

COPD & Me
Information Booklet



NATIONAL CLINICAL PROGRAMME RESPIRATORY



COPD
Support Ireland
www.copd.ie

www.copd.ie

FACEBOOK
[@COPDSupportGroupsIreland](https://www.facebook.com/COPDSupportGroupsIreland)

TWITTER
[@COPDSupportIre](https://twitter.com/COPDSupportIre)

info@copd.ie

COPD Adviceline
1800-832146

COPD Support
Ireland Office
086-0415128



COPD
Support Ireland
www.copd.ie

Contents

Glossary of terms	2
Foreword	3
1. What is COPD?	4
2. Diagnosing COPD	5
2.1 Risk Factors	5
2.2 Symptoms	6
2.3 Investigations	7
3. Self-Management	9
4. Stopping Smoking	11
5. Exercise, COPD & Me	13
5.1 What happens if I don't exercise	13
5.2 Exercises to do at home	15
5.3 Pulmonary Rehabilitation	17
5.4 Saving your Energy	18
6. Management & Treatment of COPD	20
6.1 COPD Medications	20
6.2 COPD Self Management	22
6.3 Coping with Breathlessness	24
6.4 Clearing Phlegm	26
6.5 What are flare ups	27
6.6 Oxygen	29
6.7 Non Invasive Ventilation (NIV)	30
6.8 Vaccinations	31
7. Food, Nutrition & COPD and Me	32
8. Mental Health & Wellbeing	37
9. Caring for a loved one living with COPD	44
10. COPD Support Ireland Programmes & Supports	46
Appendix	48
11. References	51

Glossary of terms

Alpha-1	Antitrypsin Deficiency (Alpha-1) is a genetic (inherited) condition which can lead to a lung disease similar to COPD. It is often called "genetic COPD".
COPD	Chronic Obstructive Pulmonary Disease
Care Plan	A written plan of your individual needs
Self-management plan	A plan to teach you how to monitor and manage your COPD
Spirometry test	A test used to measure how well your lungs work by measuring the air you inhale and exhale
Inflamed	This is the body's response to injury and infection, it includes pain and swelling
Chronic	Happening for a long time or keeps occurring
Cardiac disease	Diseases that involve the heart and blood vessels
Osteoporosis	A disease of the bones where the body loses or makes too little bone
Diabetes	Condition affecting insulin levels in the body that results in high blood sugar levels
Chest clearance	Techniques used to help you get phlegm off your lungs
ACBT	Active Cycle of Breathing Technique
Exacerbation	Flare up
NIV	Non- invasive ventilation
Spacer	This is a device that attaches to a meter dose and spray inhalers and helps to deliver inhaled medication better into our airways

Foreword

September 2021

On behalf of COPD Support Ireland I am very pleased to release this third edition of “COPD and Me” a comprehensive information booklet for people living with COPD and their carers. COPD is a huge problem in Ireland with approximately half a million people living with the disease according to HSE figures. Worryingly only half of these have been formally diagnosed. Between 2016 and 2018 there were 40,653 acute admissions to Irish hospitals because of COPD. (NHQRS Annual Report 2020).

You know the burden COPD places on people living with the condition and their carers. With proper treatment and support we can do much to improve the quality of life of people living with COPD. Because smoking is the major factor in causing COPD many people bear a degree of guilt on learning of their diagnosis. Recent research, however, has highlighted that there are a significant proportion of people living with the disease where other factors such as chronic asthma, air pollution, occupational exposures and family history have 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.

People living with COPD experience “flare-ups”, also called exacerbations, of their underlying condition. Through education and support these can be self-managed in the community thereby reducing hospitalisations. Much of the modern treatment of COPD is focused on reducing these exacerbations. This includes Pulmonary Rehabilitation which has an important role in improving quality of life for people living with COPD. A key aim of COPD Support Ireland is to see Pulmonary Rehabilitation available in a timely fashion, to all who are suitable and would benefit from it. This should be supplemented with follow on exercise programmes in the community. Physical activity is crucial to maintenance of wellbeing for people with COPD. Our national network of local COPD Support Groups can provide these exercise and education programmes as well as offering peer support. 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.

Professor Timothy McDonnell, FRCPI

Chair COPD Support Ireland

1. What is COPD?

Chronic Obstructive Pulmonary Disease (COPD) is a common, treatable lung condition. A person living with COPD will have persistent symptoms (for example cough and phlegm) and difficulty in breathing. COPD is a chronic disease so it 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 chronic bronchitis and is mainly due to exposure to harmful particles or gases that are inhaled, causing abnormalities to the airways and within the lungs. Tobacco smoking is the greatest cause of COPD. This means that the disease could be prevented by never smoking and/or by avoiding long term exposure to harmful fumes, dust or gases in the environment or work place.

If you are diagnosed with COPD, your healthcare team will give you a care plan which will help you in preventing flare ups of your symptoms. 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 book will assist you in caring for yourself if you have COPD, or if you are caring for someone living with COPD. It contains information on strategies to manage the symptoms of COPD as well as tips on living well with COPD.

2. Diagnosing COPD

The diagnosis of COPD is based on a combination of

- Your medical history
- A physical examination
- An assessment of your symptoms
- Results of a spirometry test which looks at the pattern of your breathing
- Symptoms such as breathlessness and chronic cough, with or without phlegm, and
- 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. The lungs become inflamed and you may develop a cough.

Other risks that can lead to the development of COPD include:

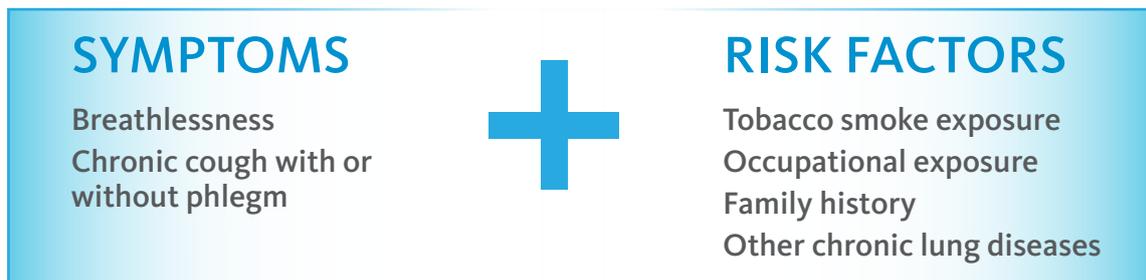
- Contact with (exposure to) indoor and outdoor air pollution, inhaling dusts, chemicals or fumes in the workplace over many years.
- Exposure to second hand tobacco smoke over many years
- An existing illness, such as chronic asthma. Some people who have never smoked develop COPD.
- Family history including hereditary conditions such as Alpha-1 antitrypsin deficiency.

2.2 Symptoms

- Chronic breathlessness which is getting worse is the most common symptom of COPD.
- Chronic cough with or without phlegm.
- 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 can worsen over time, and they can vary from day to day. A flare up happens when these symptoms worsen suddenly. This may be 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.



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 flare ups and/or previous hospital admissions for breathing problems.
- Other diseases including cardiac disease, osteoporosis and diabetes.

- 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 gives a score. This 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 listening to your breathing and lungs. These are important for general health and wellbeing.

Spirometry Test

Spirometry measures how much and how fast you blow the air out of your lungs after you have taken in a full deep breath. This test confirms 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.



Other investigations

Other tests may be necessary in some situations:

- Chest X-Ray and CT of the chest. A CT scan (Computed Tomography) scan allows the doctor to see images of the inside of your body.
- More detailed lung function tests in a Pulmonary Laboratory in the hospital.
- Pulse Oximetry which is a simple, painless way to check the amount of oxygen circulating in your blood. This is done using a monitor on your finger.
- Arterial blood gas which is a special blood test used to help decide on treatment. This is usually done at your wrist.
- 6 minute walk test – this tells us how far you can walk in 6 minutes and how walking for that time affects your oxygen levels, heart rate and breathlessness.

