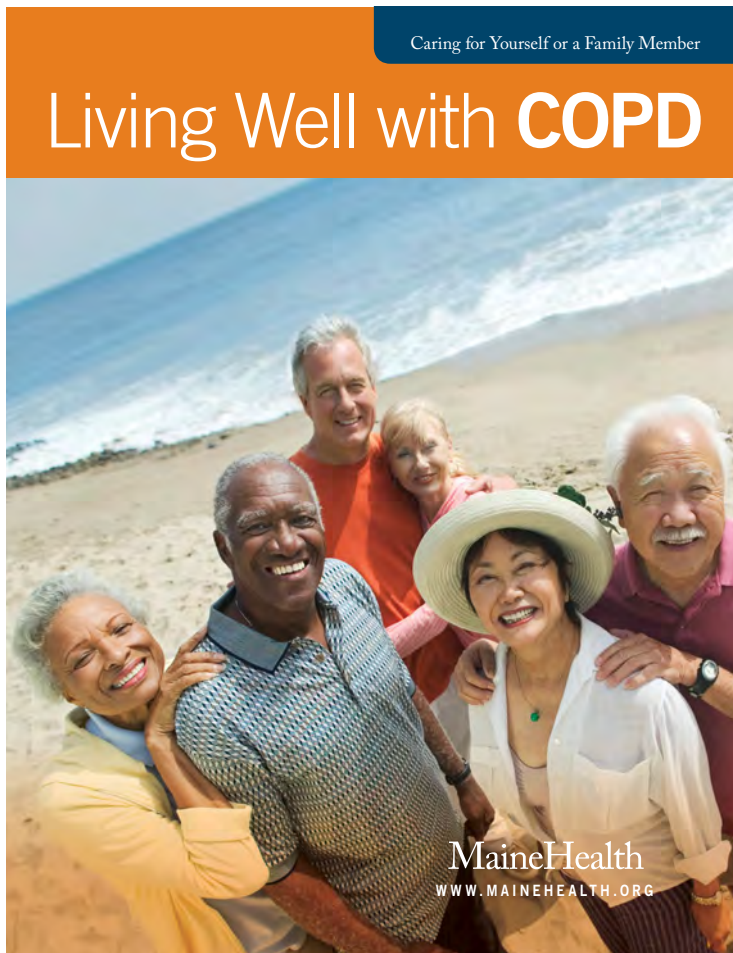


# Living Well with COPD

This information is part of the MaineHealth  
Living Well with COPD patient education book.



This book was created for patients and their families to help them manage their lung disease.

Your doctor or nurse chose this section because they felt it would be most helpful for you.

There are 10 sections in the COPD book and a list of definitions in the glossary section. Share this information with family, friends and those who help care for you.

## SECTION

# 10

## Dealing With Advanced Illness

### In This Section:

- When You Are Dealing With Advanced Illness
- Glossary

MaineHealth

WWW.MAINEHEALTH.ORG

# 10 Dealing with Advanced Illness



## When You Are Dealing with Advanced Illness

There is no cure for COPD. It is a progressive lung disease that can be managed with treatment for many years. COPD will get worse over time. You will need to think about choices for the care you want to receive as you get sicker and closer to the end of life.

Although it may be hard, talking with your doctor and family about your wishes while you are feeling well is very important. By planning ahead, your doctors and family will be able to understand how you wish to be cared for and what matters most to you.

### Advance care planning

**Advance directives** (sometimes called living wills) are forms that you fill out to let your doctor know what your healthcare goals are and what is important to you. These forms are recommended for all adults.

Advance directives include information about:

#### A healthcare agent (sometimes called a medical power of attorney):

This is the person you want to speak for you if you cannot speak for yourself.

#### Medical care:

The medical care you wish to receive if you become too sick to make decisions or communicate with others.

#### Treatments:

The types of treatments you do and do not wish to receive.

It is important to talk to your **healthcare agent** about what is important to you. Your agent should be someone you trust, who is willing to accept the responsibility and follow the instructions you have given. These conversations are complex and sensitive. Ask your healthcare team for help making these decisions.

After completing your Advance Directive, share it with your doctor, family and healthcare agent.



