Getting the Care You Want

- An advance directive helps give you peace of mind.
- You can't be sure about your health or the care you'll need in the future. But you can make your wishes known now if you can no longer speak for yourself later.

Where to Get Help

- If you have questions or need forms, call your local hospital, hospice program, or senior citizen center. You can also call a lawyer.
- Or call **Eldercare Locator** at 800-677-1116. You will be given the name of a local service agency that may be able to help you.
- The following groups can also help:

American Bar Association

Commission on Law and Aging 202-662-8690 www.abanet.org/aging/toolkit/home.html

National Hospice & Palliative Care Organization

800-658-8898 www.nhpco.org

Physician Orders for Life-Sustaining Treatment Paradigm www.polst.org

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Why Have an Advance Medical Directive?



"My husband didn't make an advance directive. Now he can't tell us what he wants We don't know what to do."

- What if you had a serious illness or injury? Would anyone know the medical treatment you'd want?
- You can tell them by making an advance medical directive. (This is also called an advance directive.)
- This form lets you list the care you'd want if you could no longer express your wishes. It may also let you name someone to speak for you.



Deciding What You Want

- The first step is to think about what has meaning for you in life.
- The next step is to understand what each type of treatment can and cannot do.
- Then you can decide on the treatment, if any, you'd want. This will depend on your health and the likely result of the treatment.
- An advance directive is important whether you're young or old. Injury or illness can strike at any age.

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Tips for Getting Started

- Find a quiet place where it will be easy to talk.
- Choose a relaxed time, such as during a meal or a walk in a park. Try not to talk around holidays, weddings, or other busy times.
- Listen to everyone's concerns and feelings. Let them ask questions. Then gently explain that these are *your* wishes.



Talking to Your Doctor

- Your doctor, like your agent, has a duty to carry out your wishes.
- Give a copy of your advance directive to your primary care doctor. Also give one to any other doctors you see often.
- Set up a time to talk about these things:
- 1. What's important to you.
- 2. Your treatment wishes.
- 3. How you feel about refusing or stopping food and fluids or pain medicine.
- 4. Whether or not you'd want CPR. (See page 7.)
- 5. Whether your doctor will support your wishes. If not, you have the right to choose another doctor.
- Talk with your doctor about the Physician Orders for Life-Sustaining Treatment program (POLST). The POLST form translates your wishes into medical orders. These go with you across care settings, such as a hospital, a nursing home, or a hospice program.
- Ask to have your advance directive and your POLST form (if your state accepts it) placed in your medical file.
- Make sure your doctor knows who and where your agent and alternates are.

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Telling Your Wishes to Others



"It was a relief to us when we sat down and talked about my wishes."

- Talking to your loved ones and to your doctors about your wishes can be hard. But it's the best way to make sure you'll get the care you want.
- Try to talk with them *before* you become seriously ill or injured. In a crisis, they might not agree on what you'd want.



What to Tell Them

- Tell your loved ones the treatment you'd want if you had a chronic or deadly illness, or if you were in an endless coma. And tell them what's important to you in life. This will help them carry out your wishes.
- Tell them who your agent and alternates are.
- Give each person a copy of your advance directive.

How to Tell Them

- You could talk with each person alone. This may work best if your family or close friends don't live nearby, or if they don't get along. Start with those you think will support your wishes.
- You could bring them together as a group. This can help make sure that everyone has the same understanding of your values and treatment wishes.

Writing Down Your Wishes

- Decide what's important to you and the treatment you'd want. Then you can write down your wishes.
- You can name someone else to decide on treatment for you. This is called a **durable power of attorney for healthcare**.
- Or you can state which treatments you would or would not want. This is called a **living will**.
- Some states allow only one kind of advance directive. Some let you do both kinds. And some put both kinds on the same form.

A Durable Power of Attorney for Healthcare

- This form lets you name someone else to be your **agent**.
- This person can decide on treatment for you *only* when you can't express your wishes. But you do not have to be at the end of your life. He or she could speak for you if you were in a coma but were likely to recover.

A Living Will

- This form lets you list the care you want at the end of your life.
- A living will often applies *only* if you won't live without medical treatment.
- It takes effect *only* when you can no longer express your wishes.



Table of Contents

Deciding What's Important to You



"There's so much
I still want to do.
If I had any chance
of getting well, I'd
want my doctors
to try everything."

- What makes you happy to be alive? Could there come a time when life would no longer have meaning for you?
- Think about what's important to you in life. That will help you decide on the treatment you'd want if you were seriously ill or injured.
- Your feelings may change as you get older. They may also change as your health changes. So ask yourself these questions from time to time.

