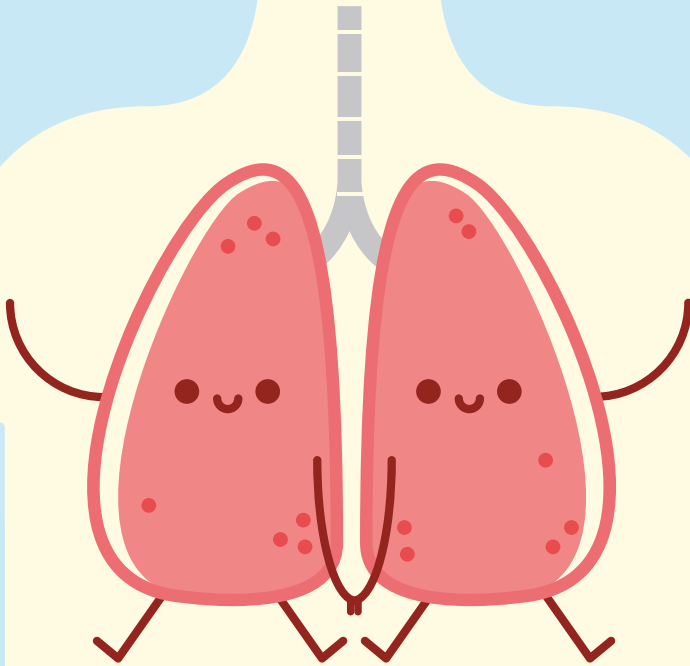


# Planning for the future with COPD



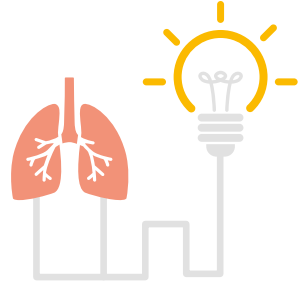


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# Introduction

This booklet provides information that might be useful to people living with a range of illnesses. However, it is specifically intended for people who are living with Chronic Obstructive Pulmonary Disease (COPD). It may also be beneficial to their family members and friends.



This booklet was developed in a collaborative way by people living with COPD, family carers, a respiratory healthcare professional, COPD Support Ireland and The Irish Hospice Foundation.

The purpose of this booklet is to support people living with COPD in planning for their future. It is important to remember that everyone's journey with COPD is different. Therefore some of the information provided here may not be applicable to you right now. This booklet aims to help you:

- Understand your COPD.
- Manage your COPD.
- Understand how palliative care can help you with your COPD.
- Understand why planning for the future can be helpful.

- Give you information on how you can plan for your care in advance.
- Talk to your family about your plans.

As you consider each section, it can be helpful to understand the nature of your own COPD.

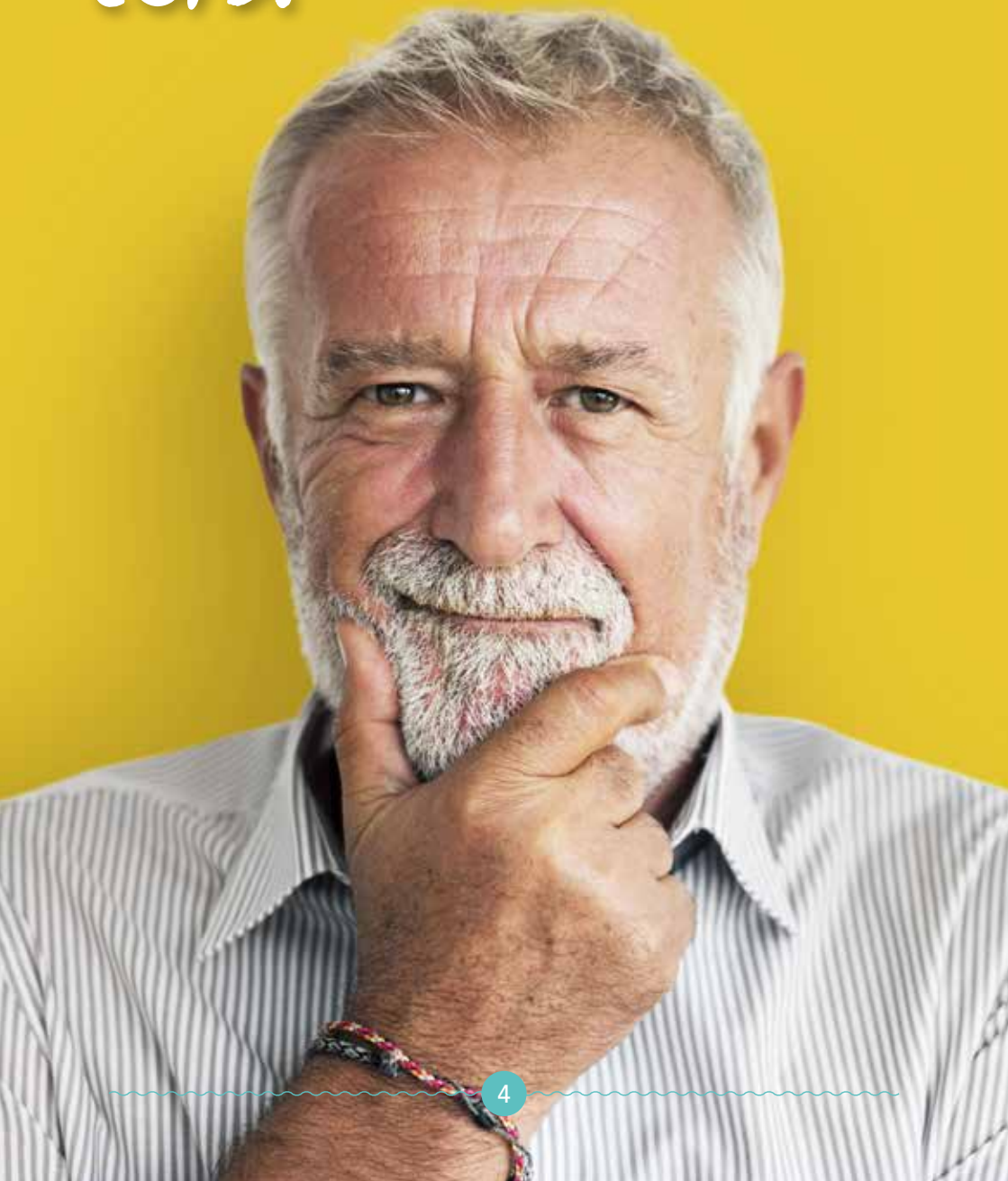
Some information about this is provided in this booklet. More information is available



