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[www.uptodate.com](http://www.uptodate.com) ©2013 UpToDate®**Patient information: Medical care during advanced illness (The Basics)**Written by the doctors and editors at UpToDate

**Choosing medical care when you have an advanced illness** — Most people are used to going to the doctor with a problem, and having the problem “fixed” or cured with treatment. Unfortunately, some advanced illnesses such as advanced cancer or end-stage heart or liver disease can be slowed down but not cured. Plus, many advanced illnesses can be treated in more than 1 way. Often treatments for advanced illness are intended to relieve symptoms rather than extend life very much.

When there is more than 1 treatment option for an advanced illness, the choices between options often involve trade-offs. One treatment might be more likely to prolong life but have a greater risk of side effects. Another treatment might be less risky, but also less likely to extend life. Sometimes treatment options differ in the side effects they cause, such as how tired or sick they make you feel, or how long they keep you in the hospital. This means that people with life-threatening illnesses often have tough choices to make. They might have to weigh the pros and cons of treatments, and decide—with help from their doctors and nurses—which treatments are right for them.

If you have a life-threatening illness, it's important for you to take part in your own care. As you work with your doctors and nurses to choose the care that is right for you, try to stay as informed as possible. Any time your doctors offer a new treatment, make sure you understand:

- What are the benefits of this treatment? Is it likely to help me live longer? Will it reduce or prevent symptoms?
- What are the downsides to this treatment?
- Do I have other options besides this treatment?
- What will happen if I do not have this treatment?

If you have trouble understanding your choices, ask your doctors and nurses to explain them in a different way. The right treatment for you will depend a lot on how you feel about what might happen with each choice.

**Take part in your own care** — When patients and doctors work together to make decisions, it is called “shared decision making.” Research shows that people who take part in shared decision making are more likely to get the care they want and to feel satisfied with their care.

Doctors and nurses are experts in medicine. They know which treatment options might work for you, and how likely they are to help. But you are the expert in what matters most to you. That's important, because 2 people could have exactly the same medical problem but choose different treatments based on how they feel about their options and what they value most.

Imagine, for example, 2 men with the same form of advanced cancer. One of them might choose to have a type of treatment that makes him feel tired and weak, because it might extend his life by a few months. The second man, on the other hand, might prefer to skip the treatment and instead have more energy, even if this means that his life might be cut a little short. In this situation there is no 1 right answer. There is only a right answer for each individual. People with life-threatening illnesses other than cancer also face similar choices.

Here are some questions for you to think about: Do you want to live for as long as possible, no matter what? Or

would you rather be as independent and active as possible during the time you have left? Would you rather skip some treatments, so you can be home more of the time? Or would you rather do everything possible to fight your disease, even if it means spending more time in the hospital?

Your answers to these questions and others like them can help shape your treatment. That's why it's so important to talk openly with your doctors and nurses about what you want out of your treatment.

**Aggressive care** — You should also think about how aggressive you would want your treatment to be, if things don't go as well as you hope. Do you want doctors to do everything possible to keep you alive? Or would you prefer to skip aggressive care and have the doctors focus on making you as comfortable as possible?

It is best to do this before you get very sick so that you and your loved ones don't have to make big decisions under pressure.

**What's aggressive care like?** — As you decide whether you want aggressive care, make sure you understand what it means to get that type of care. Aggressive care can help you live longer. But it has downsides, too.

Some people with advanced illnesses who choose aggressive care end up in the intensive care unit (ICU). That usually means that they:

- Stay in an open room and are constantly being watched
- Are surrounded by lots of activity and noise at all times of the day and night
- Will likely have to stay in bed and might even be secured to the bed for their own safety
- Have tubes going in and out of various body parts
- Have blood drawn many times a day, and have several procedures done

People in the ICU often get aggressive treatments, such as breathing tubes, that are intended to keep them alive but that don't help their basic illness. In people with advanced illness, these treatments might cause discomfort and yet not prolong life in a meaningful way.

**Ask "what if" questions** — As you decide whether you want aggressive care, think about important "what if" questions. For example, ask yourself:

- **What if I stop breathing? Do I want to be put on a breathing machine?** – If you are put on a breathing machine, you will have a tube that goes down your throat and into your lungs. When the tube is in place, you will not be able to eat. You will also not be able to talk, at least at first. Plus, you will probably be sedated, meaning that you will be on medicines that make you sleep.

