and live well.

Remember, your mental health is just as important as your physical health. You can keep well, cope with your COPD and enjoy a good quality of life.

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