from your doctor, nurse, other healthcare professional, or from a voluntary organisation supporting people living with COPD (see Resources section on page 39). If there is any uncertainty about your diagnosis it is important to speak with your GP or other healthcare professional.

If you or someone you know has just recently been diagnosed with COPD this booklet may not be appropriate to read as a first resource. Other information is available. We recommend reading this booklet in conjunction with other materials and as part of a conversation with your doctor, nurse or other health and social care professional.

# What is COPD?



# What is COPD?



**Chronic Obstructive Pulmonary Disease (COPD)** is an umbrella term used to describe progressive lung diseases including chronic bronchitis, emphysema or both.

COPD is a disease that makes it hard to empty air out of your lungs. When this happens the airways (breathing tubes) get smaller, leading to air flow obstruction. This can result in shortness of breath or tiredness because your body is working harder to breathe. COPD is a long-term illness that cannot be cured, but it can be controlled.

**Chronic bronchitis** is caused by inflammation and increased mucus (phlegm) in the breathing tubes (airways). Because of the swelling and extra mucus, the inside of the breathing tubes become smaller, causing obstruction to airflow.

**Emphysema** is caused by damage to the alveoli (air sacs) of the lung. Each person has more than 300 million tiny air sacs in the lungs. If the walls of these air sacs are damaged, they lose their elasticity and then they trap air. This causes extra air to remain in the lungs after you breathe out. This extra air means more effort is needed to breathe which results in shortness of breath.

**Known causes of COPD** include exposure to smoke, dust or other fumes. An inherited condition called ALPHA – 1 – ANTITRYPSIN deficiency can also cause COPD.

## WHAT IS COPD?

**COPD is not Asthma** - it is important to remember that although airway obstruction occurs with both COPD and asthma, COPD usually shows up in adults over the age of 35. Asthma symptoms usually start in childhood. Also, asthma is usually made worse by exposure to allergens, cold air, and exercise. COPD flare ups (exacerbations - see page 13) are largely caused by infections such as pneumonia, the flu, and other common viruses and bacteria. These can be made worse by exposure to environmental pollutants.

Some people find it helpful to find out as much as possible about COPD. This helps them to understand the condition and it also gives them the knowledge and the language to speak knowledgably with their healthcare professionals. COPD Support Ireland, the European Lung Foundation and GOLD COPD provide trustworthy information and useful tips on managing your COPD (see Resources section for details).

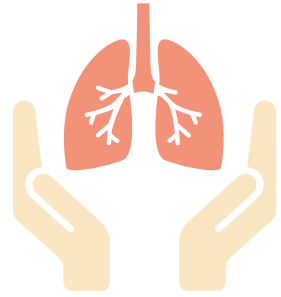
**It is important to remember that  
COPD is not Asthma.**



# Getting to know your COPD



# Getting to know your COPD



COPD can be classified into the following stages: mild, moderate, severe and very severe. These groupings are used by medical professionals in order to decide which treatment options are most appropriate (GOLD; see Resources section).

