

Getting the End-of-Life Care You Want:

# A PATIENT'S GUIDE TO PERSONAL ADVOCACY WITH DOCTORS, HEALTHCARE SYSTEMS, AND HOSPICE

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Compassion & Choices is the nation's oldest, largest, and most active nonprofit working to improve care and expand options for the end of life. For more than 40 years we have sought to change attitudes, practices, and policies so that everyone can access the information and care they need. Compassion & Choices is committed to collaborating with legislators from every state and political party who seek to honor their constituents by engaging in this mission with us.

The quality of your end-of-life care can be greatly improved through thoughtful planning: finding the right care setting, working with providers who align with your values, and being an active participant in your care decisions.

Understanding the healthcare system becomes easier with the right guidance and preparation. When you and your medical team have open conversations about your values and preferences, you're much more likely to receive care that truly reflects what matters most to you.

This guide provides information and additional tools that will help you advocate for the care you want, need, and deserve. It can also help individuals who may have a doctor or healthcare system that does not align with their end-of-life values and priorities.

For more information about end-of-life care and options, please visit our End-of-Life Consultation Center at [CandC.org/eolc](https://CandC.org/eolc).

## Be ready for your healthcare visit

Make sure you and your provider fully understand each other. There is potential for misinterpretation in patient care conversations, so it's important to be as clear and direct as possible. Come prepared with [a list of questions](#) and don't be afraid to ask follow up questions, too.

## During the visit

Ask the doctor to explain their reasoning in detail, including what evidence supports their recommendation. Share your specific concerns by saying something like "I'm worried about **[side effect/cost/lifestyle impact]** because..." and explaining how it relates to your situation.

Don't hesitate to ask about alternatives with questions such as "What other treatment options exist, and why do you think this one is best for me?"

You should also request information about the risks, benefits, and success rates of different approaches so you can make an informed decision that aligns with your values and circumstances.

To ensure you understand what your doctor is saying and that you are on the same page, restate in your own words what you think they are telling you and confirm if it is correct.

## When you and your provider disagree

If your provider won't honor your preferences, ask why. Some healthcare systems, particularly Catholic-run hospitals, do not support the full range of care options. Other times, your provider may be required to comply with standards set by the government or, in some cases, refer you to a specialist. You can always ask for a second opinion, too.

Our [End-of-Life Consultation \(EOLC\)](#) program is available to support both patients and healthcare providers. You or your provider can connect with an experienced consultant to receive reliable information, resources, and guidance on end-of-life care. This can help you

better understand your options and help your provider feel more prepared to honor them. Visit [CandC.org/eolc](https://CandC.org/eolc) to learn more.

## If your healthcare system prohibits supporting your personal decisions

Institutions should never impose their beliefs on their staff or patients, nor should they intrude into the sacred relationship between healthcare providers and patients. Nevertheless, some health systems have policies that prohibit practices such as [voluntary stopping eating and drinking \(VSED\)](#), [palliative sedation](#), stopping treatment, refusing some level of treatment, or [medical aid in dying](#). Certain institutions may even attempt to prevent their staff from providing you with information about these options. Learn more about end-of-life options at [CandC.org/eolc](https://CandC.org/eolc).

Your provider has a duty to provide you with all of the information that you need to be able to make an informed decision about your end-of-life care or to refer you to another provider who can and will honor your preferences.

### Remember:

- > You have the right to refuse treatment or seek care elsewhere.
- > Good doctors welcome informed patients and thoughtful questions.
- > If a doctor seems dismissive of your concerns, that might signal it's time to find a new provider.

## Finding a new provider or system that supports your end-of-life decisions

You always have the right to seek care from another healthcare or hospice provider if yours will not support your care wishes. Remember, this is your life. Don't be afraid to advocate for the end-of-life experience you want.

Your provider can and should refer you elsewhere in the event that they personally disagree with or are prohibited from participating in your end-of-life care. If your healthcare or hospice system has policies in place that do not allow your provider to participate in your care, they may refer you to another provider outside of their system, or you will have to seek one on your own.

You may also consider asking friends or family for advice. Keep in mind that while personal recommendations are a good place to start, other people may have different priorities and values when it comes to their own care.

Additionally, some insurance companies are contracted and will only pay for services provided by a particular system or group of providers. Contact your insurance company for a list of in-network options.

## Navigating hospice care

Hospice offers compassionate, holistic care for people who are terminally ill and have a prognosis of six months or less to live. Hospice is provided by a team of professionals that address your needs as well as the needs of your caregivers and loved ones. The aim is to relieve suffering and help people live as fully and comfortably as possible in their final days. For many, hospice allows people to fulfill their wish of dying at home.

If you think you may be eligible for hospice and are interested in this form of care, schedule an appointment with your primary care provider to start the process or contact hospices in your area directly.

Not all hospices are the same, so explore your local options, ask around for personal recommendations, and if possible, interview providers. Look for a hospice that aligns with your values and will honor your end-of-life wishes. Doing this research ahead of time can give you peace of mind and ensure you are ready if or when you decide to utilize hospice.

Additionally, it is important to note that hospice care is fully covered by Medicare (Part A) and Medicaid, and most private insurance plans also include a hospice benefit. For those without insurance, many hospice providers offer care at no or reduced cost through donations and

other financial support, and hospice staff may be able to help individuals access additional financial support if needed.

Learn more about hospice — including how to start the conversation with your provider and find a service that’s a good fit — at [CandC.org/hospice](https://CandC.org/hospice).

