

Advance Directives: Planning and Empowerment



The COPD Foundation's mission is to prevent and cure chronic obstructive pulmonary disease and to improve the lives of all people affected by COPD.

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Advance Directives: Planning and Empowerment

Nobody likes to think about dying or losing a loved one. But dying is a natural part of all our lives. And when we die, it should be on our own terms.

For some people, “living” means being active and doing things that are meaningful to them. For others, “living” means having a heartbeat, no matter how sick they are.

Whatever the case, it’s important to make sure your wishes (not what others think you want) are known. This may be hard to think about, but there may come a time when you are not able to speak for yourself. Your family members might then be asked to make decisions for you. This could lead them to make a decision you would not have wanted.

Having your plans and wishes in writing – something called an advance directive – assures you that your wishes will be carried out if you are very sick or unable to speak for yourself about your medical care.

***COPD** is an umbrella term used to describe progressive lung diseases including emphysema (em-fa-see-ma), chronic bronchitis (kron-ick brawn-kie-tis), and refractory (non-reversible) asthma. This disease is characterized by increasing breathlessness.

Does This Mean I'm Giving Up?

Having an advance directive does not mean you're planning to die anytime soon. It does not mean that you are "giving up." Everybody should have plans for their last days, even if they are young and don't have a chronic disease.

Sometimes our family members do not want to talk about this. It may be too painful to think about losing a loved one. They should understand, though, that if a time comes when you are unable to speak for yourself, it will be a lot easier for them if your wishes are known in advance.

Sometimes even doctors are not at ease with this topic. It may be hard for them because they are so focused on health and finding cures.

Common Questions

As you begin to think about your advance directive, it is normal to have a lot of questions. Not having answers can cause you to feel frustrated and anxious. But learning now about options for treatment and care will give you the information you need to help you to live more fully and comfortably.



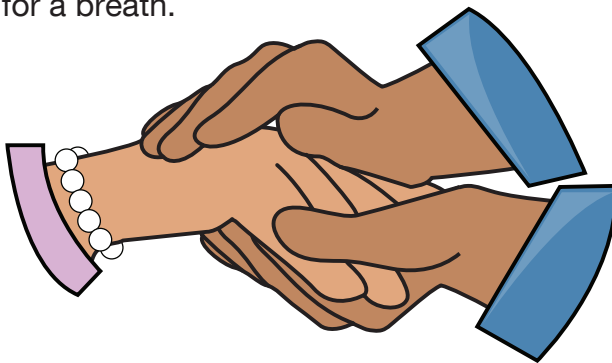
You may be asking:

- What treatment choices do I have?
- If I am hooked up to a breathing machine, can they take me off of it?
- If I am in the hospital in my last days, will I still need to have blood tests, x-rays, and other procedures?
- What will happen to me as I die?
- Will I feel like I am suffocating?
- Will I be in pain?
- What about hospice care?

Let's take a look at two common concerns people with COPD have when they think about their last days.

Fear of Suffocating

Many people with COPD are afraid they will feel like they are drowning or being smothered in their last days. It's important to know that extreme shortness of breath can be treated with oxygen. Also, some medications can reduce the feeling of struggling for a breath.



Sometimes in very advanced COPD, the lungs are not able to breathe out carbon dioxide. When this happens, the high level of carbon dioxide can have a sedative, or calming, effect. This leads to a state of drowsiness and, finally, to a coma.

Pain Control

Those with COPD nearing the end of life do not usually require pain control; however, many people are worried about pain when they think about end-of-life issues. Your doctor may first suggest over-the-counter medications. If these medications are not working, he or she will want to know more about your pain, and ask: “Does your pain come and go? Do you have pain all the time?” How you describe your pain will help your healthcare provider find its cause.

Pain medications come in many forms and strengths. Your healthcare provider may suggest a pill, capsule, or liquid medication. If these do not help, some medications can be given through a patch on the skin. Others can be given by a shot or by a small pump attached to tubes placed under the skin.

In the time nearing the end of life with any illness, your healthcare provider will take all steps needed to make sure you are given comfort and are as pain-free as possible.



Palliative Care and Hospice Care

There is often confusion about palliative and hospice care and the differences between the two.

Palliative (*pal-yuh-tiv*) Care

Palliative care focuses on relief from physical suffering. Individuals under palliative care may be in treatment for a disease, may be living with a chronic disease, and may or may not be terminally ill. Palliative care can be given to people at all stages of a chronic disease and is based on their needs at any time. The goal of palliative care is to improve quality of life for the person being cared for and his or her family.

Medications that prolong life can be used. A multi-disciplinary team of special healthcare professionals work to help individuals with their physical, mental, social, and spiritual well-being. Ask your healthcare provider – no matter where you are on your COPD journey – if palliative care is right for you.