COPD is diagnosed through a short breathing test called Spirometry, where you blow through a mouthpiece. A combination of your spirometry results and an assessment of your lungs and the history of your exposure to known causes aids in classifying the stage of your COPD.

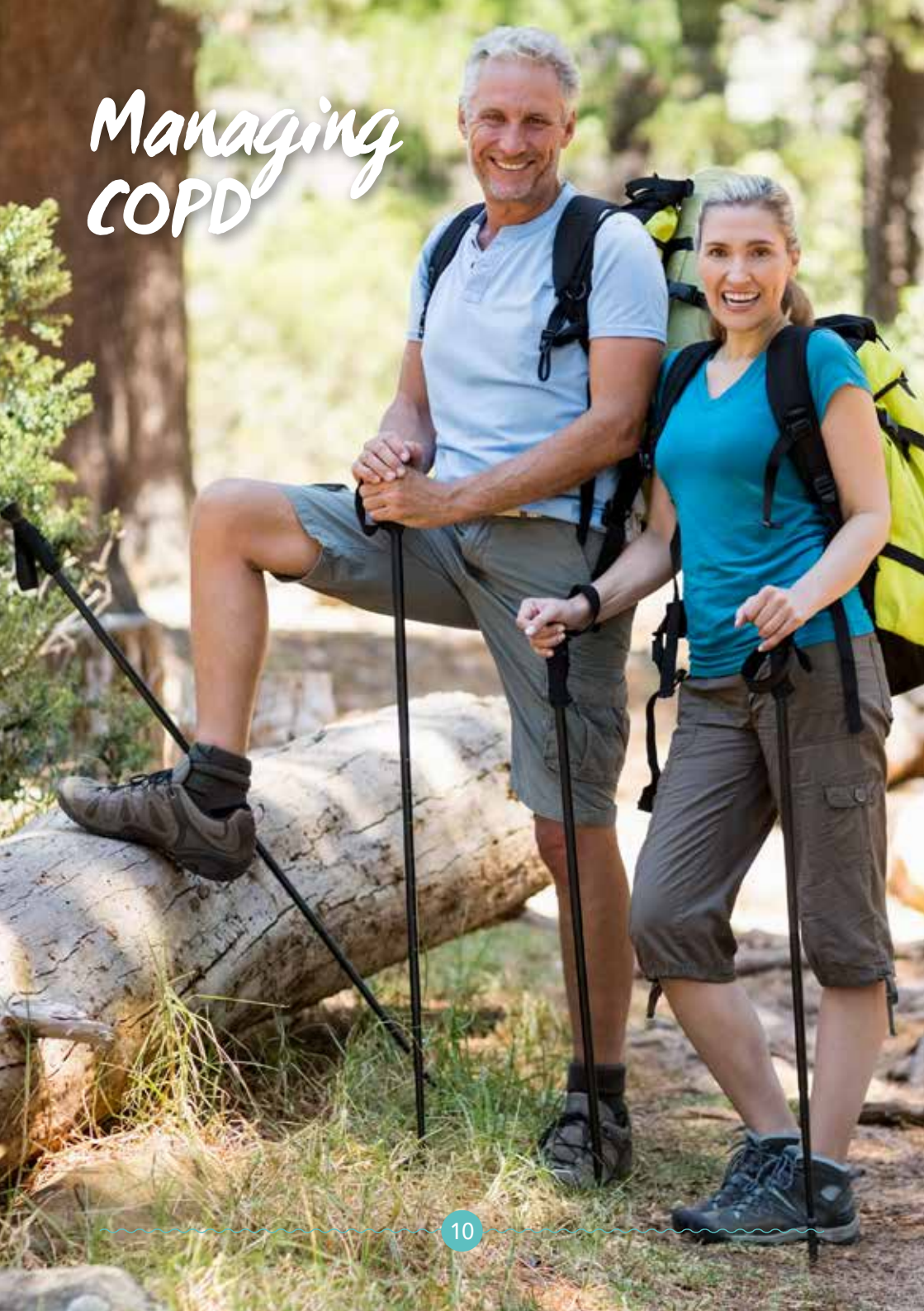
With mild COPD you may be regularly coughing, bringing up phlegm and feeling a bit out of breath when walking and doing work. As COPD progresses towards moderate and severe stages, these symptoms may increase in severity and your physical ability to do things may decline gradually. You may find it harder to recover from chest infections, your sleep may be affected, and other illnesses and conditions can arise as a result of your COPD. However, it is important to remember that every person's journey with COPD is different, and that there is no clear pathway between each stage.