Your Quality of Life

- What things give meaning to your life? If you lost some of them, how would you feel?
- Answering the questions below can help you decide. You may want to talk with family, close friends, or a counselor, too.
 - 1. What do you fear most about being seriously ill or injured?
- 2. How would you feel if you couldn't do the things you enjoy most?
- 3. How would you feel if you couldn't get around by yourself or think for yourself?
- 4. Would you want to be moved from your present home?
- 5. Would you want to be in a nursing home or hospital at the end of your life?



Do You Have Questions?

You may have questions as you fill out your forms. Here are answers to some questions. If you have others, talk with your doctor or lawyer.

Do I need both a living will and a durable power of attorney for healthcare?

No. But if your state allows both, this can help make sure you get the care you want.

What if I don't know who to name as my agent?

You can still write down the treatment you'd want. You can also ask a hospice or senior citizen program to help you find an agent.

Must I have an advance directive to receive care?

No. You can't be refused medical care or health insurance because you don't have a directive.

Will I be refused care if I have an advance directive?

No. Treatment will not be refused or stopped until your doctors are sure that it wouldn't provide the results you'd want.

What if I travel?

Take a copy of your directive with you when you travel. Tell someone with you where it is. Many states honor a directive from another state.

What if I move?

It's best to make a new directive if you move to a new state. If you live part of the year in another state, do a form for each state.

What if I change my mind?

You can change or cancel the directive at any time.

What if I make a new directive?

Destroy all copies of the old directive. Then give copies of the new one to those who got the old one.



Making Your Wishes Legal



"I called the local hospital and got the forms I need."

- Writing down your wishes helps make them legal.
- Be sure to use the right forms for your state. This may be a living will or a durable power of attorney for healthcare. Or it may be both.

Fill Out the Directive

- Get the forms for your state. Ask your doctor, hospital, senior citizen center, or lawyer.
- Read the forms carefully and follow all the steps.
- Attach extra pages if there isn't room to write all your wishes.

Sign the Forms

- Sign and date the forms. You may need to do this in front of two witnesses or a notary public. The forms will tell you.
- If you add pages, sign and date each page. Write on the form the number of pages you've added.

Make Copies

- Keep the forms you signed in a place where they can be found easily. Don't lock them in a safe-deposit box.
- Give a copy to your agent and alternates, your doctors, and loved ones. Keep extra copies in case you go to a hospital or nursing home.
- In some states, you also need to send your signed forms to a state court or office. These will be listed on the form.



Your Beliefs

- What do you believe about life and death?
- Answering the questions below can help you understand your beliefs. Your answers will affect the care you'd choose or refuse at the end of your life.
- 1. Do pain and suffering have a role in life?
- 2. Should treatment keep you alive as long as possible?
- 3. When does life stop?



"My cancer is under control now. But I never want to be in a lot of pain."

Your Values

Read each statement below. How important is it					
for you to do each of these things? Very important? Somewhat important? Not very important? Check	IMPORTANCE				
the box that best describes your feelings.	Very	Somewhat	Not Very		
1. Care for myself.					
2. Get out of bed every day.					
3. Go out on my own.					
4. Recognize my family and friends.					
5. Talk to and understand others.					
6. Decide things for myself.					
7. Stay in my home as long as I live.					
8. Live without a lot of pain.					
9. Live without needing medical treatment or machines to keep me alive.					
10. Pay my own expenses.					
11. Leave money to my family or a cause I believe in.					
12. Be faithful to my beliefs.					
13. Live as long as I can.					
14. Try all medical treatment possible.					
15. Not linger before I die.					

Other things that are important to me:

Knowing Your Treatment Choices



"I don't want to live if I have to be hooked up to machines."

- Which types of treatment would you choose if your life were in danger?
- Your choices might depend on your health. They might also depend on how the treatment would affect your quality of life.
- You may want to talk to your doctor about your choices.



What Will Your Quality of Life Be?

- The quality of life you'd have with treatment depends on your state of health.
- Think about the four cases below. In each case, you could do everything to keep yourself alive. You could try some types of treatment and refuse others. Or you could ask for care that controls pain but does not keep you alive longer. What would you choose?
- 1. You have a sudden complication during routine surgery. You are likely to recover fully if you are treated quickly.
- **2.** You have **a chronic illness.** Treatment may keep you feeling pretty good for many years.
- **3.** You have **a deadly illness**. Treatment may keep you alive longer, but it can't make you well.
- **4.** You are in **an endless coma**. Treatment may keep your heart and lungs working. But you will never again be aware of the world around you.

Get Your Agent's Agreement

- Talk to each person you are thinking of naming as your agent or alternate. Do this before you decide.
- Make sure your agent and alternates understand what they will have to do.
- Make sure they are willing to carry out your wishes.
- Make sure they can be there when needed.