Please be aware that not all these tests will be available in your GP practice, many of them are carried out in the hospital or community setting only.

3. Self-Management

If you have a chronic condition like COPD, it can affect every part of your life and you may find that things you used to do can become more difficult. Self-management is about helping you to learn more about COPD, learning new skills 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. Your healthcare team will help you develop a COPD Self-Management Plan. This plan will help you to manage your condition when you are well and to be aware of your symptoms and know what to do in the event of a flare up of your COPD.

What can I do?

There is a lot you can do to manage your symptoms, prevent 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.

Stop Smoking: if you smoke, stopping smoking is the most important thing you can do to improve your health. If you stop smoking, this will improve your cough and phlegm production. There are many supports available to help you to stop. (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. Take care of your emotional health - there are supports available (Section 8).

Avoiding flare ups:	recognise your symptoms; know what is usual for you. Monitor your symptoms and make sure you know when you may need to change your medication or start treatment early for flare ups. You should know when and how to seek help. You can discuss this with your healthcare professional using a COPD Self-Management Plan to guide you (Section 6).
Breathing exercises and clearing phlegm:	use controlled breathing techniques and chest clearance techniques to help you get rid of phlegm and also help with relaxation techniques (Section 6.3 & 6.4).
Exercise:	regular exercise is important – even a small amount of exercise helps. Exercise contributes to improving your general feeling of wellbeing. It can also help you sleep better at night and it is very good in strengthening or maintaining strength in the big muscle groups the big muscle groups (Section 5).
Food & 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 a flare up (Section 7).
Vaccinations:	It is important that you get the flu vaccine every year and a pneumonia vaccination - your healthcare professional will tell you how often you need this and may also recommend other vaccines for you (Section 6.8).
Relaxation techniques:	relaxation techniques can help with breathlessness, feelings of anxiety or during times of a flare up.
Rest:	ensure you get good sleep and plenty of rest particularly during times of a flare up.

Equipment:

if you are using any medical equipment, for example nebulisers or oxygen, please make ensure they are serviced regularly, and that masks, mouthpieces and filters are cleaned and changed often.

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.

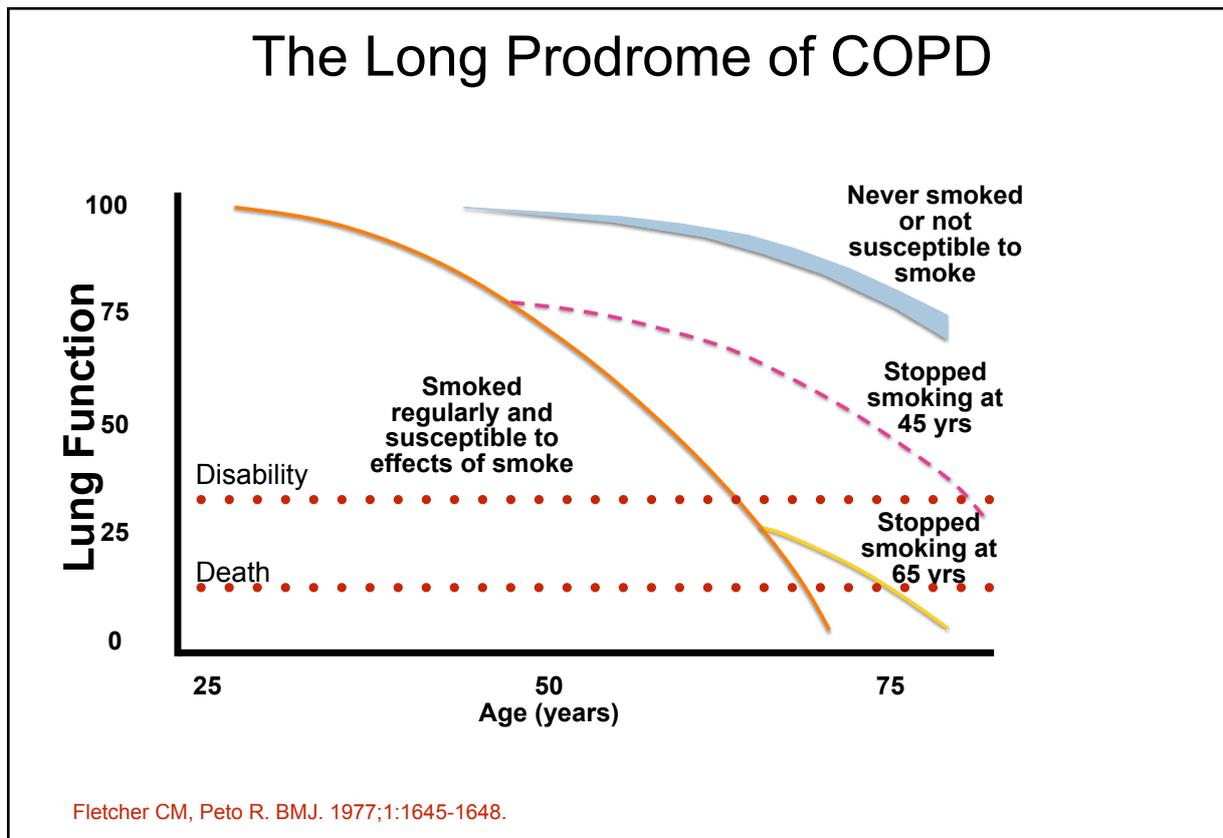
Bone health:

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. These can be monitored with you doctor and there are many things you can do to improve and maintain bone health. Exercise and vitamin supplements can be discussed 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. Stopping Smoking

If you smoke, stopping is the most important thing you can do to help your lungs and its never too late to quit.



This diagram shows the lung function of a person living with COPD over their lifetime. As we age, our lung function naturally declines, smoking accelerates this decline as you see with the orange line but quitting smoking halts it and allows lung function to decline naturally from that point onwards as seen with the yellow and pink lines. So its never too late to quit, and if you have tried unsuccessfully in the past, remember its a process and **don't quit on quitting**.

3 Steps to Quitting Smoking



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.
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.
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.

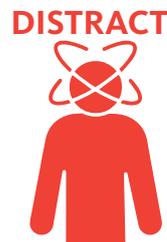
Learn to deal with cravings: the 4 Ds:



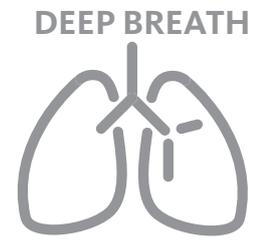
Delay at least 3 – 5 minutes and the urge will pass



Drink a glass of water or fruit juice



Distract yourself - move away from the situation



Deep breaths - breathe slowly and deeply

QUIT
National
Smokers'
Quit line

Find local HSE QUIT support groups on QUIT.ie or by calling the QUIT team. Tweet the QUIT team @hseQUITteam Join the Facebook page www.facebook.com/HSEquit Share your QUIT Story on the **QUIT Heroes App**