As each person's experience with COPD is different, it is not possible to predict exactly how a person's COPD will progress over time. Many people with COPD will experience an exacerbation or flare up of the disease. This is an episode when your breathing is worse than usual and you become sick. This is usually linked to an infection and can be serious, causing you to see your doctor or attend the hospital.

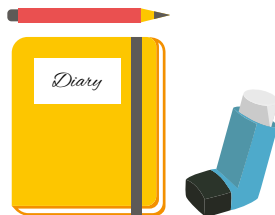
Although COPD cannot be cured, its symptoms can be treated and managed, meaning your quality of life can be improved. Knowledge of your COPD can be powerful in helping you control and manage your symptoms. Over time you should know:

- What triggers flare ups (exacerbations) of your COPD.
- How to recognise flare ups (exacerbations) of your COPD.
- Your regular and rescue medicines.
- How to control breathlessness.

# Managing COPD



# Managing COPD



Many people with COPD will also be living with other conditions such as diabetes, osteoporosis, heart disease, incontinence, anxiety and social isolation. It may be helpful to discuss these with your doctor or nurse who can advise you on what steps to take to ease your symptoms.

There are also lots of steps you can take to manage your COPD. Some tips are outlined below:

## 1 Take your medication:

It is important to take your medication as prescribed. Regular medication use can improve your symptoms and help prevent exacerbations. It is also important to get the annual flu vaccine and check that you are covered for pneumovax (pneumonia vaccine). If you have questions or concerns about the medication you are taking, talk to your doctor, nurse, pharmacist, physiotherapist or other health and social care professional. It is a good idea to keep an up-to-date list of medications you are taking with you that can be brought to medical appointments.

- 2 Exercise:**

Exercising helps to improve breathing and can contribute to less severe symptoms, greater sense of wellbeing and therefore a better quality of life. Ask your healthcare professional about being referred to a Pulmonary Rehabilitation programme.
- 3 Maintain a healthy weight:**

Carrying extra weight can make your breathing worse. It is a good idea to lose weight if you are overweight. Other people with COPD are underweight and have difficulty putting on weight. If you are concerned about your weight, speak with your doctor or nurse, or ask to speak with a dietician.
- 4 Talk to others:**

If you are feeling down or depressed or have questions about your COPD, talk to your GP or nurse. Some people also find it helpful to talk to other people who have COPD through a local support group (see [www.copd.ie](http://www.copd.ie)).
- 5 Air quality:**

If you are a smoker or exposed to passive smoke, it is important to stop or reduce the amount you smoke as that will help slow down the damage to your lungs. Some people get triggered by environmental fumes (for instance cooking, heating and traffic). Find out if this affects you and reduce your exposure.



## 6 Recognise exacerbations:

An exacerbation is a flare up of COPD. It usually occurs very quickly and can be recognised by a worsening of your symptoms. Some of the signs to be aware of include: increased breathlessness, increased coughing, a change in the amount and colour of mucus or phlegm, increased tiredness, unusual problems sleeping and sometimes a high temperature. If a cough develops it is a good idea to see your GP or practice nurse sooner rather than later.

It is important to remember that an exacerbation is different for everyone. It can be a frightening experience. Here is some advice for dealing with exacerbations:

- Stay calm, don't panic and breathe as deeply as you can.
- Use your self-management plan.
- Be aware of where medications including inhalers are kept and have them nearby.
- Take a nebuliser if prescribed and available.
- Call a family member, friend or neighbour to stay with you.
- Contact your GP or the out-of-hours service.
- Be aware of colour changes, i.e. blue lips or hands.
- Monitor symptoms and call an ambulance if necessary.
- Keep an overnight bag ready that can be accessed easily if a trip to hospital is required.

It takes time to recognise your exacerbations and to learn how to manage them as well as possible. It is a good idea to take stock after an exacerbation and reflect on how well you managed it and what you would do differently the next time. Some people find it useful to keep a diary.

Throughout your journey with COPD your regular doctor may need to check with other healthcare professionals to manage your symptoms effectively. This could include referring to palliative care. This is discussed in more detail on page 19.



## *When a family member has COPD*

If someone you know has COPD it is important to remember that the person hasn't changed. Although COPD is now part of your life and will change your life, it doesn't have to define it. Here is some advice with regard to supporting someone living with COPD.

### **DO's:**

- Look after yourself and try to live as normally as possible. Consider taking up training or engaging in activities that are useful to you.
- Be aware of any anxiety you may be feeling.
- Reach out and seek support from others.
- Know what to do when the person with COPD is unwell (see above).
- Reassure the person with COPD that you are there for them.