## Palliative care

The goal of **palliative care** is to help people with a serious illness live fully. It focuses on preventing suffering, managing symptoms and coordinating communication between many caregivers. Palliative care is a medical specialty, and the palliative care team includes a doctor, nurse, social worker, behavioral health therapist and chaplain. The team makes sure that all the patient and family needs are met. Palliative care can be provided at any stage of an illness, from diagnosis through the end of life, and combined with ongoing treatment.

## Physician Orders for Life-Sustaining Treatment (POLST)

The POLST form is a medical order stating a patient's wishes regarding treatments. The form helps to define the goals of treatment when an illness becomes more advanced so that the patient's choices are respected and followed. It must be completed by a physician, physician assistant or advanced practice nurse and is printed on special colored paper. Emergency personnel—such as paramedics, emergency medical technicians (**EMT**), and emergency doctors—will understand these orders. POLST is also helpful in guiding treatment after the initial emergency.



**Keep a copy of your POLST posted on your refrigerator where the emergency responders can find it.**

---





### Questions to ask yourself

Consider these issues to discuss with your doctor, nurse and family:

- ☐ What does living well mean to you as you are dealing with COPD?  
\_\_\_\_\_
- ☐ If you get sicker, what kinds of treatments would you consider having for the possibility of gaining time? \_\_\_\_\_
- ☐ When time might become short, what matters most to you?  
\_\_\_\_\_
- ☐ What treatments will help you achieve your goals?  
\_\_\_\_\_
- ☐ If your heart stops or you stop breathing, will **cardiopulmonary resuscitation** (CPR) and being placed on a breathing machine help you? \_\_\_\_\_
- ☐ What medicines can be used to ease shortness of breath and anxiety?  
\_\_\_\_\_
- ☐ What support services are available for you and your family?  
\_\_\_\_\_
- ☐ Who do you want making choices for you if you cannot speak for yourself? \_\_\_\_\_
- ☐ Where would you like to be cared for as your lung disease gets worse?  
\_\_\_\_\_

## Hospice

**Hospice** is unique care for people closer to the end of life who want their treatment to focus on comfort. Usually people who get hospice care have a life expectancy of a few months, not years. Even if life cannot be prolonged, comfort can be provided with oxygen, medicines and other treatments by a team of healthcare professionals. This care also includes physical, emotional and spiritual care for the patient, family and caregivers. Hospice care can be provided in the home or in other settings for you and your family.

# Glossary

**Advance directives (sometimes called living wills):** forms that you fill out once you decide what is important to you if you should get into a health crisis

**Air trapping:** when it is difficult to exhale completely

**Allergic rhinitis:** runny nose caused by allergies

**Alpha-1 antitrypsin deficiency:** a genetic disease that can cause COPD

**Alveoli:** air sacs

**Arteries:** blood vessels that carry oxygenated blood away from the heart to the body's cells, tissues and organs

**Arterial blood gas (ABG):** a blood test from an artery that measures how well your lungs are able to move oxygen into your blood and remove carbon dioxide from your blood

**Asbestos:** mineral that can be woven into fabrics and is used in fire-resistant and insulating materials such as brake linings

**Bone density test:** x-ray that measures bone loss

**Bronchial tubes:** air passages or airways

**Bronchodilators:** medicines that make you breathe better by relaxing the muscles in your air passages and keep them from squeezing

**Carbon dioxide:** waste air

**Cardiopulmonary resuscitation:** emergency lifesaving procedure that is done when someone's heart has stopped

**Cataracts:** clouding of the lens in your eye

**Comorbidities:** other chronic diseases a person has that make treating chronic disease more difficult

**Continuous flow oxygen:** oxygen that runs constantly through a tube into your nose and throat

**Continuous positive airway pressure (CPAP):** a device prescribed by a doctor or nurse to treat OSA

**COPD Action Plan:** a guide to help you recognize the early signs of a flare-up and what you should do when a flare-up occurs