Freephone 1800 201 203 | Freetext QUIT to 50100 | www.quit.ie

5. Exercise, COPD and Me

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

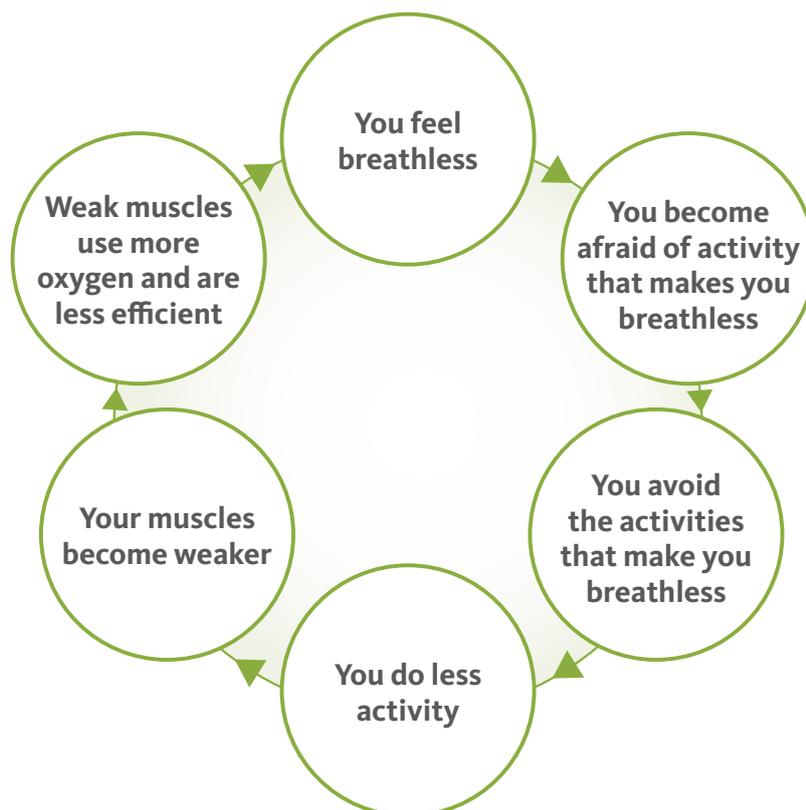
It’s very normal to feel this way if you’re short of breath with COPD. Exercise, done in a safe way, is one of the best things you can do to improve your breathlessness.

Many people with COPD find that being breathless is the hardest part of their condition to deal with. Breathlessness can cause 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 What happens if I don’t exercise?



"It may come as a surprise but breathlessness when you exercise is good for you"

It is a normal response to 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 need more oxygen to work. Exercising regularly can make your muscles stronger so that they need less oxygen to do the same amount of work. If you avoid activity that makes you breathless then muscles may weaken and this can cause more breathlessness.

Exercise cannot cure COPD, but it can change how you manage and experience your breathlessness, improve fitness levels and improve your quality of life. It has a positive effect 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.

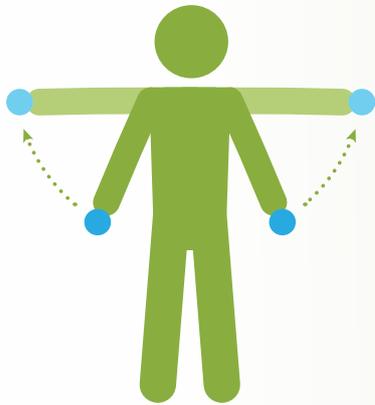
Tips for Safe Exercise

- 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 but not sing whilst exercising
- Stop the exercise if you become too breathless

5.2 Exercises to do at Home

Make some kind of exercise part of your daily routine. Walking 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 another plan.

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

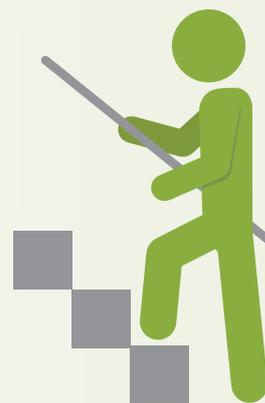


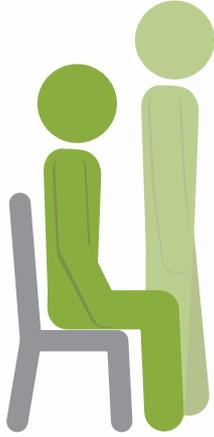
Arm Wings

- 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.



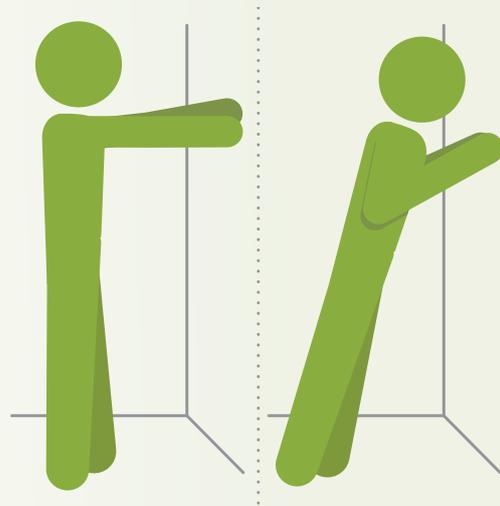


Sit to Stand Exercise

- 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 086-0415128 to check if there are exercise classes in your area with the local COPD Support Group.

"Exercise is like 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 group exercise sessions a week. You will work with a team of healthcare professionals who will teach and help you to exercise safely and to manage your COPD better. The knowledge and skills you gain during the class will help you to stay healthy and active long after you complete the programme.

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

- how to clear phlegm
- medications
- nutrition
- coping with breathlessness and relaxation techniques
- oxygen treatment if needed
- pacing yourself, learn how to do everyday tasks with breathlessness
- how to stay healthy and avoid COPD flare ups

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

When you start the class 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 oxygen in the class 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.

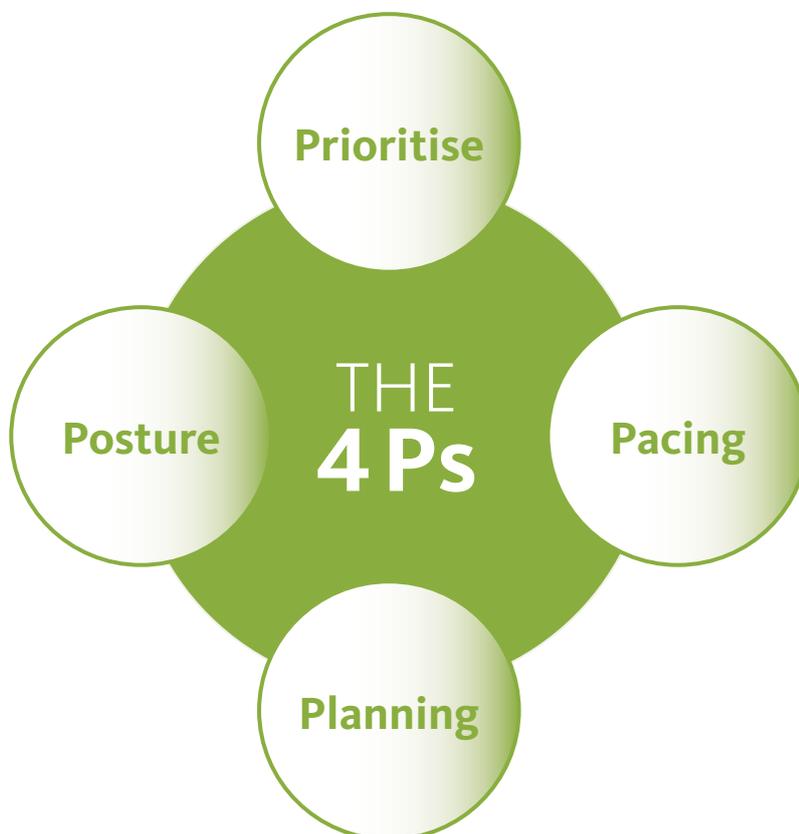
What Can I do?

You should speak to your healthcare professional to see if you are suitable for this class. They will then refer you to a local pulmonary rehabilitation programme. The team will do an assessment with you before starting on a programme and after finishing the programme. These assessments help to see the effects the programme had on you.

Pulmonary Rehabilitation teaches you how to manage your COPD. You will need to 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 such as the local COPD Support Ireland group exercise classes.

5.4 Saving your Energy

Saving your energy is changing the way you do activities to reduce the amount of energy needed. To be able to do this you will need to plan your day by keeping a balance of work, rest and play. This is called conserving energy.