**DO:** ✓

**Offer to exercise  
with the person  
with COPD**

## MANAGING 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 and plans, for example learn about medications (see pages 11 and 30 for more information with regard to this).

### 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 COPD Support Ireland, support group networks or the AllHPC Palliative Hub Caring for Carers (see Resources section).

# Palliative Care



# Palliative care

Many people find the words “palliative care” difficult and think that palliative care relates only to terminal care, signalling the end of life. In fact, palliative care is appropriate at any stage of COPD and can be provided together with regular treatment to complement the treatment you receive from your respiratory healthcare team. As your COPD progresses, the care provided to you will focus on keeping you as well as possible and maintaining the best possible quality of life. This is called a palliative care approach which aims to:



- Provide relief from symptoms such as pain, breathlessness or fatigue.
- Give you and your family psychological support to assist you to adapt to the progression of your disease.
- Help you plan for the future.

## *Who provides palliative care?*

Depending on the severity of your symptoms, input from healthcare professionals that are specialised in palliative care (Specialist Palliative Care team) may be required along your journey with COPD. This can be arranged through your GP or any member of the healthcare team. Palliative care is available in hospitals, in your own home, in community hospitals, nursing homes and hospices. Palliative care is delivered by all healthcare professionals.



*Planning for the future*

# Planning for the future



## *What does planning for the future mean?*

We plan so we can prepare for and influence events that may happen in the future. People plan for the future in different ways; by saving for a rainy day, contributing to a pension, by making a will or by making an advance healthcare directive. Planning for the future also includes talking with your family and doctors about your wishes and preferences should you become very unwell and unable to communicate for yourself. Everyone should plan for the future as anyone's health can change suddenly.

For some people, planning for the future can feel overwhelming. When you are living day-to-day with COPD, it may feel like the last thing you want to do. However, planning for the future can be helpful because it can give you some control over matters that may affect you in the future.

Some people plan for the future by saving for a rainy day or by making a will.





People who have planned ahead report feeling relieved that arrangements are in place. They also report being able to focus on living their life rather than worrying about the future.

Planning for the future can help you to:

- Create opportunities to do enjoyable things.
- Say important things to the people you care about.
- Be prepared for various situations that might arise.
- Reduce the practical and emotional burden on family and friends.
- Address concerns and fears you and your loved ones may have.
- Remain in control at a time when this may become limited, for instance during a crisis situation.
- Enjoy life knowing that important things have been discussed.

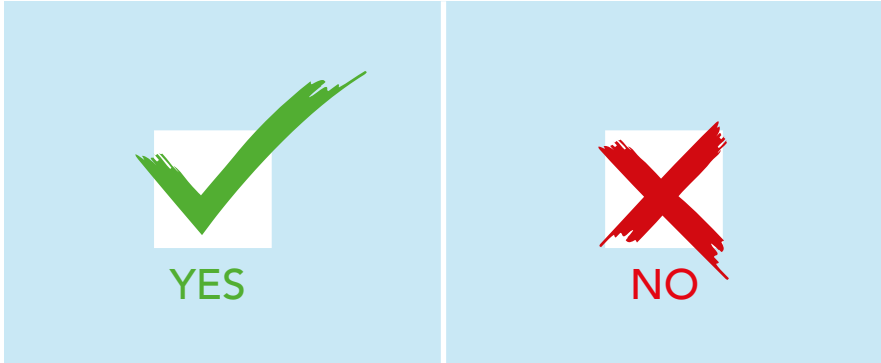
## *What is advance care planning?*

You are the best judge of what matters to you and your treatment preferences. It is important that your doctor, nurses and family understand and respect your wishes for the care you would like to receive, especially towards the end of your life. Normally, you would make an advance care plan with your healthcare team. If you wish, you can also include your family and friends in these discussions (see page 30 for useful tips on starting the conversation).

Advance care plans can be useful if the situation arises that you are no longer able to communicate your wishes or make decisions. Your advance care plan will allow your doctors to continue to care for you according to your wishes and care preferences.

You may wish to continue to receive treatments designed to make you comfortable and reduce your distress. You may want to be much more specific about which treatments you want or don't want. It may be helpful, and make your loved ones feel more confident about ensuring your wishes are respected as much as is possible, if you write down the details of the type of care you want.

You have a right to refuse any medical or surgical treatment. Your doctors and/or nurses can help you understand how your disease may progress in the future and what treatments will be available to maximise your quality of life. If you wish, your doctor can also help you put your advance healthcare directive in place.



## *Advance healthcare directives*

An advance healthcare directive is where you write down what you would like to happen in relation to the use of certain medical and care treatments. This includes for instance:

- Cardiopulmonary resuscitation (CPR) if your heart stops.
- Artificial invasive ventilation (a machine to breathe for you or support your breathing if you stop breathing).
- Artificial nutrition (tubes that feed you if you can no longer swallow).