Hospice Care

Hospice care is one type of palliative care. It is available to those who are terminally ill and is given by a hospice nurse. It is offered at a place you prefer such as in your home, a care facility, or a hospital. Hospice care may last for six months or up to 12 months depending on the policies in your local area.

A major goal of hospice is to keep you comfortable and help you and your family to get ready for the time when some treatments may be stopped. Life-prolonging medications are not used in hospice care.

Advance Directives

Let's get back to the topic of advance directives. These can be one or more documents that explain what you want, and what you do not want, as you are nearing the end of life.

Advance directives can be written in many ways. You can get special forms from your healthcare provider or hospital, a lawyer can help you prepare them, or you can find free forms and help online.

Advance directives do not have to be complex legal documents. They can be short, simple statements about what you do or do not want done. You can start by simply writing down your wishes. You may want to have this read by your doctor or lawyer. You should also have it notarized. Copies should be given to your family and your healthcare providers.

The best way to make sure your wishes are followed is to put them in writing and talk with your family and healthcare providers.



Free advance directive forms for each state and online help

American Association of Retired Persons (AARP)
www.aarp.org/caregiving/financial-legal/free-printable-advance-directives/

US Advance Care Plan Registry (USACPR)
www.usacpr.net/

Advance directives may be:

- A living will, which may or may not include a resuscitation directive.
- A durable medical power of attorney.

Living Will

A living will has information about medical procedures that you may or may not want done to keep you alive. Some of the examples of issues addressed in a living will are:

- If it is known that you will not wake up or will not be able to use your body in a meaningful way, do you want to be kept alive? Do you want to be on a machine that would breathe for you?
- If it is known that you will not wake up, do you want to be fed through a feeding tube? A feeding tube gives you liquid food to help you stay alive. The tube is passed through your nose, down into your stomach, or directly into your stomach through a small hole.
- When your heart stops beating or your breathing stops, cardiopulmonary resuscitation, or CPR, is begun. This is done to try to restart your heart and/or breathing. There may be certain situations in which you would not want CPR done. If you do not want CPR done, you can state that in your living will.



A living will can be very specific, or it can be a broad statement of what you do and do not want. A living will should be a guide to help your family understand your wishes. They might be asked to make decisions for you if you are unable.

Durable Medical Power of Attorney

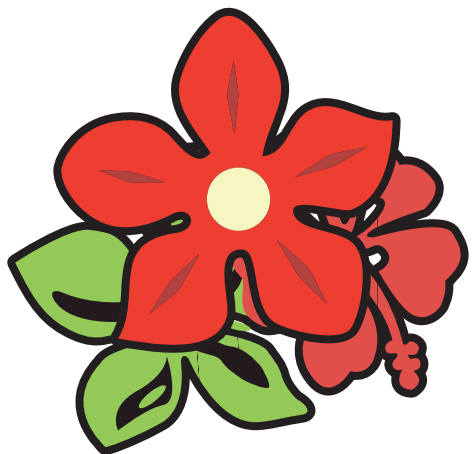
A Durable Medical Power of Attorney paper allows you to choose a person you trust to make medical decisions for you. Hospitals and healthcare providers do not want to make your medical decisions. This is true even if you have a living will. The person named in your Durable Medical Power of Attorney has the right to make only medical decisions for you. This document does not allow the person to make financial or other decisions for you.

Advance Directives Planning Empowers You

For many people, this time in their life, their last days, is a time to do the things they had put off. For some, this time gives them the chance to find answers to long-held problems.

Some people actually describe this as a happy period. It can be a time when family and friends come together. It can be a time to share what they have learned with others. It can be a time to be assured that they are loved and to tell others that they love them. During this time, some people want to visit with close friends, family, and spiritual leaders. Other people do not want to spend a lot of time with too many visitors. Still others find comfort in spending time alone. You should feel free to tell your family your wishes about this.

You and your family should also talk with your healthcare provider about where you would like to be during this time in your life. You might choose to be in the hospital. Or you might choose to be at home.



Nobody likes to think about dying or losing a loved one. But dying is a natural part of life for all of us. Plan ahead. Consider talking about these issues long before you need to make any decisions. This will give you and your family enough time to talk about all your wishes and concerns. Then you will have the peace of mind that the planning has been done. You can forget about it and go on living!

Be empowered. You, and only you, should be the one to decide what is meaningful to you. You have the right to say what kind of treatment you want and don't want. Advance directives help you have the dignity to live, and die, as you wish.



www.copdfoundation.org
www.COPD360social.org

**This Slim Skinny Reference Guide® (SSRG)
was created by the COPD Foundation.**

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