



You deserve end-of-life care that reflects who you are. Your background, beliefs, and traditions all matter. Having a say in your care delivery and incorporating your wishes into your care plan will provide you and your loved ones with peace of mind and improve your quality of life, even as it nears its end.



WHAT IS END-OF-LIFE CARE?

End-of-life care is the support and medical care provided to people who are nearing the end of their lives. It's not just about the final moments; end-of-life care can last weeks, months, or even years. The focus is on providing comfort, managing pain and other symptoms, and respecting your wishes.

Some key aspects of end-of-life care include:

- **Pain and symptom management:** This can involve medication, physical therapy, and other interventions to keep you comfortable.
- **Emotional and spiritual support:** Chaplains, social workers, and counselors can provide support for you and your family.
- **Respecting wishes:** End-of-life care should be tailored to your preferences. This includes considering your cultural background, religious beliefs, and wishes for treatment.

PALLIATIVE CARE

Palliative care, sometimes called supportive care, is specialized medical care for people living with a serious illness. It focuses on providing relief from the symptoms and stress of the illness, to improve the quality of life for both the patient and their loved ones. Palliative care is provided by a team of specially trained doctors, nurses, and other specialists who work together with a patient's other doctors to provide an extra layer of support.

Palliative care is based on the needs of the patient, not on the patient's prognosis. This means that palliative care can be helpful at any stage of a serious illness, from diagnosis to the end of life.

HOSPICE CARE

Hospice care is specialized care for people nearing the end of life. Hospice focuses on quality of life over curing any condition or disease. The goal of hospice is to provide relief from pain or symptoms. It also provides support for the emotional, psychosocial, and spiritual aspects of end-of-life for you and your loved ones.

Hospice services are a benefit included in many health insurance plans. Just like your plan covers in-network doctors or facilities, you have in-network hospice agencies. Once you decide to enter hospice, your doctor will provide you with a list of agencies that can take over your care. If you are covered under Medicare, they will pay for hospice if your doctor certifies they believe you have six months or less to live. If you live longer than six months, that does not mean that you become ineligible for hospice care. You can continue hospice care, and the doctor will need to re-certify that your condition is worsening and that you require continuing hospice services.



HOSPICE CARE (CONTINUED)

Medicare covers home visits by nurses, social workers, chaplains, and more. They also cover medications, supplies, and durable medical equipment related to your hospice diagnosis. You pay nothing for hospice care. You can receive Medicare-certified hospice care in your home or another facility where you live, like an assisted living facility or nursing home. You can also get hospice care in an inpatient hospice facility.

To learn more about how Medicare covers hospice services, visit <https://www.medicare.gov/coverage/hospice-care>. If you have different insurance and are curious how they pay for hospice services, reach out to your plan at the customer service number listed on your insurance card.

HOW ARE HOSPICE AND PALLIATIVE CARE DIFFERENT?

Palliative care and hospice care are both meant to improve a patient's quality of life, but they differ in their focus and timing.

Palliative care focuses on managing symptoms and improving the quality of life for people with serious illnesses. This can include anything from cancer to heart disease. **Palliative care can be provided alongside curative treatment.** The goal is to help you live as well as possible, even if you're undergoing treatment aimed at curing your illness.

Hospice care focuses on comfort care for people nearing the end of life. This typically means someone with a terminal illness who has a life expectancy of 6 months or less. **Hospice care stops curative treatment.** The main goal of care is to make you comfortable in your remaining time.

Think of palliative care as a broad umbrella of support for people with serious illnesses. Hospice care is a specific type of palliative care that's used when someone is nearing the end of life. If you're unsure which type of care is right for you or a loved one, talk to your doctor. Together you can make the best decision for your situation.



HOW DO MY BELIEFS IMPACT MY END-OF-LIFE CARE?

Your personal beliefs influence your decision-making about end-of-life. In some cultures, families make decisions collectively, while others prioritize individual wishes. Your beliefs may impact your preferred communication styles or the way you prefer to receive information about pain management, death, and dying. Some cultures prefer a direct discussion about death, while others may find it disrespectful.

HOW CAN I ENSURE MY WISHES ARE KNOWN AT THE END OF LIFE?

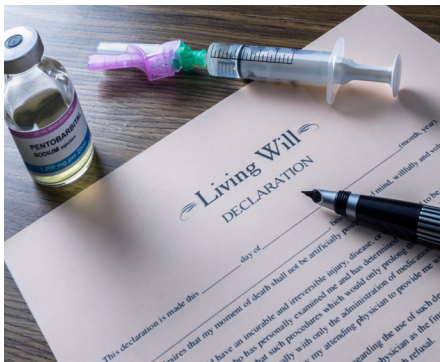
Advance directives and living wills are legal documents that allow you to communicate your wishes for medical care in situations where you can't speak for yourself.

Advance directive: A broader term encompassing any legal document that outlines your healthcare wishes in advance. This can include a living will but also allows you to appoint a representative to make decisions on your behalf. Advance directives can cover a wider range of situations, including pain management, organ donation preferences, and appointing a healthcare power of attorney (sometimes called a healthcare proxy or healthcare agent) to make healthcare decisions for you, if you're incapacitated.