If you create an advance healthcare directive, you can nominate someone to speak for you if a time comes when you can no longer speak for yourself, and/or state what you would and would not want to happen regarding certain medical and care treatments.

Issues that may be covered in an advance healthcare directive include:

- Treatments that you **would not want** in the future – this is legally binding.
- Treatments that you **would like** in the future – this is NOT legally binding. Your views will be taken into account, but doctors cannot be forced to provide a treatment that, for various reasons, they don't believe is appropriate or beneficial (see [www.hospicefoundation.ie](http://www.hospicefoundation.ie)).

### *How do I create an advance healthcare directive?*

Your doctor can help you to create your advance healthcare directive, and answer questions you may have (see page 31 for tips on having conversations with your doctor). There are forms that can help you to write your advance healthcare directive.



You can get the ***Think Ahead: Speak for Yourself*** form (developed by the Irish Hospice Foundation) at [www.thinkahead.ie](http://www.thinkahead.ie) or from your local Citizens Information Centre.

You can change your advance healthcare directive at any time. It is important that you regularly check it still reflects your wishes and preferences. Remember, advance healthcare directives only come into action when you are no longer able to communicate your wishes.

Make sure your family and healthcare providers are aware that you have an advance healthcare directive. It is a good idea to store this document in an accessible and known place should the time arise.

## *Planning legal affairs*

Things you can do to plan your legal affairs include:

### 1 **Make a Will**

A will is a legal document that sets out who you want to inherit your possessions, property and money when you die. Your possessions, property and money are called your estate. The people you want to receive or inherit your estate are called your beneficiaries. As part of making your will you appoint one or two people to manage your estate. These people are called your executors and they make sure your wishes are followed. If you do not make a will then everything you own will be distributed in accordance with the law as set out in the Succession Act 1965. Dying without a will is called dying intestate. If you die without a will,

the law sets out who may inherit from you and in what order they may inherit. If you have no living relatives, the State will inherit your estate.

**2 Set up an Enduring Power of Attorney**

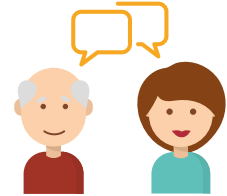
An Enduring Power of Attorney, EPA, is a legal document that sets out who you would like to manage legal, financial and certain personal care decisions for you if you reach a point where you cannot make these decisions yourself. This person or people are called your Attorney(s). You can choose family members or friends to become an Attorney. Setting up an EPA is a good idea. It means you can state who you want to manage these areas for you when you can no longer do this yourself.



*Talking about  
your wishes*

# Talking about your wishes

## Talking about your wishes with your family or someone you trust



Talking openly and honestly gives everyone a shared understanding about what matters most to you at the end of life. You may find that some people are open about your illness and are there to talk, however difficult the conversation may be. Others may seem withdrawn or even uninterested. People cope with this in different ways.

Finding the right moment can be difficult. Who you tell, and the amount of detail you want to share, is up to you. Your family may find it easier to know you have made plans. Be honest about what your COPD means, how you feel and why you have taken these steps.

Below is what people have said about why they like to plan ahead:



*"As much as I can, I want to avoid any legal or financial problems."*



*"I want to make sure my family don't have to face these decisions later without knowing what I want."*



*"We should all plan ahead. We shouldn't be afraid of planning. It makes life much easier in the end."*





*"It is important that I do this now, it is much easier for me to do this early."*



*"This is not a topic I like to talk about but I want to make sure my family knows what kind of care I want to receive if I can no longer decide for myself."*



*"I like to be in control of my affairs till the very end."*



*"Thinking and talking about this now gives me peace of mind."*

## *Talking about your wishes with your doctor or members of your healthcare team*

After you have had the conversation with your family and/or friends, the next step is talking to your doctor or nurse about your wishes. Don't wait for a medical crisis to happen; talking with your doctor or nurse early makes it easier to make medical decisions when the time comes. Even if you are in good health, it's still important to make sure your healthcare

Don't wait for a medical  
crisis to happen.

Take action early!



team knows your wishes and care preferences, since anyone's health can change suddenly. It's particularly important to have this conversation if you or a loved one has a chronic illness like COPD.

Remember: you are the expert about what matters most to you. Your doctor and healthcare team's role is to listen carefully to you, and then help you make the most appropriate decisions about your care.

You will probably have several conversations with your doctor over time, and each one will be a little different. Every conversation will help your healthcare team understand what matters to you. Most importantly - don't wait until there is a crisis. And don't wait for your doctor to bring it up. It always seems too early ... until it's too late.