To conserve energy, follow the 4 P's:

Prioritise

- Make a list of what you have to do
- Place the task in order of importance, into what you need to do, want to do and should do.
- Get rid of any unnecessary tasks
- Decide if someone else can do some tasks for you
- Change 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 breathlessness as a guide
- Space difficult and heavy tasks evenly throughout the week.

Planning

- Change the activities to keep the energy you use low to do the job
- Sit rather than stand when possible, use a perching or high stool when possible
- Organise yourself, your home and your working environment
- Put items you frequently use in an easy to reach 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 your legs, not your back
- Use your strongest, largest joints
- Keep your arm movements at a low rate
- Avoid bending, reaching or twisting.

6. Management & Treatment of COPD

6.1 COPD Medications

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

Inhalers

Short Acting Inhaler: These can be used if you become breathless occasionally or during activity. It is called a reliever. They can be taken by inhaler, with a spacer device and more often during flare ups.

Long Acting Inhaler: These can be prescribed if you get breathless daily. Some may 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 flare-ups. They can be combined with a long acting Inhaler. They may help to reduce inflammation and swelling in the lungs.



Types of inhaler devices

- There are many different types of inhalers devices available. Your healthcare professional will decide which one(s) are best for you and your COPD.
- **It is important to discuss how to use the inhaler correctly with your healthcare professional.**
- Spacers attach to some inhalers and help to deliver inhaled medication better into our airways.
- A Nebuliser may also be prescribed by your healthcare professional - **remember a spacer device can be just as effective.**
- If you do not like your inhaler or you have problems taking it or do not take it consistently, discuss this with your healthcare professional.

Other Medicines for COPD

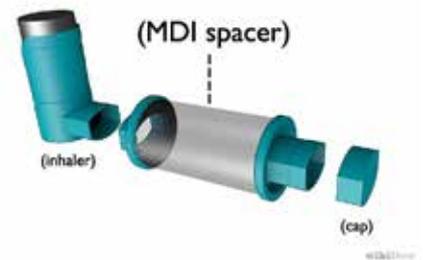
- **Tablets:** Theophylline (Uniphylline) can be used to open the airways, but inhalers are first choice in stable COPD **as they have fewer side effects.**
- **Medicine to loosen your phlegm/mucus:** this usually comes in the form of a cough bottle or occasionally a tablet and helps to make the phlegm 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 a flare up. They help to reduce the inflammation in the airways and help to reduce breathlessness. Steroids should be taken in the morning when prescribed as they can affect sleep. Steroid tablets are NOT a long term solution as they have a lot of side effects.
- **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. This helps to choose the right antibiotic for you.
- **Long-term antibiotic:** occasionally long term antibiotics are prescribed for more severe COPD or if you continue to get frequent flare ups despite taking all your treatment and your self-management.
- **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:

- Get to know your inhalers and make sure you can use them properly.
- Ask your healthcare professional or pharmacist to show you the correct way to use your inhalers.
- 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, keep your machine clean and change the filters as per manufacturers instructions.
- It is also important to wash your spacer as instructed and allow it to air dry.



6.2 COPD Self- Management

Communications Card

A COPD Communication Card, which may be given to you by your healthcare professional, can be a guide to recognising and managing a flare up. This will contain all the information relevant to your COPD and a Self-Management action plan (see opposite) 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



Self-Management Plan Chronic Obstructive Pulmonary Disease (COPD)

A guide to managing your symptoms. It's important to look after your own health and wellbeing, with support from your team of health professionals. To learn more about using this self care plan, call the free COPD Adviceline on 1800 832146 to make an appointment to speak with a Respiratory Nurse Specialist.

SYMPTOMS		ADVICE
 Feeling Well	<ul style="list-style-type: none"> I am able to carry out my usual activities My phlegm is a normal colour and amount for me 	<ul style="list-style-type: none"> Continue with my medication as prescribed and continue my day as normal Keep as active as possible
 Bad Day	<ul style="list-style-type: none"> My COPD may be bothering me. For example, I am more breathless than usual 	<ul style="list-style-type: none"> Use chest clearance techniques Use my reliever inhaler Use breathing control exercises If no relief I may be unwell. Move onto "feeling unwell" section for guidance
 Feeling Unwell	<ul style="list-style-type: none"> I am more wheezy, breathless I have more phlegm which is yellow or green in colour 	<ul style="list-style-type: none"> Take my normal medications and inhalers Take my reliever medication every 4 to 6 hours Start rescue antibiotics and steroids Call GP or GP out of hours service for advice Call my COPD Outreach team or COPD Adviceline on 1800 832146
 Very Unwell	<ul style="list-style-type: none"> My reliever and rescue prescription are not helpful or I feel worse 	<ul style="list-style-type: none"> I should urgently contact my GP or Out-of-Hours GP service. Go to the Hospital Emergency Department if GP is not available. If I am short of breath at rest, have chest pain or confusion this is an emergency. CALL 112 or 999 and ask for an ambulance

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. You 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 worry 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



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 2: Reliever inhaler

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



6.4 Clearing Your Phlegm/Airway Clearance

A common symptom of COPD can be a lot of mucous/phlegm in the lungs, which can often be hard to clear. If there is a big build-up of phlegm in the lungs this can lead to chest infections.

What can I do?

There are number of techniques that can be of use. Please ask your Physiotherapist for further advice on a technique which best suits you.

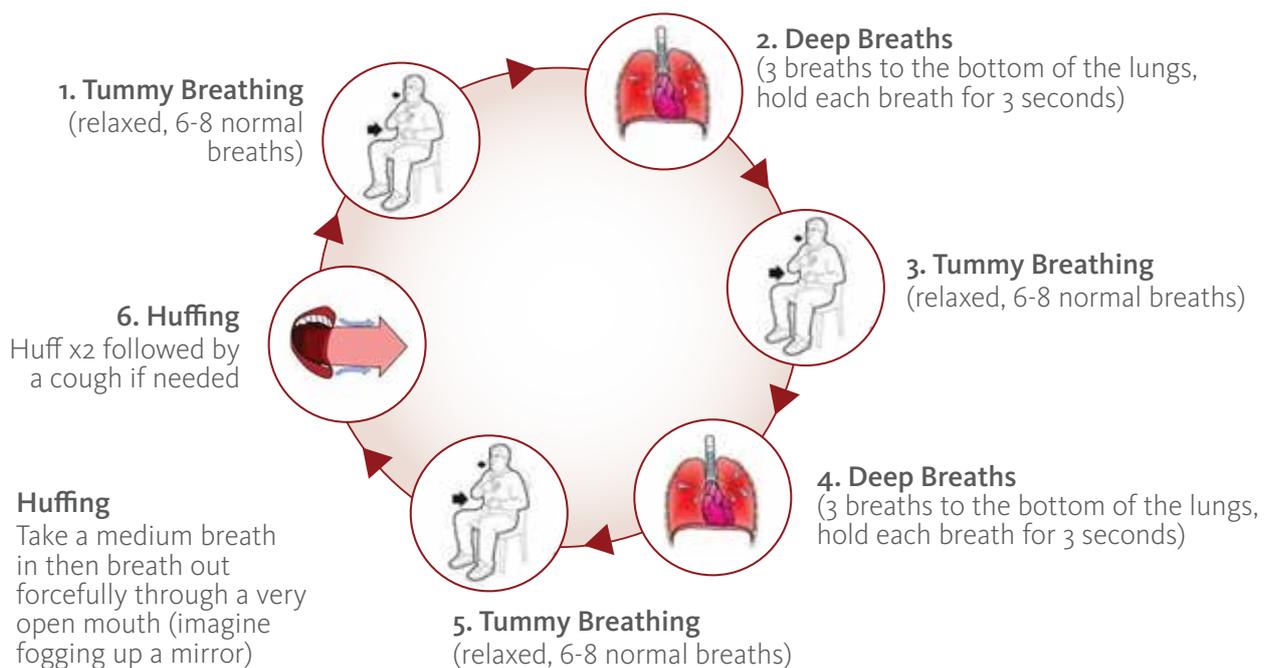
The Active Cycle of Breathing Technique (ACBT) is a set of breathing exercises, which is used to help loosen and clear any phlegm you may have. (See below diagram)

It is good practice to clear your chest with these exercises every morning and evening if you suffer from a 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 phlegm is gone 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 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 a 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 breathless 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 flare ups include:

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

What to do after a flare up:

- 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 as well as any other vaccines recommended by your healthcare professional. (Section 6.8).
- Stop smoking if you are a smoker and make your house a smoke free zone (Section 4).
- Take all your medication including your inhalers as prescribed and check your inhaler technique regularly with your healthcare professional.
- Clear your phlegm as advised by your healthcare professional (Section 6.4).
- 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 sanitisers 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

Some people with COPD will need to use Oxygen because they have 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, it is called long term oxygen therapy or LTOT for short. When it is prescribed you will be told how long you are to use the oxygen for every day.