Tell your agent what your wishes are. You may also want to write them down and give a copy to your agent. Be sure your agent knows:

- 1. What's important to you in your life.
- 2. When you'd want CPR, tube feeding, and other treatments.
- 3. How you feel about hospice, nursing home, and hospital care.
- 4. If you want to donate any of your organs.
- 5. If you want an autopsy after your death.





Naming Your Agent



"I chose a close friend as my agent because I feel it might be hard for my family to decide about my care."

How can you be sure your agent will do what you want?

- Choose someone you trust.
- Tell that person what your wishes are.
- *Make sure* he or she is willing to carry out your wishes.

Who to Choose

- You can name a family member, a close friend, or a minister, priest, or rabbi.
- You should name one person as your agent. Then name one or two alternates. You need a backup person in case your first choice can't be reached when needed.

Your Agent Should Be...

- An adult 18 years or older.
- Someone you trust and can talk to about the care you want.
- Someone who knows what is important to you and supports your choices.
- Someone who will be able to stand up for your wishes.

Check Your State Laws

In many states, your agent can't be:

- Your doctor or healthcare provider.
- Someone who works for your doctor.
- Someone who works for a hospital, nursing home, or hospice program where you get care.

Be sure to find out about the laws in your state.

Which Will You Choose or Refuse?

- You can choose from three kinds of care when your life is in danger:
 - Life supporting
 - Life sustaining
 - Life enhancing
- You can usually choose or refuse them at any time.
- In most cases, you can also try a treatment, and then stop it.
- Laws on refusing or stopping treatment may vary by state.



Life Supporting

This care keeps your heart and lungs going when they can no longer work on their own.

CPR tries to restart your heart and lungs if they stop working.

A respirator keeps you breathing. Air is pumped into your lungs through a tube that's put into your windpipe.

Life Sustaining

This care keeps you alive longer when you have an illness that can't be cured.

Tube feeding provides food and fluids through a tube or IV. It is given if you can't chew or swallow on your own.

A kidney machine cleans your blood when your kidneys can no longer work on their own.

Life Enhancing

This care controls pain. Nothing is done to keep you alive longer.

Hospice care is comfort care. It might provide food and fluids by mouth or help with bathing. Hospice care is given during the last stages of a deadly illness.

Strong pain medicine can be given to help keep you comfortable.

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If You Don't Want CPR

What if your heart and lungs stopped while you were a patient in a hospital or nursing home? Would you want CPR? If not, talk to your doctor about a **DNR** (**Do Not Resuscitate**) order.

Be Aware

DNRs and advance directives may not apply when emergency teams respond to 9-1-1 calls. They may also not apply in emergency rooms. Ask your doctor how to make sure your wishes will be followed.

Deciding on the Treatment You'd Want

- Imagine yourself in each case below. What quality of life would you want during or after treatment?
- Then ask yourself which treatment you'd choose in each case. Write yes or no in each box.

If I Had I Would Want								
	CPR	Respirator	Tube Feeding	Kidney Machine	Pain Medication	No Treatment		
A Sudden Complication								
and no other severe health problem.								
- and other severe health problems, such as heart disease or a stroke.								
A Chronic Illness								
- and treatment controlled it.								
– and treatment could no longer control it.								
A Deadly Illness								
 and treatment could still keep me active and comfortable. 								
- and treatment could no longer keep me active and comfortable.								
An Endless Coma								
– and no other health problem.								
– and a lasting or deadly illness.								

If you have a deadly illness or are in an endless coma, you can also choose hospice care. Hospice care keeps you comfortable until death occurs. Would you want hospice care?

Knowing an Agent's Role

- Often it's hard to know which treatment choices you might face. Would you rather let someone you trust decide for you?
- A durable power of attorney for healthcare lets you name an agent to carry out your wishes. This happens only if you can't express your own wishes.
- Your agent can talk with your doctors about your care at the time of your illness or injury.



"My role as my brother's agent is to make sure his wishes are followed."

An Agent's Duty

- Your agent's duty is to see that your wishes are followed.
- If your wishes aren't known, your agent should try to decide what *you* would want.
- Your agent is allowed to make choices about your healthcare.
- Your agent has no control over your money. Your agent also can't be made to pay your bills.



Find Out What Your Agent Can Do

Each state has its own rules about what an agent can or can't do. Check your state laws. In most states, your agent can:

- Choose or refuse treatment for you.
- Try a treatment and then stop it if your health doesn't get better.
- Release your medical records.
- Order an autopsy or donate your organs. However, you can say on your advance directive that you don't want this.

Find out if your agent can:

- Refuse or stop food or fluids or pain medicine.
- Refuse or stop tube feeding or other care that keeps you alive—even if your advance directive doesn't say to refuse or stop them.