### *Here are a few things to consider that might help in having this conversation:*

**Who do you want to speak with?** – Your GP or practice nurse, respiratory doctor or nurse, perhaps another healthcare professional?

**When is a good time to have this conversation?** – Make plans and ideally let the clinic/doctor/nurse know in advance that you wish to talk about your future care plans, so they can be prepared and make time for it.

Here are some questions you can have written down in advance to help you understand your or your loved one's medical problems:



*"Can you tell me what I can expect from this illness? What is my life likely to look like six months from now, one year from now, and five years from now?"*



*"What can I expect about my ability to maintain my independence?"*



*"What are some possible big changes in my health that my family and I should be prepared for?"*



*"What can I expect to improve (or not improve) if I choose this course of treatment, or another course of treatment?"*



*"What can I expect if I decide to do nothing?"*

**Ask a lot of questions:** *"I don't understand - can you explain it in a different way?"*

**You don't have to decide about anything right away.**

It is important to have follow-up conversations to revisit the issues that come up in these conversations. Your preferences may change as time passes. Your healthcare team may ask you to consider treatment options that you need to think about for a bit.

**More information about starting a conversation with your loved ones and your healthcare provider is available from the *Conversation Project* (see Resources section).**

# Glossary of terms



# Glossary of terms



**Advance healthcare directive** is an expression made by a person who has capacity (in writing, to include voice, video recording and speech recognition technologies) of their will and preferences concerning specific treatment decisions in the context of an anticipated deterioration in their condition with loss of decision making capacity to make these decisions, to give consent to or refuse treatment and communicate them to others. An advance healthcare directive is legally binding (therefore certain formalities must be followed) when a person writes down what treatments they would refuse in the future and the circumstances in which the refusal is intended to apply. The Assisted Decision Making (Capacity) Act 2015 provides that a request for a specific treatment is not legally binding but should be followed if relevant to the medical condition for which treatment is required (Oireachtas, 2015).

**Chronic Obstructive Pulmonary Disease (COPD)** is an umbrella term used to describe progressive lung diseases including chronic bronchitis, emphysema or a combination of both. COPD is an illness that makes it hard to empty air out of your lungs. When this happens the airways get smaller leading to airflow obstruction (COPDSI, 2016).

**Disease** is the medical term to describe an *illness*. The term *illness* is often preferred by people to describe an ailment, affliction or infirmity.

**Enduring Power of Attorney** is a document, drawn up with a person who has legal capacity, which gives another person(s) the power to make general and/or specific decisions. This comes into effect when a person lacks decision making capacity, and their enduring power is registered with the Wards of Court Office (Oireachtas, 2015).

**Family members** are those people closest to the person with COPD in knowledge, care and affection. This includes people not related biologically or by marriage, and can include those identified by people as being key in their lives, for instance close friends.

**Illness** – see Disease.

**Palliative Care** is an approach that improves the quality of life of people and their families facing the problems associated with progressive and life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems; physical, psychosocial and spiritual.