**Coronary arteries:** blood vessels that supply oxygen-rich blood to your heart muscle

**Coronary artery disease:** a disease in which a waxy substance called plaque builds up inside your coronary arteries

**Cor pulmonale:** a condition that causes the right side of the heart to fail

**CT scan:** a picture of the inside of a part of your body

**Diabetes:** a condition in which your body does not make enough insulin or does not use insulin correctly

**Diaphragm:** a large muscle that sits below your lungs and does most of the work of breathing

**Dose:** amount of medicine

**Echocardiogram:** an **ultrasound** of the heart

**Electrocardiogram:** a test that checks for problems with the electrical activity of your heart

**Energy conservation:** saving energy

**Esophagus:** passage that connects the mouth and the stomach

**Exacerbation:** flare-up of your symptoms

**Expectorant:** medicine that loosens mucus so it's easier to cough up

**Gastroesophageal reflux disease (GERD):** acid reflux

**Glaucoma:** a condition of increased pressure within your eyeball, causing gradual loss of sight

**Healthcare agent:** the person you want to speak for you if you cannot speak for yourself

**Heart failure:** a condition in which your heart can't pump enough blood to meet your body's needs

**Hospice:** care for people closer to the end of life who want their treatment focused on comfort

**Hypertension:** high blood pressure

**Inflammatory:** swelling

**Inhaler:** device that contains medicine as a mist or powder

**Insulin:** hormone that carries sugar into your cells so that it can be used for energy

**Intravenous:** in a vein

**Long-acting (controller) medicines:** medicines taken once or twice a day that prevent shortness of breath

**Lung transplantation:** surgically replacing one or both of your lungs

**Lung volume reduction surgery:** surgically removing diseased parts of one or both of your lungs

**Mucolytics:** medicines that break up mucus

**Nebulizer:** device that turns liquid medicine into mist

**Nicotine replacement:** medicines that replace the nicotine you do not get when you quit smoking

**Obstructive sleep apnea (OSA):** a condition that causes you to have periods when you stop breathing during sleep

**Osteoarthritis:** mechanical wear and tear on joints

**Osteoporosis:** illness that makes your bones brittle and fragile

**Oxygenated:** combined or mixed with oxygen

**Palliative care:** care provided at any stage of an illness focused on preventing suffering, managing symptoms and coordinating communication between the many caregivers

**Peripheral vascular/arterial disease:** a condition of the blood vessels that supply the legs and feet. It leads to narrowing and hardening of the **arteries**. This causes decreased blood flow, which can injure nerves and other tissues.

**Pneumonia:** lung infection

**Pollutants:** waste materials that are harmful to air, soil or water

**Physician Orders for Life-Sustaining Treatment (POLST):** a medical order stating a patient's wishes regarding treatments that are commonly used in a medical crisis

**Pulmonary hypertension:** high blood pressure in the arteries of the lungs

**Pulse dose oxygen:** oxygen that flows when you breathe in through your nose and stops when you breathe out

**Pulse oximeter:** a machine that measures the oxygen in your blood with a clip that goes on your finger, toe or earlobe

**Quick-relief (rescue) medicine:** medicine that starts to work in a few minutes and lasts a few hours

**Reflux:** when stomach acid backs up and irritates the esophagus

**Rheumatoid arthritis:** when your immune system mistakenly attacks the lining of your joints, causing a painful swelling that can eventually result in joint deformity

**Secondhand smoke:** smoke from a burning cigarette, cigar, pipe or hookah

**Silica:** a very common mineral found in many materials common on construction sites, including soil, sand, concrete, masonry, rock, granite and landscaping materials. The dust created by cutting, grinding or drilling can cause lung disease and cancer.

**Sinusitis:** swelling of the air cavities within the passages of the nose. Sinusitis can be caused by infection, but also can be caused by allergies and irritation of the sinuses.

**Spirometry:** a test to see how well your lungs are working

**Sputum:** mucus in your lungs

**Stroke:** when blood flow to an area of your brain is cut off

**Suppressant:** medicine to help you cough less

**Thirdhand smoke:** tobacco particles that stay on surfaces long after burning tobacco has been put out

**Thrush:** infection of the mouth and throat

**Trachea:** windpipe

**Ultrasound:** a test that uses sound waves to see inside your body

**Vaping devices:** electronic cigarettes, cigars and pipes that produce steam vapor when smoked