Sometimes a breathing machine is needed only for a short time. For instance, some people need a breathing tube just while they recover from a lung infection. But any time a breathing tube is used, it is hard to know for sure if and when it will be able to come out.

- **What if my heart stops? Do I want the doctors to try to shock my heart back into action?** – If a person's heart stops beating suddenly, doctors can sometimes restart it with an electric shock and special medicines. Some people recover completely after their heart is restarted. Others have permanent brain damage from a lack of blood flow to the brain; this is most likely in people who have an advanced, serious illness.
- **What if I can't eat? Do I want a feeding tube put in?** – Some advanced medical conditions make you unable to eat. If you have 1 of these conditions, your doctor might ask whether you want a feeding tube. Getting fed through a tube might keep your body alive for a long time. But this might not be the best choice if you are unlikely to recover from your main illness.

“What if” questions are hard to ask. But if you think about them ahead of time and let your doctor and your family know what you would want in these situations, it makes it much more likely that you will be able to choose your own path. It also makes things easier for your family.

**Make your wishes known** — If you would like to make your wishes known, there are legal documents that can help you. These documents are called “advance directives.” There are many kinds of advance directives, but the 2 most useful kinds are called:

- **Healthcare proxy (also called medical power of attorney)** – A healthcare proxy allows you to choose someone to make medical decisions for you if you become unable to speak for yourself. The benefit of having this document is that it makes it clear to your doctors and to your family members who you want to speak for you. When you choose a healthcare proxy, it is important to talk to the person you choose about the things that you want. That way he or she will know how to make decisions for you.
- **Living will** – A living will allows you to choose now the type of care you want if you become unable to speak for yourself. For instance, a living will allows you to document whether you want a breathing tube or a feeding tube put in.
  - One specific type of living will is called a “**Do not resuscitate/do not intubate order**” (also called a DNR/DNI). A DNR/DNI is a form that tells your doctors and other members of your healthcare team that you do not want your heart restarted and you do not want a breathing tube put in.

The Table lists resources that can help you learn more about making your own advance directives ([table 1](#)).

**What if I don’t want aggressive care?** — If you decide you do not want aggressive care, that does not mean that you have to live with the discomfort of your illness. You can and should get comfort care to control symptoms no matter what.

Comfort care, also called “palliative care,” is treatment to help with uncomfortable symptoms, such as:

- Pain
- Breathing trouble
- Nausea
- Tiredness
- Depression or anxiety
- Confusion

If you have severe trouble breathing but decide not to have a breathing tube put in, you will still get treatments to help you feel less out of breath. In the same way, if you decide to stop treatments to fight your disease, you will get effective treatments to ease your pain.

**Hospice care** — There is a kind of palliative care called “hospice care.” It includes regular comfort care, but it also includes lots of other special services. For example, people in hospice care can often get:

- Nurses and aides who come to the home
- Special equipment, such as a hospital bed, to use at home
- Counseling and support for themselves and their family members

Hospice care is only for people who are not expected to live longer than 6 months, but this does not mean that hospice care will stop if a person lives longer. Hospice care is paid for by Medicare or by private insurance, but people usually get approved for hospice care only if they are willing to stop treatments that are meant to cure them or help them live longer. For example, to get hospice care, you must decide you do not want efforts to restart your heart if it stops.

Deciding to use hospice care can make the last months of life much easier. People who choose hospice care often decide that they want to die at home, and they can get medicines and helpers who can make the last stages of illness as comfortable as possible. If dying at home is not right for you, there are other options.

**More on this topic**

[Patient information: Advance directives \(The Basics\)](#)

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**This topic retrieved from UpToDate on:** Oct 10, 2013.

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Topic 16582 Version 5.0

## GRAPHICS

### Resources that can help you make advance directives

	Address	Phone number	Website
AARP	601 E Street NW Washington, DC 20049	Toll-free: (888) OUR-AARP [(888) 687-2277]	<a href="http://assets.aarp.org/external_sites/caregiving/multimedia/EG_AdvanceDirectives.html">http://assets.aarp.org/external_sites/caregiving/multimedia/EG_AdvanceDirectives.html</a>
Aging with Dignity (Five Wishes® form)	PO Box 1661 Tallahassee, FL 32302	Toll-free: (888) 5WISHES [(888) 594-7437]	<a href="http://www.agingwithdignity.org">www.agingwithdignity.org</a>
Caring Connections		Toll-free: (800) 658-8898	<a href="http://www.caringinfo.org">www.caringinfo.org</a>