## Protect yourself financially

Healthcare can be expensive, and unexpected bills can add stress during an already difficult time. But you can take steps to inform yourself and avoid potential financial surprises.

Health insurance can include Medicare, Medicaid, coverage through the ACA marketplace, and commercial coverage through an employer. It’s an important part of paying for the medical care associated with end-of-life care, such as doctor visits, hospital and emergency care, tests, and medications.

- > **Medicare** is federal health insurance for people 65 or older and some people under 65 who have certain disabilities or conditions. It covers hospice services, eligible short-term stays in skilled nursing facilities, and more. Details at: [Medicare.gov](https://www.Medicare.gov).
- > **Medicaid** is a joint federal and state program that helps cover medical costs for individuals, children, and families with limited income and resources. Eligibility requirements and benefits vary by state. It covers hospice, long-term care in nursing homes, and home and community-based care. Additional services, such as palliative care, may be available depending on your state of residence. Details at: [Medicaid.gov](https://www.Medicaid.gov).

Check your health insurance plan’s Summary of Benefits and Coverage (SBC), to learn what your plan will or won’t cover and how much you might have to pay. If your insurance has an online portal or app, use it to learn more about your options, generate estimates, and research in-network providers.

Many insurance plans now include care management assistance, nurse lines (free help with questions), help with transportation, and more. For those who qualify, Medicaid programs offer a number of home and community-based services.

If you're worried about costs, ask your provider, hospital or healthcare system about financial assistance programs and payment plan options. Other financial support can include Veterans Affairs (VA) Benefits, FSA or HSA accounts, personal savings and retirement accounts, cash value of life insurance policies, home equity line of credit, and state and community-based financial assistance programs.

Taking these steps up front can provide clarity, avoid financial burdens down the road, and help you focus on what matters most — your health and well-being.

## Designating a healthcare proxy who will advocate for you

There may be times when you are unable to speak for yourself or make decisions about your care. That's why it is essential to choose a healthcare proxy who you trust to represent you.

A healthcare proxy — also known as a healthcare power of attorney or medical power of attorney — is a person you legally authorize to make healthcare decisions on your behalf. They could be a family member, friend, neighbor, or any adult who understands your values and is willing to advocate for you.

It's encouraged to choose someone who:

- > Can advocate confidently. They should be comfortable communicating with healthcare providers and speaking for you.
- > Is comfortable having hard conversations and discussing topics like illness, death, and end-of-life care.
- > Respects your wishes for your care and is willing to defend them.
- > Is available when needed. Ideally, your proxy lives nearby and is likely to be available during a health crisis.

Learn more about proxies and how to designate one at [CandC.org/proxy](https://CandC.org/proxy).

## Encourage change within your healthcare system

Healthcare systems are businesses. Businesses facilitate services for consumers, and you – the patient – are the consumer. If healthcare systems want to deliver on their commitment to person-directed care then they must implement policies that respect the values of consumers, including respecting personal care preferences, especially at the end of life.

If we want real change toward autonomy, self-determination, and availability of the full range of end-of-life options, healthcare systems need to hear from you.

On the next page is a sample letter that you can personalize to let your healthcare provider and system know that you value being able to access all end-of-life care options available (including medical aid in dying in authorized states) and want their policies to reflect their patients' wishes and needs.

To ensure that your request gets in front of the right people, we recommend sending your letter to:

- > Your primary care provider
- > Your provider's medical group
- > The hospital or clinic's Chief Executive Officer
- > The hospital or clinic's Quality Improvement Department

The sample letter below is designed for someone who has a disease or terminal illness, but you do not need to be ill in order to begin advocating for yourself and others! If you want a healthcare provider and system that honors every person's agency to chart their own end-of-life journey, then start advocating for it now. Feel free to use our suggestions and edit the letter to make it right for you.

## Sample letter to your healthcare system

Dear (health system's name) practitioners and staff:

I am a (age)-year-old resident of (city or state) and patient of (physician/practice name). I have visited (provider/practice name) (number) times over the past (number) months or so.

In (date), I was diagnosed with (disease or terminal illness). Since my diagnosis, I have (considered or pursued) (describe any treatment options or end-of-life care options you have considered). I received (describe the care you received while considering or pursuing these treatment options or end-of-life care options).

I would like the option of (medical aid in dying, voluntarily stopping eating and drinking, palliative sedation, etc.) in my final days (should I wish to choose them at that time). When I consulted with (physician name) about whether this would be an option for me and whether (he/she/they) they would feel comfortable providing me that care, (he/she/they) told me they (would not/could not). I now understand that (healthcare system name) has a policy forbidding their providers from offering (care option).

As a consumer of services at (healthcare system name), I must be able to build a relationship with a care team who will walk with me on the end-of-life path that feels best for me. I ask that you reconsider this policy that deprives patients like me autonomy and self-determination in our final days, and instead allow your providers to provide the full range of end-of-life care options.

To the extent that anyone can, I am coming to terms with the severity of my health condition. I know that (disease or terminal illness) will bring an end to my life, but I am doing everything within my power to stay healthy and live a full life for the time I have left.

I have a healthcare proxy who knows my wishes and is ready to advocate for me if I cannot advocate for myself. My advance directive is on file at **(list where you have copies on file, including doctor's office/hospital etc.)**.

Thank you for your attention to a matter of great importance to me. I look forward to your reply with hope that my request may be honored.

With great respect for the people and expertise at **(healthcare system name)**,

**(Name)**

CC: **(Physician)**, **(healthcare system leadership)**