



Care and Choice at the End of Life

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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Navigating the healthcare system, especially around end-of-life care, can be challenging and confusing. Some people, including doctors and other medical providers, 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.

After you have used our Diagnosis Decoder and other end-of-life care tools, including our popular End-of-Life Decision Guide, and talked with your family, friends and physician about what is most important to you at the end of life, you may find that your doctor or healthcare system do not share your values. This guide provides information and additional tools that will help you advocate for the care that's right for you.

Be Ready for Your Doctor's Response

Make sure you and your doctor fully understand each other. What may seem like a simple question or request to you, may not be recognized as such by your doctor. Similarly, you may assume you understand what your doctor is saying, but you may have a misunderstanding. Be sure to be as clear and direct as possible in your questions and ask lots of them. Restate in your own words what you think your doctor is saying to ensure that you are on the same page. Your doctor is there to support you.

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 patient 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.

Compassion & Choices' [Doc2Doc Consultation Program](#) is a confidential consultation line with one of our seasoned medical directors, each with years of experience in end-of-life medical care.

If Your Healthcare System Prohibits Your Personal Choices

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, palliative sedation, or medical aid in dying. Some institutions may even attempt to prevent their staff from providing you information about these options.

However, providing information is different than 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.

Choosing a New Doctor or Healthcare System That Supports Patient Choice

You always have the right to seek care from another provider if yours will not support your end-of-life care preferences.

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, others 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.

Finding a Healthcare System that is Supportive: [Find Care Tool](#)

If you live in California, Colorado, Oregon or the District of Columbia, then our Find Care Tool may be able to help you. It identifies facilities near you that policies supportive of patient preference. Check it out: [Find Care Tool](#)

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-centered care then they must implement policies that respect the values of consumers, including respecting a patient’s personal care preferences particularly 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 is seriously considered, we recommend sending your letter to:

- Your physician
- The medical group your physician is a part of
- 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 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 below letter to make it right for you.*

Sample Letter to Your Healthcare System

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

I write to you after giving much thought to my purpose. I trust you will read this with open hearts and minds, and consider seriously what I ask of you.

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)*.

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 spoken at great length with my family and friends about my end-of-life care preferences. They support my decisions and are doing what they can to ensure that my wishes are respected. My advance directive is on file at *(list where you have copies on file, including doctor's office/hospital etc.)*.

I have much to live for, but I don't want to experience needless suffering. I would like the option of *(MAID, VSED, PS, etc.)* in my final days. 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 down 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.

Thank you for your attention to a matter of great importance to me. I hope you understand the urgency I feel about having all the end-of-life options available to me while I am still able to

communicate easily for myself, and 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)