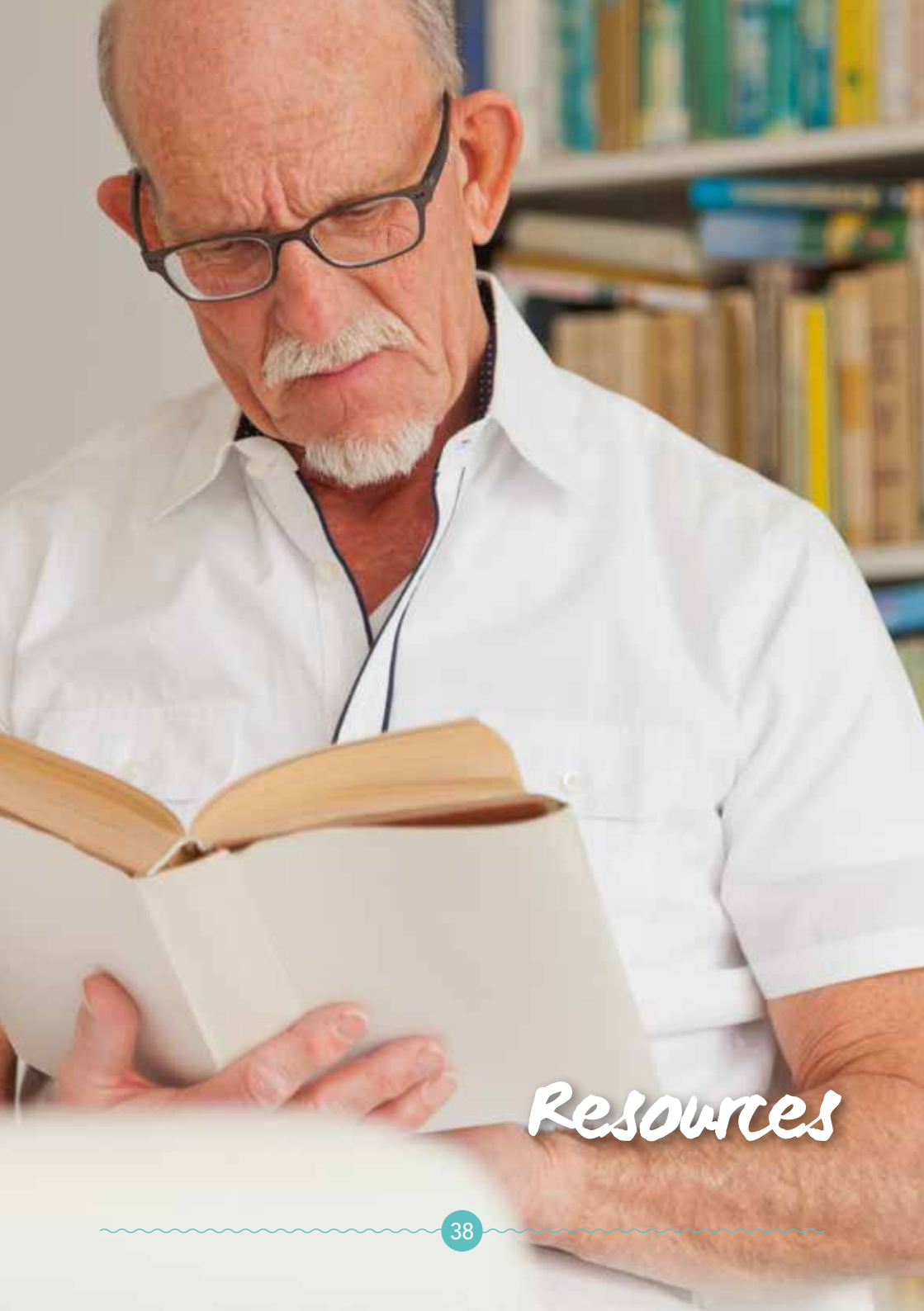
Palliative care provides:

- Relief from pain and other distressing symptoms.
- Affirms life and regards dying as a normal process.
- Intends neither to hasten nor postpone death.
- Integrates the psychological and spiritual aspects of patient care.

- Offers a support system to help people live as actively as possible until death.
- Offers a support system to help the family cope during a person's illness and in their own bereavement.
- Uses a team approach to address the needs of people and their families, including bereavement counselling, if indicated.
- Enhances quality of life, and may also positively influence the course of illness.
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

(World Health Organisation, 2014)

A **Will** is a legal document that sets out who you want to inherit your possessions, property and money when you die.



## *Resources*



# Resources



1. AllHPC Palliative Hub Caring For Carers: [www.carers.thepalliativehub.com](http://www.carers.thepalliativehub.com)
2. Citizens Information: [www.citizensinformation.ie](http://www.citizensinformation.ie)
3. COPDSI: [www.copd.ie](http://www.copd.ie)
4. European Lung Foundation: [www.europeanlung.org](http://www.europeanlung.org)
5. Family Carers Ireland: [www.familycarers.ie](http://www.familycarers.ie)
6. Global Initiative for COPD (GOLD): [www.goldcopd.org](http://www.goldcopd.org)
7. Irish Hospice Foundation: [www.hospicefoundation.ie](http://www.hospicefoundation.ie)
8. National Council for Palliative Care (UK) (2010) *Difficult Conversations Communicating with people with Chronic Obstructive Pulmonary Disorder and the End of Life*: [http://www.ncpc.org.uk/difficult\\_conversations](http://www.ncpc.org.uk/difficult_conversations)
9. Palliative Care Senior Nurses Network (2015) *Asking the questions that matter to me*: <http://www.adultpalliativehub.com/resources/helpful-documents/palliative-ca>
10. The Institute for Health Care Improvements (2013) *The Conversation Project*; available at: <http://www.ihc.org/Engage/Initiatives/ConversationProject/Pages/default.aspx>
11. Think Ahead Form: [www.thinkahead.ie](http://www.thinkahead.ie)

# Acknowledgements

We wish to express our gratitude and appreciation to the working group members for their dedication and committed participation in the workshops and development of this booklet.



**Picture from L-R:** Deirdre Shanagher, Gerardine Malone, Pauline O’Neill, Ann Murphy, Michael Drohan, Terri McDonnell, Damien Peelo and Bettina Korn; working group members not pictured: Janet O’Leary, Marie Ritchie, Veronica Taffe, Peter McQuillan and Bernie Murphy.

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## REFERENCE

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