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 flare up. It is important to have a follow up appointment with your doctor, specialist physiotherapist or specialist 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 oxygen dials on the equipment 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:

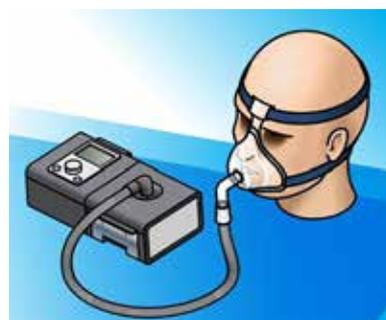
- Look after your equipment and follow the instructions provided by your oxygen supplier.
- Do not expose your oxygen to naked flames or other heat sources.
- Do not smoke near oxygen equipment.
- Store oxygen equipment safely, your oxygen supplier will provide advice.
- If you are not using your oxygen, 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 which 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 able to take oxygen in and to breathe out carbon dioxide.



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

BiPAP® machines provide relief to overworked lungs and chest muscles by giving you air and a pressure to the lungs as you breathe in. This helps to keep the airways open reducing the amount of energy it takes you to breathe and ensures a steady supply of oxygen to your body. When you breathe out the machine drops its pressure so that you can breathe out easily. This machine 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, helping 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. If you are over 65 regardless of any underlying disease you need one dose of vaccine. If you are under 65, most adults in risk groups which include 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 about this.

Vaccination against Covid 19 in accordance with HSE guidelines is strongly recommended for all people living with COPD

Covid-19 vaccine

People with COPD are at high risk of severe complications from COVID-19 infection. Vaccination against Covid 19 in accordance with HSE guidelines is strongly recommended for all people living with COPD.

7. Food & Nutrition: COPD, Food & Me

Why does nutrition matter when I have COPD?

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

Good food and 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?

We use the food pyramid to make a daily food plan. This is a good way to ensure you are getting the nutrients your body needs. Variety is important as different food groups contain different nutrients.

Healthy Food for Life
www.healthyireland.ie

The Food Pyramid For adults, teenagers and children aged five and over

Not needed for good health.

Needed for good health. Enjoy a variety every day.

NOT every day

Maximum once or twice a week

In very small amounts

2 Servings a day

3 Servings a day
5 for children age 9-12 and teenagers age 13-18

3-5 Servings a day
Up to 7* for teenage boys and men age 19-50

5-7 Servings a day

***Daily Servings Guide – wholemeal cereals and breads, potatoes, pasta and rice**

Active	Child (5-12)				Teenager (13-18)				Adult (19-50)			
	Child (5-12)	Teenager (13-18)	Adult (19-50)	Adult (51+)	Inactive	Teenager (13-18)	Adult (19-50)	Adult (51+)				
♂	3-4	4	4-5	3-4	3	3-4	3					
♀	3-5	5-7	5-7	4-5	4-5	4-6	4					

There is no guideline for inactive children as it is essential that all children are active.

Drink at least 8 cups of fluid a day – water is best

Get Active!
To maintain a healthy weight adults need at least 30 minutes a day of moderate activity on 5 days a week (or 150 minutes a week), children need to be active at a moderate to vigorous level for at least 60 minutes every day.

Source: Department of Health, December 2016.

- **Vegetables, salad and fruit** contain antioxidants, which fight harmful free radicals and can help **support 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 you can 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 tired.

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:

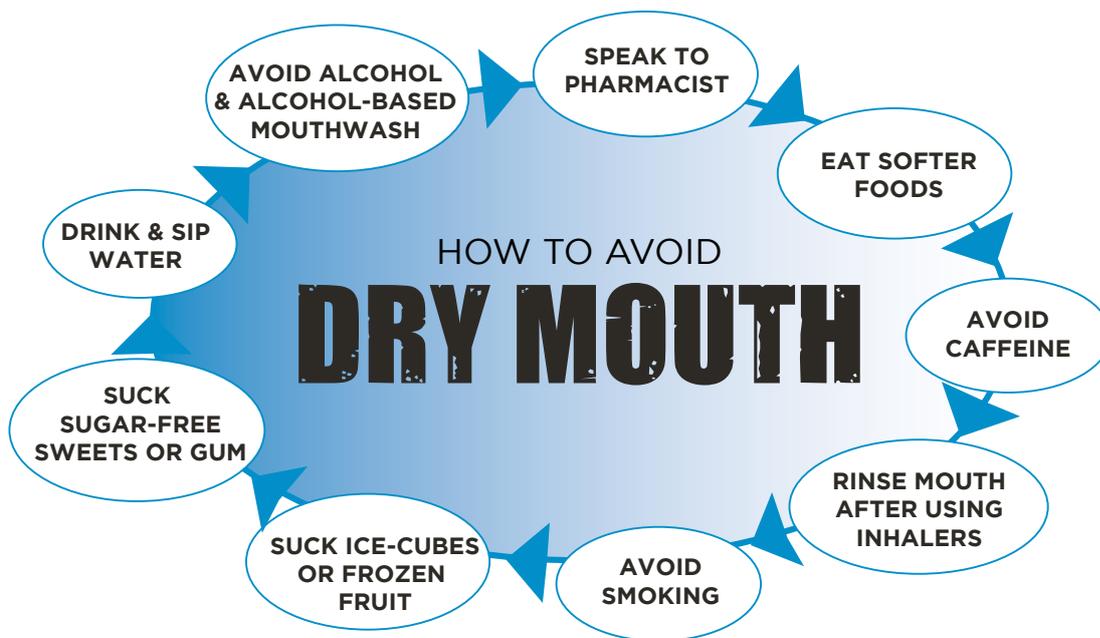
- Write down or think about **why you want to lose weight**, this helps motivation.
- **Don't skip meals**; you're less likely to overeat if you have regular meals.
- Keep a diary; **keep track of what you eat and drink**, your weight or physical activity.
- Keep foods on the **top shelf of the food 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 food and 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:



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.

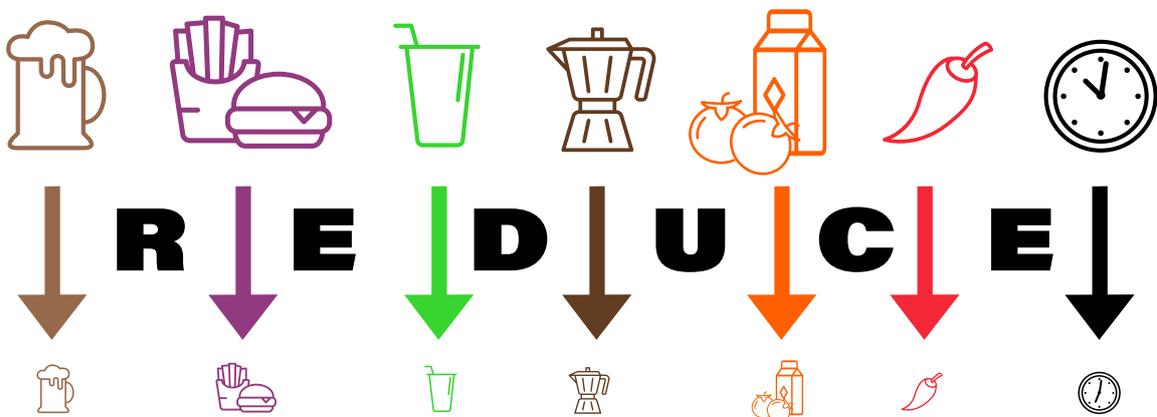
Reflux or Indigestion

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:



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.

