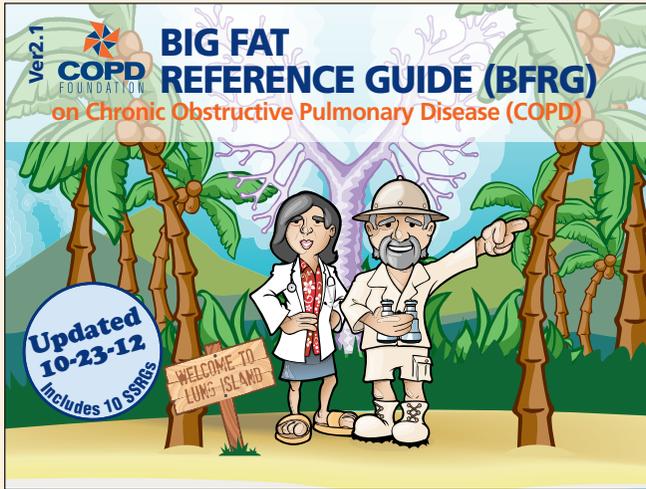


End of Life Issues
COPD Foundation's
Slim Skinny Reference Guide® (SSRG)

End-of-Life Issues





This “Slim Skinny Reference Guide: End-of-Life Issues” is part of the COPD Foundation’s *Slim Skinny Reference Guide*® series which has been taken from the *COPD Big Fat Reference Guide*®.

To access the complete *COPD Big Fat Reference Guide*®, visit www.copdbfrg.org.

The mission of the COPD Foundation is to develop and support programs which improve the quality of life through research, education, early diagnosis, and enhanced therapy for persons whose lives are impacted by Chronic Obstructive Pulmonary Disease (COPD).

End-of-Life Issues

Talking about death or “end of life” is not easy for anyone. Most of us have some fears about it. Sometimes our family members do not want to talk about it. It can be too painful for them to think about losing a loved one. Sometimes even doctors are not at ease with the topic. It may be hard for them because they are so focused on health and finding cures.

***COPD** is an umbrella term used to describe the progressive lung diseases including: emphysema (em-fa-see-ma), chronic bronchitis (kron-ick-brawn-kie-tis), refractory (re-frac-ta-ree) asthma (az-ma) and some forms of bronchiectasis (brawn-key-eck-tay-sis). If you have COPD you have trouble moving air in and out of your lungs because of damage to the airways and/or the air sacs.



Often when we ask questions about death we are told to “think positively.” But just thinking positively may not help you know how to plan for your death. It does not answer your questions about your future. Not knowing where to turn for answers can make you feel depressed and frustrated.

It is ok and you are not “giving up” if you ask end-of-life questions. You may want to know:

- What will happen to me as I die?
- Will it be painful?
- What treatment choices do I have?

This *Slim Skinny Reference Guide*® cannot fully answer all of your questions. But there is some general information here that may help you and your family prepare for the future.

Common End-of-Life Concerns

Fear of suffocating: Many lung disease patients are afraid their death will feel like they are drowning or being smothered.

Remember: extreme shortness of breath can be treated with oxygen.

Also, medicines called **sedatives** (*said-ah-tives*) can be taken.

These calming drugs can reduce the feeling of struggling for a breath.

During the final stages of lung disease, the lungs are not able to breathe out carbon dioxide. This causes carbon dioxide **narcosis** (*nar-coe-sis*).

This means that the high level of carbon dioxide can have a sedative or calming effect. This leads to a state of drowsiness and then finally, to a coma.



Pain control: Many people are concerned that they or their loved one not suffer pain as the end-of-life is near. End stage lung disease does not usually require pain control. However, many people are worried about pain when they talk about end-of-life issues. Your doctor may first suggest over-the-counter medicines. You may have taken these before. If these medicines are not working, your doctor will want to know more about your pain. Your doctor may ask: Does your pain come and go? Do you have pain all the time? How you describe your pain will help your doctor find its cause. Pain medicines come in many forms and strengths. Your doctor may suggest a pill, capsule or liquid medicine. If these do not help, some medicines can be given by a patch on the skin. Other medicines can be given by shot or by small pumps attached to needles placed under the skin.

During the end stage of your lung disease, your doctor will take all steps needed to make sure you are given comfort. You and your family should talk with your doctor about where you wish to be during this stage of life. You might choose to be in the hospital.

Or you might choose hospice care, perhaps at home. *(Hospice care is given to patients at the end stage of their disease. Patients getting hospice care usually have less than 6 months to live. It focuses on no suffering, managing symptoms and giving comfort. It can be provided at home or in a facility. It is covered by Medicare and often Medicaid.)*

During this stage of life, some people want to visit with close friends and family. Other people do not want to spend too much time with too many visitors. You should feel free to tell your family your wishes about this.

Do not feel that you have to put off discussing any of these issues until the end is near. You may want to talk 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.

