



**Getting the End-of-Life Care You Want:**  
A PATIENT'S GUIDE TO  
PERSONAL ADVOCACY  
WITH DOCTORS,  
HEALTHCARE SYSTEMS  
AND HOSPICE

Many people don't realize that your end-of-life experience greatly depends on where you receive care, who your doctor(s) and other medical providers are and on how well you advocate for yourself. This guide provides information and additional tools that will help you advocate for the care that's right for you.

Navigating the healthcare system can be challenging and confusing. Some people, including doctors and other medical providers, may find it difficult to discuss terminal illness or other end-of-life issues, which can lead to delivery of care that does not align with someone's values.

This guide is meant to 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 Plan Your Care Resource Center at [CandC.org/plan-your-care](https://CandC.org/plan-your-care)

## Be Ready for Your Doctor's Visit

Make sure you and your doctor fully understand each other. There is a lot of potential for misinterpretation in patient care conversations, so it's important to be as clear and direct as possible with your doctor. Come prepared with a list of questions, and don't be afraid to ask follow up questions too. To make sure you understand what your doctor is saying, restate in your own words what you think they are telling you to ensure that you're on the same page.

## When You and Your Doctor Disagree

If your doctor will not honor your preferences, first explore why. Some healthcare systems, particularly Catholic-run hospitals, do not support the full range of care options. Other times, your doctor may simply not know enough about the care you are asking for to feel comfortable providing it. If that is the case, our Doc2Doc Consultation Program could be helpful for your doctor. Healthcare providers refer to many members of the healthcare team, not just doctors. Any healthcare provider can use the Doc2Doc line.

Compassion & Choices' Doc2Doc Consultation Program is a confidential consultation line for your doctor to speak to one of our seasoned medical directors, each with years of experience in end-of-life medical care. Visit [CandC.org/D2D](https://CandC.org/D2D) for more information.

## If Your Healthcare System Prohibits Supporting Your Personal Decisions

Institutions should never impose their beliefs and morality on their staff or patients, nor should they intrude into the sacred relationship between physicians 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. Some institutions may even attempt to prevent their staff from providing you information about these options. Learn more about these options at [CandC.org/end-of-life-planning](https://CandC.org/end-of-life-planning)

However, providing information is different from participating. Your physician 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 at the very least refer you to another physician who can and will honor your health care preferences.

## Finding a New Doctor or Healthcare System That Supports Patient Directed Care

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

Your physician can and should refer you to another provider in the event that they personally disagree with or are prohibited from participating in your end-of-life care. If your healthcare system has policies in place that do not allow your physician to participate, 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. There is no obligation to select a physician or health system based on a recommendation.

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

## 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 a patient's 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 options at the end of life, healthcare systems need to hear from you.

Below is a sample letter that you can personalize to let your provider and health system know that you may want access to the full range of end-of-life care options (including medical aid in dying in authorized states) and want their policies to reflect their patients' needs.

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

- Your physician
- Your physician's medical group
- The hospital or clinic's Chief Executive Officer
- The hospital or clinic Quality Improvement Department

\*The sample letter below is designed for someone who is ill, but you do not need to be ill in order to begin advocating for yourself and others! If you want a physician and healthcare system that honors the full range of end-of-life care, 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 (physician/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 would feel comfortable providing me that care, (he/she) told me they (would not/could not). I now understand that (healthcare system name) has a policy forbidding their physicians from providing (care option).

As a consumer of services at (healthcare system name) I must be able to build a relationship with a care team at (healthcare system name) who will walk with me on the end-of-life path that feels best for me, a final act of serving and caring for a patient who is fully engaged in their own healthcare. 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 do exactly that - 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 whatever 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. End-of-life options are urgent to people like 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)