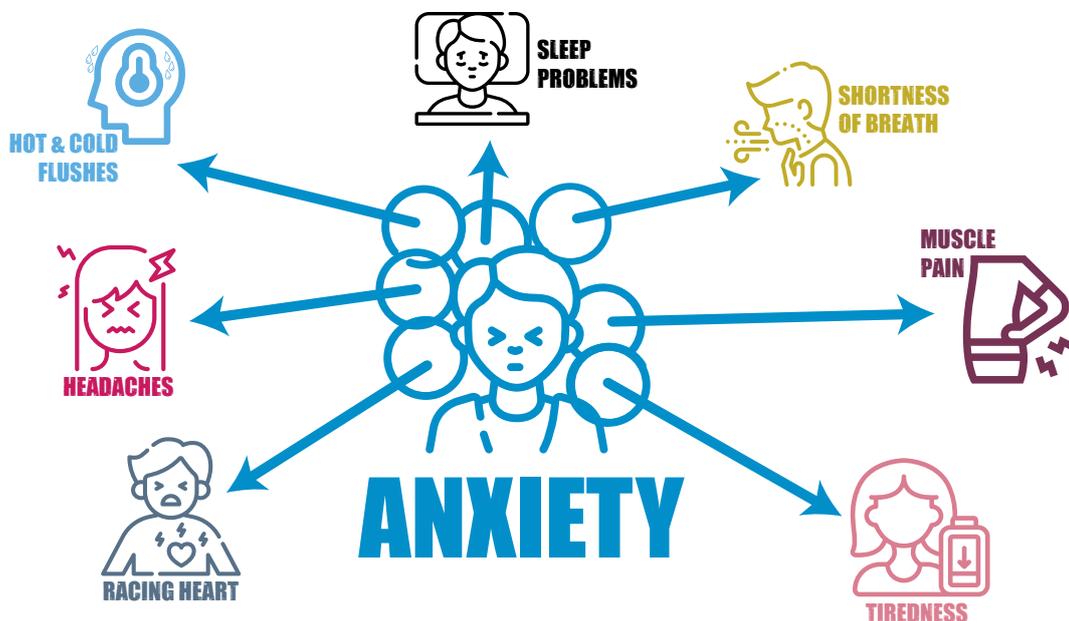
8. Mental Health & Wellbeing

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 people 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. This helps you to 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 this can cause us to 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:



Stress and anxiety also have emotional effects: people can feel

- Fear and worry
- Panic
- Tense and nervous
- 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.

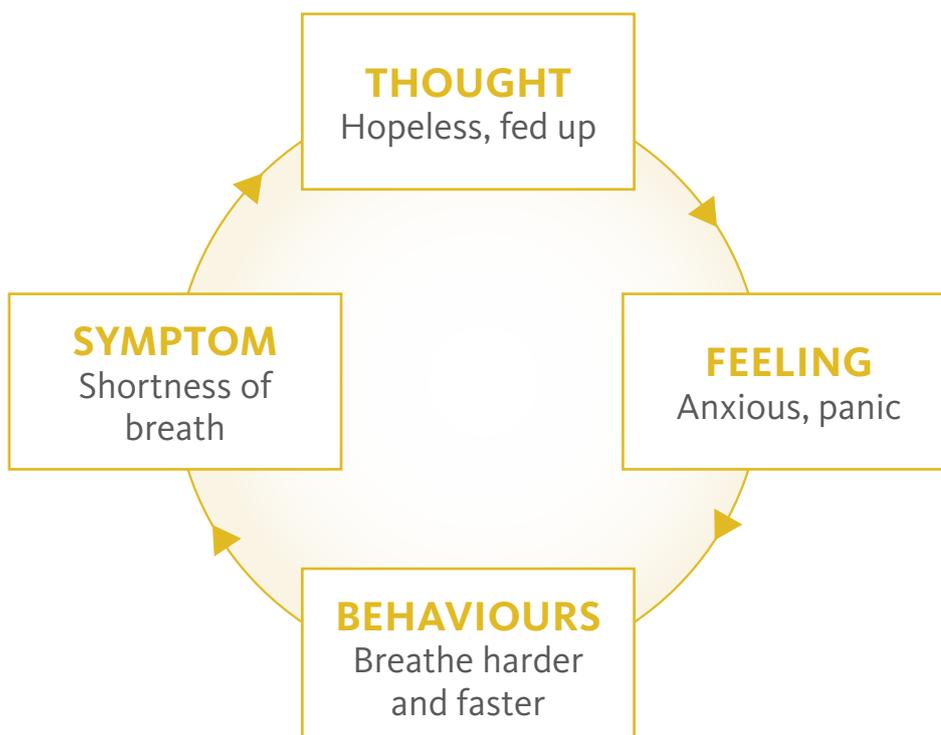


FIGURE 1. CYCLE OF THOUGHTS, FEELINGS, BEHAVIOURS AND SYMPTOMS.

Depression

COPD has a significant impact on your life and it is normal to feel sad and helpless at times, especially during flare ups. 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:

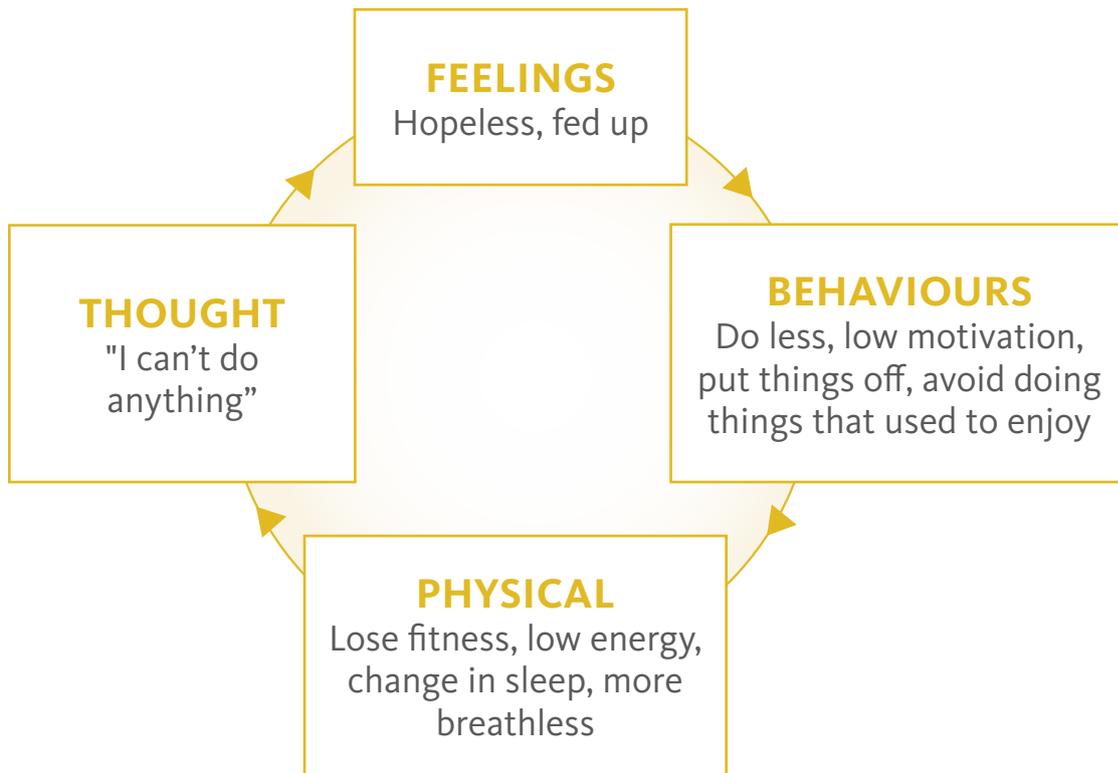
- withdrawing from other people
- lack of enjoyment in activities you used to enjoy
- feeling sad and worthless nearly all of the time
- feeling irritable, frustrated and moody nearly all of the time
- feeling guilty and helpless nearly all of the time
- finding it hard to concentrate
- changes in eating (either too much or too little)
- changes in sleeping (either too much or too little)
- decreased interest in sex and intimacy
- 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 self-manage the disease, and can make you feel depressed.

