

5 Tips to Help With Advance Care Planning

1. Think about planning for the last stages of life, rather than the last moments of life. I've found that people often equate advance care planning with thinking about "end-of-life." For many, this means thinking about how we hope we will die. This is an important issue to think about. However, many serious healthcare decisions must be made beforehand, in the weeks, months, or even years before an older person dies.

By expanding the planning frame to think about last stages of life, rather than last moments, you'll improve the chances of having plans that help an older person, a family, and a clinical team navigate the healthcare dilemmas that often come up.

The book "Knocking on Heaven's Door," by Katy Butler, does a wonderful job of illustrating common healthcare dilemmas that family caregivers face, in the last few years of an aging parent's life. I also like "Handbook for Mortals," written by geriatrician Joanne Lynn and her colleagues.

2. Learn to ask doctors about what kinds of health crises and declines to expect. This is especially important if your loved one has a progressive chronic condition, such as dementia, heart failure, or chronic obstructive pulmonary disease (COPD).

Studies have repeatedly found that many patients and families have not been told what to expect as these chronic conditions progress. So, don't assume the doctors will tell you, if one of these conditions has advanced to the point that there's a high chance of dying within the next year or two.

However, if you ask "What kinds of health crises should we expect?" when it comes to a given condition, many doctors will be able to share useful information. You may also want to look online for additional information from medical experts, as well as from other patients and caregivers.

3. Find tools to help an older person through the process of reflection. Thinking through one's wishes, preferences, and values is no small thing. We are, after all, talking about life and death and the many things that often lie in between!

Fortunately, several tools exist online to guide aging adults through this process:

PREPARE, a web-based planning tool developed by geriatrician Dr. Rebecca Sudore. (You can find it at PrepareForYourCare.org.)

It guides aging adults through 5 key steps:

- o How to choose a medical decision-maker
- o How to decide on what matters most in life
- o How much flexibility to give your decision-maker
- o How to tell others about your wishes
- o How to ask doctors the right questions about your medical care

American Bar Association's Toolkit for Health Care Advance Planning

The Conversation Project's Starter Kits

4. Ask the doctors to help you think through goals of care. Medical care — especially in the hospital — often places the highest priority on the goal of extending life and minimizing the chance of dying. There are other goals of care to consider including relief from pain and suffering, as well as the ability to participate in one's daily life. In most cases, we can and should provide care that addresses all three fronts: longevity, comfort, and function.

However, in aging adults who have advanced chronic illnesses, we often find ourselves facing trade-offs. For instance, a hospitalization to try to treat and reverse an acute illness will impose a certain suffering on an aging person, especially if she has previously said she is "sick of going to hospitals." Thinking through and trying to articulate goals of care can help align medical care with an older person's situation, preferences, and values. To discuss goals of care, start by asking the primary care doctor, or another clinician who knows your older loved one well. Your doctors should know what your family is hoping for, and can help you understand how the current medical situation affects your options for working towards your goals.

However, bear in mind that many doctors have not received training in discussing goals of care, and may be unsure of how to help you with this. If your own doctors seem to struggle with this, consider asking to speak to a clinician with training in palliative care or geriatrics.

5. Prepare to face dilemmas and uncertainty.

To help physicians and other health care providers discuss and convey a patient's wishes regarding cardiopulmonary resuscitation (CPR) and other life-sustaining treatment, the Department of Health has approved a physician order form, Medical Orders for Life-Sustaining Treatment (MOLST) , Studies find that prior advance care planning does reduce the stress that people endure, and can also reduce the chance of guilt and post-traumatic stress disorder in family caregivers after a loved one dies.