Other Comfort Measures:

Meditation (med-ee-tay-shun)

Relaxation exercise

Imagery

Hypnosis (hip-no-sis)

Support groups

Pastoral and spiritual support

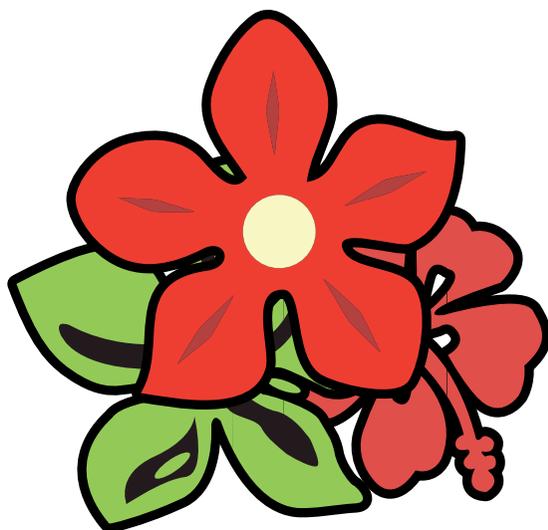
Making End-of-Life Plans

Being prepared will help you to live more fully and comfortably in your final days. You and your family should talk about your disease and all your treatment choices. If you wait until you are very sick and in the hospital, you may not be able to make your wishes known. Your family members may be asked to make decisions for you. They could make a decision that you would not have wanted.

It is important for you to talk with your family and your doctor about:

- Being in the hospital—do you want to stay there or have hospice care at home?
- The use of **ventilators** (*vin-ta-lay-tors*)—this is a machine that breathes for you when you no longer can.
- **Cardiopulmonary resuscitation** (*car-dee-oh-puhl-mon-airy ree-su si-ta-shun*) (CPR)—this is an emergency medical procedure done when a person’s heart stops or they stop breathing.

Often the best way to make your wishes known is to prepare Advance Directives.



Advance Directives

Advance directives can be one or more documents that explain what you do and do not want done for you at the end-of-life stage. The list is written out so that your wishes can be followed even if you are not able to talk. Advance directives can be written in many ways. You can get special forms from your doctor or the hospital. A lawyer can help you prepare them. Or many groups have information about preparing advance directives. (*See the Groups sidebar*). They offer free forms and online help.

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 choose to simply write your wishes down. You may want to have what you have written read by your doctor or lawyer. You should also have it **notarized** (*no-tore-rized*). (*This means it is signed by a notary public. By signing it, the notary confirms the document was signed by you.*) Copies should be given to your family and your doctor. You should also *talk* with your family and doctors. This is very important.

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

Advance directives may be:

- A living will
- A **durable** (*der-rah-bull*) medical power of attorney
- A resuscitation directive

Groups That Offer Advance Directives Help:

American Medical Association

American Academy of Family Physicians

American Bar Association

American Association of Retired Persons

American Cancer Society

U.S. Living Will Registry



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 **mechanical ventilation** (*meh-can-ni-cal ven-ti-lay-shun*)? This means a machine would breathe for you.
- If 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 or into your stomach through a small hole.

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 select a trusted person to make medical decisions for you.

Hospitals and doctors 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 only has the right to make *medical* decisions for you. This document does not allow the person to make financial or other decisions for you.

Resuscitation Directives

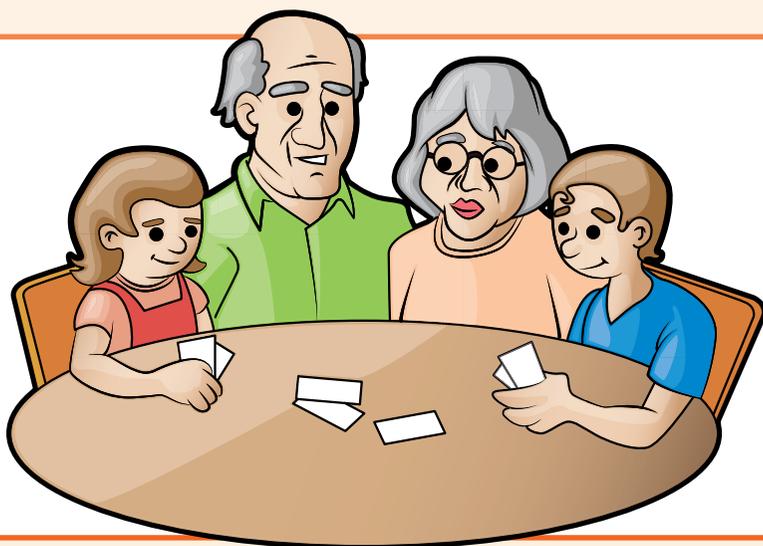
When your heart stops working or your breathing stops, cardiopulmonary resuscitation or CPR is begun. This is done to try and restart your heart or breathing. There may be certain situations in which you might choose that CPR not be done. If you do not want CPR done in these situations you can create a document asking that you be listed as “DNR—do not resuscitate.”

And finally...

For many people, the final stage of their life is a time to do many of the things they put off. Some people describe this time of life as a happy period. It can be a time when family and friends come together and share. For some, this stage gives them the chance to find answers to long-held problems. Many people see this stage of their life as a chance to share what they have learned with others. And still others find comfort in spending time alone. **What we decide is meaningful and is different for each of us.**

“I wanted a perfect ending. Now I’ve learned, the hard way, that some poems don’t rhyme, and some stories don’t have a clear beginning, middle and end. Life is about not knowing, having to change, taking the moment and making the best of it, without knowing what’s going to happen next. Delicious ambiguity.”

— Gilda Radner, actress, comedian.



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

Take Action Today. Breathe Better Tomorrow.



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