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



Managing your 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.** Discussing your concerns with a General Practitioner (GP) is a good first step. It can be difficult to discuss your feelings with others, but your GP can:
 - make a diagnosis after your check up
 - discuss available treatments
 - refer you to a mental health specialist for psychological treatment
 - provide brief counselling or, in some cases, psychological therapies
 - 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 health care professional 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 or primary care centre or join a COPD Support Ireland



exercise class if there is one in your area. 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 catching up with friends and family. If you cannot get out, ask them to call round or to phone for a 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. Visit www.copd.ie or call 086-0415128 for a list of support groups in Ireland including the singing for lung health programme SingStrong.
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 your 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.

9. When a loved one is living with COPD



If someone you know has COPD it is important to remember that the person hasn't changed. Although COPD is now part of and will change your lives, it doesn't have to define it.

These are some suggestions on how to support someone living with COPD.

DO's:

- Know what to do when the person with COPD is unwell.
- Reassure the person with COPD that you are there for them.
- Offer to exercise with the person with COPD
- Give the person with COPD time to seek help and be clear about when help is needed. It can be useful to agree on a code word that can be used when help is needed; for example, "red" might mean that things are really bad.
- Remember that some tasks may take the person with COPD longer to do but it's important to let the person do as much as they can.
- When offering help, ask the person what they would like from you.
- If help is initially declined, offer to help again at a later stage.
- Ensure that the person with COPD has easy access to the toilet.
- Offer to exercise with the person with COPD.
- Engage in conversation about being involved in the person's care, needs and wishes.

DON'T:

- Don't offer uninvited advice or actions, for example repeatedly offering to make cups of tea.
- Don't take over decision-making unless you are being asked to.
- If a person is coughing, don't slap them on the back.

If you are caring for a family member or friend with COPD, it is important that you understand as much as possible about COPD and how it affects the person. Listening to the person and finding out what matters to them is a good way of starting a conversation about how you can best support them. However, as a carer you will have many roles in the management of the person's COPD. It is a good idea to get information and support specifically for you as a carer, for example from Family Carers Ireland or the COPD Support Ireland support group network.

Most importantly, remember to look after your own physical and mental health. Try to live as normally as possible. Consider taking up exercise or engaging in activities that are enjoyable for you. Be aware of any anxiety you may be feeling and reach out to seek support from others. Caring for a person living with a chronic disease such as COPD can be physically and mentally exhausting at times so ensuring that you take care of yourself as well as the loved one living with a chronic disease is paramount to weathering those times.

As they say on the aeroplanes, "In case of a loss of cabin pressure, oxygen masks above your seat will deploy, place this mask over your nose and mouth and only after doing so, should you assist your child or other passengers with their mask"

The reasoning is simple, if you become incapacitated, you can't help others. In taking care of yourself first, others will then benefit from your unimpeded care and attention.

(Adapted from COPD Support Ireland and The Irish Hospice Foundation. Planning for the future with COPD.)



10. COPD Support Ireland:

Peer to peer support:

Peer-to-peer support can have many benefits for those living with COPD. We believe it is a key part of COPD disease self-management, with a structured but personalised approach for everyone. The goal of these peer-to-peer support groups is to motivate, engage and support members and carers to help them overcome any challenging feelings and physical symptoms in their day-to-day life through the integration of peer support with self-management education. Interacting with those who in your local community who are living with the same or a similar condition can be a positive outlet for those experiencing both physical and mental health symptoms of COPD.

Get in touch today with us and email support@copd.ie to find out more about your local peer support group

COPD & Me Exercise Programme and Events:

There are multiple benefits from exercising when living with a chronic health condition, or as an older adult. COPD Support Ireland has developed an exercise programme delivered by a trained professional, who is able to tailor the exercises to your needs and ability. These classes are designed to help improve your physical, and mental health; they take place one or twice a week, either virtually through Zoom or in person at a local support group location, depending on the region. Participation in these classes can lead to an increase in muscle strength, flexibility, a reduction in breathlessness and most importantly an improvement in your quality of life.

For more information on Joining a local COPD Support Group please contact us on 086-0415128 or visit <http://copd.ie/> to sign up as a member, or be referred by your healthcare practitioner

SingStrong – Singing for better Lung Health

As part of a COPD self-management programme, many people are encouraged to use breathing techniques to clear any lung secretions and to help control the symptom of breathlessness. These breathing techniques can be quite effective in optimising airway clearance and minimising the experience of breathlessness by people living with COPD.

SingStrong is a novel and fun way to learn and implement these breathing techniques through singing. It is a choir created by vocal coach Ms. Ciara Meade and lecturer of cardiovascular and respiratory physiotherapy, Dr. Roisin Cahalan. The SingStrong programme has proven exceptionally popular with our members and is delivered either virtually or in person in a small number of locations, over a 10-week period, with two sessions a week taking place. We plan to expand this programme to be delivered in our local support groups as a regular activity.

For more information on SingStrong and how you can join, email SingStrong@copd.ie.

COPD Adviceline:

The COPD Adviceline is a HSE funded, free telephone call back service for people living with or caring for somebody with COPD. The COPD Adviceline is a resource for you to further understand your COPD and your symptoms, to advise you on Self-Management strategies, answer any questions you have about your COPD and to connect you with local supports in your area. It is staffed by Respiratory Specialist Health Professionals with extensive experience in helping people to Live Well with COPD. All conversations are confidential, with the purpose of looking after your individual needs. This service can be used as often as you need, no query is too small, we are here to help you. To make an appointment to speak with one of the Respiratory Specialists on our adviceline, Call Freephone 1800 832146

The graphic features a blue background with a white cloud in the top right corner containing the COPD Support Ireland logo. On the left, the text 'WORRIED ABOUT YOUR COPD?' is written in white on blue rectangular backgrounds. Below this, it says 'Call the COPD Adviceline today and one of our specialist nurses will help put your mind at ease!'. In the center, a white cloud contains the text 'COPD ADVICELINE 1800 83 21 46'. To the right, a cartoon nurse in blue scrubs and a headset holds a green medical bag. At the bottom, there are four circular icons: lungs, a telephone, an envelope, and a speech bubble.

Appendix

Modified Borg Dyspnea Scale

*Instructions for Borg Dyspnea Scale. Use this scale to rate the difficulty of your breathing. It starts at number 0 where your breathing is causing you no difficulty at all and progresses through to number 10 where your breathing difficulty is maximal.

How much difficulty is your breathing causing you right now?

- 0 Nothing at all
- 0.5 Very, very slight (just noticeable)
- 1 Very slight
- 2 Slight
- 3 Moderate
- 4 Somewhat severe
- 5 Severe
- 6
- 7 Very severe
- 8
- 9 Very, very severe (almost maximal)
- 10 Maximal (breathing difficulty is maximal)

How much difficulty is your breathing causing you right now?