HOW CAN I ENSURE MY WISHES ARE KNOWN AT THE END OF LIFE? (CONTINUED)

Living will: A specific type of advance directive that focuses on your preferences for life-sustaining treatments at the end of life, especially if you're terminally ill or unable to communicate. Living wills typically address things like the use of artificial respiration, hydration, and feeding tubes.



NOTE: Choosing a healthcare power of attorney (HPOA) is an important decision. This person will be responsible for making medical decisions on your behalf if you're unable to do so yourself. Many people leave power of attorney responsibilities to a family member, while others choose a close friend or hired professionals like an estate planning attorney for their HPOA. Whomever you choose, you should ensure that they are aware of your cultural and religious practices and agree to uphold them in the way you choose. If you become incapacitated and have not selected an HPOA, it is up to state law to determine who makes decisions on your behalf. In most states, your next of kin will be your automatic HPOA if you don't name one.

TIPS ON CHOOSING YOUR HPOA

- Pick someone you trust completely to make decisions that reflect your wishes and values. This person should be someone you feel comfortable discussing your medical care with openly and honestly. Ensure they understand your views on medical treatment, including life support and pain management. Discuss hypothetical scenarios to help them understand your preferences in different situations. Some may include:
 - If your heart stops, would you like to have CPR performed on you?
 - If you are near death, would you want artificial nutrition? If so, for how long?
 - If you are unable to breathe on your own, do you want to be placed on a ventilator? If so, for how long?
- Make sure they understand the responsibility and are willing to act as your HPOA.
- Also, consider their age, health, and proximity to you. Ideally, your HPOA should be someone who can be readily available to communicate with your medical providers when needed.

ADDITIONAL TIPS AND LEGAL CONSIDERATIONS REGARDING YOUR HPOA

- **HPOA Laws Vary by State:** Research the specific laws in your state regarding HPOAs. You can find this information on your state's health department website (find yours at <https://www.usa.gov/state-health>) or by talking to an attorney.
- **It's a Formal Document:** Once you've chosen the person who will hold your HPOA, you'll need to complete a legal document outlining their authority. This document will likely need to be witnessed and notarized. It's a good idea to check with an experienced estate planning attorney so you know you are meeting the requirements for your state.
- **Choose an Alternate:** Consider naming an alternate HPOA in case your first choice is unavailable during a health crisis.
- **It's Not Automatic if You Get Sick or Injured:** A doctor may have to certify that you are unable to make your own decisions before your proxy starts making decisions for you.
- **Keep Copies:** Once it's completed (and every time you update or make changes!) give copies of the completed HPOA document to your doctor, hospital, and your chosen HPOA(s).
- **Review Regularly:** Discuss your wishes and update the HPOA document as your medical condition or preferences change.

Choosing an HPOA is an ongoing conversation. By openly discussing your wishes and expectations, you'll have someone you trust making medical decisions on your behalf during a difficult time.





HOW CAN I START THESE DIFFICULT CONVERSATIONS?

The most important thing is to start talking. There are many resources available to help with these conversations, like The Conversation Project (linked below). You can also reach out to hospices or palliative care organizations for advice.

WHY SHOULD I DOCUMENT MY END-OF-LIFE PLANS?

Having an end-of-life plan assures your wishes are known. You can make sure your doctors and loved ones know and understand your preferences for care. In doing so, it reduces stress on your loved ones because you have shared clear instructions for how you wish to handle difficult situations. Lastly, it empowers you! You remain in control over your medical care even when you can't decide for yourself.

REVIEWING AND UPDATING YOUR END-OF-LIFE PLAN

It's a good idea to review your end-of-life plan every few years or after major life events. Your values, goals, and priorities regarding end-of-life care can shift as you age or if your health status changes. You may feel differently about treatments, life-prolonging measures, or quality vs. quantity of life as time goes on. Reviewing your paperwork every so often confirms that it stays aligned with your latest preferences and circumstances to give you and your family peace of mind.

RESOURCES TO HELP YOU PLAN FOR END-OF-LIFE CARE

Here are some helpful resources to guide you through end-of-life planning:

- **AARP:** Offers resources on advance directives and care planning.
- **CaringInfo:** Houses a wealth of information on serious illness care, including hospice care and making treatment decisions. They also provide copies of free advance directives and instructions for each state.
- **The Conversation Project:** Offers resources and toolkits to facilitate conversations about end-of-life wishes with loved ones.
- **Medicare:** Explains Medicare coverage for hospice care.
- **National Hospice and Palliative Care Organization (NHPCO):** Provides information on hospice care, palliative care, and advance care planning.
- **National Institute on Aging (NIA):** Provides information on advance care planning and getting your affairs in order.

Being informed and planning ahead can help you create a meaningful plan that reflects your wishes and values, providing comfort and peace of mind to you and your loved ones.



Curious about other topics? Our newly redesigned Education Resource Library houses our resources and provides straightforward information in a variety of formats to help you make informed decisions throughout your healthcare journey. Learn about health insurance, disability, medical bill management, and more by visiting our [Education Resource Library](#) today. Call us anytime at 800-532-5274 or visit www.patientadvocate.org for help.