CAT Score

Your name:

Today's date:



How is your COPD? Take the COPD Assessment Test™ (CAT™)

This questionnaire will help you and your healthcare professional measure the impact COPD (Chronic Obstructive Pulmonary Disease) is having on your wellbeing and daily life. Your answers, and test score, can be used by you and your healthcare professional to help improve the management of your COPD and get the greatest benefit from treatment.

For each item below, place a mark (X) in the box that best describes you currently. Be sure to only select one response for each question.

Example: I am very happy	0	X	2	3	4	5	I am very sad	
I never cough	0	1	2	3	4	5	I cough all the time	SCORE
I have no phlegm (mucus) in my chest at all	0	1	2	3	4	5	My chest is completely full of phlegm (mucus)	
My chest does not feel tight at all	0	1	2	3	4	5	My chest feels very tight	
When I walk up a hill or one flight of stairs I am not breathless	0	1	2	3	4	5	When I walk up a hill or one flight of stairs I am very breathless	
I am not limited doing any activities at home	0	1	2	3	4	5	I am very limited doing activities at home	
I am confident leaving my home despite my lung condition	0	1	2	3	4	5	I am not at all confident leaving my home because of my lung condition	
I sleep soundly	0	1	2	3	4	5	I don't sleep soundly because of my lung condition	
I have lots of energy	0	1	2	3	4	5	I have no energy at all	

The COPD Assessment Test was developed by a multi-disciplinary group of international experts in COPD supported by GSK. GSK activities with respect to the COPD Assessment Test are overseen by a governance board that includes independent external experts, one of whom chairs the board. CAT, COPD Assessment Test and the CAT logo are trademarks of the GSK group of companies. ©2009 GSK. All rights reserved.

MLT_GIB/CPD/0006/14 Date of preparation: December 2014

If you experience any side effects with GSK products, please report the case to GSK (Malta) Limited, 1, De la Cruz Avenue, Qormi QRM 2458, Malta (Tel: +356 21238131).

If you have questions about a specific medical condition, please consult a healthcare professional.

TOTAL SCORE

9. References

Body weight, lifestyle, dietary habits and gastroesophageal reflux disease. Davide Festi, Eleonora Scaioli, Fabio Baldi, Amanda Vestito, Francesca Pasqui, Anna Rita Di Biase, and Antonio Colecchia. *World J Gastroenterol.* 2009 15(14): 1690–1701.

BiPAP therapy for COPD: What to expect. Healthline <http://www.healthline.com/health/copd/bipap-forcopd>

British Thoracic Society (2015) BTS Guidelines for Home Oxygen use in Adults. Available online at [https://www.brit-thoracic.org.uk/document-library/clinical-information/oxygen/home-oxygen-guideline\(adults\)/bts-guidelines-for-home-oxygen-use-in-adults/](https://www.brit-thoracic.org.uk/document-library/clinical-information/oxygen/home-oxygen-guideline(adults)/bts-guidelines-for-home-oxygen-use-in-adults/)

Borg, G. (1998). Borg's perceived exertion and pain scales. Champaign, IL: Human Kinetics.

British Thoracic Society (2016) BTS/ICS guideline for the ventilatory management of acute hypercapnic respiratory failure in adults. Available online at: <https://www.britthoracic.org.uk/document-library/clinical-information/acute-hypercapnic-respiratory-failure/btsguidelines-for-ventilatory-management-of-ahrf/>

Clinical Nutrition (2006) 25, 311–318 ESPEN Guidelines on Enteral Nutrition: Cardiology and Pulmonology S.D. Anker, M. Johnb, P.U. Pedersenc, C. Ragusod, M. Cicoirae, E. Dardaif, A. Lavianog, P. Ponikowskih, A.M.W.J. Scholsi, H.F. Becker, M. Bo`hm, F.M. Brunkhorst, C. Vogelmeier

COPD Support Ireland and The Irish Hospice Foundation. Planning for the future with COPD. Dublin: The Irish Hospice Foundation; 2018.

Dry mouth <https://www.nidcr.nih.gov/oralhealth/topics/drymouth/drymouth.htm> accessed 24.4.17

Fletcher C, Peto R. The natural history of chronic airflow obstruction. *Br Med J* 1977; 1 :1645 doi:10.1136/bmj.1.6077.1645

Global Strategy for the Diagnosis, Management and Prevention of COPD, Global Initiative for Chronic Obstructive Lung Disease (GOLD) 2017 <http://goldcopd.org>

Gupta, N., Pinto, L. M., Morogan, A., & Bourbeau, J. The COPD assessment test: a systematic review. *Eur Respir J* 2014; 44: 873-884

<http://erj.ersjournals.com/content/44/4/873.long> (last accessed: 10/10/2018) HSE (2017) Chronic Obstructive Pulmonary Disease (COPD). Available online at: https://hse.ie/eng/health/az/C/Chronic_obstructive_pulmonary_disease_COPD/

HSE (2017) Living with COPD. Patient Information. Available online at: http://www.hse.ie/eng/health/hl/living/copd/LIVING_with_COPD_Patient_Information_v_o_5.pdf

HSE (2017) Immunisation Guidelines. Available online at: <http://hse.ie/eng/health/immunisation/hcpinfo/guidelines/immunisationguidelines.html>

Lifestyle Intervention in Gastroesophageal Reflux Disease. Ness-Jensen E1, Hveem K2, El-Serag H3, Lagergren J4. Clin Gastroenterol Hepatol. 2016 Feb;14(2):175-82 Miller, M.R., et al. Standardisation of spirometry. ATS/ERS task force: standardisation of lung function testing. ERJ 2005;26:319-338.

Nutrition Support in Adults: Oral Nutrition Support, Enteral Tube Feeding and Parenteral Nutrition. National Institute for Health and Care Excellence (NICE). (2006) Available at www.nice.org.uk/cg32. Accessed 24.4.17

Nutritional support in chronic obstructive pulmonary disease: a systematic review and meta-analysis. Collins PF1, Stratton RJ, Elia M. Am J Clin Nutr. 2012 Jun;95(6):1385-95.

Pulmonary Oxygen Toxicity. Jackson R.M <https://www.ncbi.nlm.nih.gov/pubmed/3905287>

Acknowledgements

Ms Rosie Hassett	Clinical Nurse specialist
Prof Tim McDonnell	Consultant Respiratory Physician
Ms Patricia McQuillan	Professional Development Co Ordinator
Ms Orla Maria Threadgold	Physiotherapist
Ms Geraldine Nolan	Respiratory Physiologist
Mr Peter O'Toole	Clinical Nurse specialist
Ms Bernie Murphy	COPD Support Ireland
Mr Damien Peelo	COPD Support Ireland
Ms Pauline O'Neill	COPD Patient representative
Ms Janet O'Leary	COPD Patient representative
Ms Claire Sheridan	Clinical Nurse specialist
Ms Suzanne Seery	Dietician
Mr Brian Fitzgibbon	Senior Physiotherapist
Ms Marie Togher	Clinical Nurse specialist
Ms Ciara Scallon	Senior Physiotherapist
Ms Angela Ryan	HSCP Lead NCP Respiratory
Ms Susan Curtis	Programme Manager NCP Respiratory
Dr Des Murphy	Clinical Lead NCP Respiratory
Dr Miriam Owens	Specialist in Public Health Medicine
Dr Mark O'Kelly	ICGP HSE Primary Care Lead for Integrated Care Programmes (COPD)
Ms Sinead Power	Self Management Support Coordinator
Ms Geraldine Cully	Self Management Support Coordinator
Ms Joan Johnston	General Manger, COPD Support Ireland



COPD Adviceline
Freephone 1800 83 21 46



COPD
Support Ireland
www.copd.ie



NATIONAL CLINICAL
PROGRAMME RESPIRATORY