Advance Care Planning Resource List

Advance care planning involves discussing and preparing for future decisions about your medical care if you become seriously ill or unable to communicate your wishes. Having meaningful conversations with your loved ones is the most important part of advance care planning.

Here is a really helpful guide to Advance Care Planning by the National Institute of Health (NIH): Advance Care Planning: A Conversation Guide

What Matters Most?

Get started on your healthcare advance planning by thinking about your values and what matters most. Compassion & Choices offers an Advance Planning Toolkit that includes a helpful values worksheet (page 17) to guide your choices

Advance Directive

Advance directives are legal documents that provide instructions for medical care and only go into effect if you cannot communicate your own wishes.

A lawyer is not required to fill out an advance directive. In most states, one simply needs to sign in front of the required witnesses.

Everyone over 18 should have an advance directive. It provides peace of mind by explaining what healthcare people would prefer if they become severely injured or terminally ill. Keep your advance directive in an easily accessible place, and let loved ones know where it is. Sharing preferences before a medical crisis will help ensure you get the care you want.

The two most common advance directives for health care are the health care proxy/ durable medical power of attorney, and the living will.

Healthcare Proxy/ Durable medical power of attorney

A healthcare proxy is a person who can make healthcare decisions for you if you are unable to communicate these yourself. Your proxy — also known as a representative, surrogate, or agent — should be familiar with your values and wishes. A proxy can be

chosen in addition to or instead of a living will. Having a health care proxy helps you plan for situations that cannot be foreseen, such as a serious auto accident or stroke

- **How to choose a healthcare proxy?** Check out this helpful 2-minute video by The Conversation Project about the process of choosing the person who would be your healthcare proxy: Who will speak for you? Linked to this is a printable guide to choosing a healthcare proxy. In short, a good healthcare proxy is someone who:
    - Understands what is important to you
    - You trust will carry out your wishes
    - Knows how to advocate
    - Will be in the right emotional place
    - Will be able to navigate the family dynamics

- Advance Directive Form - provided courtesy of CaringInfo.org. This includes a fillable form to name someone to make decisions about your medical care when you are not able to speak for yourself, as well as helpful information about things like how to make this form officially legal, when it becomes effective, and some caveats about emergency situations. It also includes an optional organ donation form that allows you to make an anatomical gift of your organs for transplantation, therapy, medical research, or education upon your death.

Living Will/ Personal Directive

A personal directive/ living will is a personal document, not legally binding in Massachusetts, in which you give your Health Care Agent ('Agent'), your medical providers, and your loved ones information about what's important to you and instructions about the kind of care you want and do not want. You can say which common medical treatments or care you would want, which ones you would want to avoid, and under which conditions each of your choices applies.

Massachusetts does not have a statute governing the use of living wills. You may consider making your living will an addendum to your advance directive in MA.

Some tools for documenting and communicating your wishes include:

- Personal Directive (Free) - by Honoring Choices Massachusetts
- Prepare for your care (Free) - This website walks you through five steps that help you explore your wishes for your healthcare. It uses videos to show you how to talk to your family about these important questions. You can create a summary of your wishes and an Advance Directive.

- Five Wishes – this is a very popular tool used widely across the United States and available in 29 languages. It is not free (about $5 or so for each hard copy, and $15 for the digital version that you can send to various people and print as many copies as you wish).
    - Teri Ashley, founder of Mindful Endings, recommends pairing Fives Wishes with your state's official advance directive because both documents complement each other and serve different purposes. She describes using Five Wishes as a "sloppy copy," a place to write notes and really engage the questions posed in the document. Then, once you have come to your decisions about what your wishes are, transfer them onto the state form, which is typically two pages (one page, back and front) – shorter, more official, and easier for medical staff to scan into their systems.
    - Ashley goes on to encourage using the Fives Wishes with all your thoughts and ideas to guide conversations with your healthcare proxy and loved ones, so that they understand not just the end product, but the process that led you to come to your stated wishes.

Addendums to the Advance Directive

While advance directives are beneficial (and necessary), they are not a foolproof system. As noted in the book, *Finish Strong* (p. 48-49), there are limits to their efficacy:

- Limited applicability (terminal illness, permanent unconsciousness);
- Lack of dialogue (authorized people must know what they say);
- Lack of relevance (created in advance, therefore theoretical);
- Lack of access (locked away, rather than available at time of need); and
- Lack of enforcement (physicians revert to training).

One way to address these limits can be through addendums. Compassion & Choices recommend several addendums as added protection that fit various circumstances.

Dementia Provision

You may consider adding a Dementia Provision to your advance directive to advise physicians, healthcare proxies, caregivers and loved ones of your wishes should you be unable to direct your care due to Alzheimer's disease or other forms of advanced dementia. Once completed and signed, the addendum should be kept with the advance directive.

DNR and POLST

- Here is a useful document about DNR & POLST from Compassion & Choices
- DNR stands for Do Not Resuscitate. Also known as Allow Natural Death (AND)

- POLST stands for Portable Order for Life-Sustaining Treatment. As a binding, real-time order, the POLST form tells all health care providers during a medical emergency what you want. POLST ***is not*** for healthy people. It is for seriously ill or frail people. For more information, go to: https://polst.org/. To clarify the difference between a POLST and an Advance directive, please see this helpful 3:44 minute video from Princeton Health - POLST vs Advance Directive

Sectarian Healthcare Directive

Compassion & Choices created this Sectarian Healthcare Directive that you may consider adding to your advance directive to clarify that your wishes supersede those of any institution's religious policies, and that you wish to be transferred if any facility refuses to follow the preferences you've outlined in your advance directive.

Hospital Visitation Authorization addendum

Not all loved ones are recognized as family members with hospital visitation rights. This Hospital Visitation Authorization addendum is especially useful for unmarried couples or same-sex couples to ensure visitation rights.

Assisted Living Facility Rider

For people who live in assisted-living facilities and would like to stay there until they die, use the Assisted Living Facility (ALF) Rider to help ensure the individual's home is suited to their choices.

My Particular Wishes

In Massachusetts, the Advance Directive only officially includes the naming of the healthcare proxy. You can add your living will/ personal directive as an addendum.

Other End of Life Documents

The website, Freewill (which offers online tools for you to make your own will for free) offers the following checklist of 12 documents you should consider in your end-of-life planning:

1. Last will and testament
2. Revocable living trust
3. Beneficiary designations for non-probate assets
4. Durable financial power of attorney
5. Pet Trust
6. Durable medical power of attorney

7. Living will
8. Life insurance
9. DNR and POLST forms
10. End-of-life housing arrangements
11. Instructions for your digital assets
12. Funeral instructions and burial arrangements

Other helpful resources

- Diagnosis Decoder: Compassion & Choices offers an easy-to-use online tool to help patients prepare for conversations with their physician at their next medical appointment. Through the tool, users can create a personalized list of questions to ask the medical team that they can print and bring to their appointment.
- MIDEO: A video-based advance care planning platform where you can create a video advance care directive, accessible by QR code.

Having the Conversation

Documenting your wishes is just the first part. Communicating your wishes to your health care team and close circle of loved ones is just as important.

Share your documents and talk about them

- When you complete a document, keep the original document and make as many copies as you like. The copies have the same authority as the original.
- Share a copy with your Health Care Agent, family members and anyone you like.
- Give a copy to your primary care doctors and care providers to scan or place in your medical record. Plan to have an actual conversation with your healthcare providers as well. You can use the End-of-Life Wishes Letter to Medical Providers as an outline for a conversation with your doctor
- Make a list of people who have a copy and the date you shared your documents.

Review, revise & update yearly

- You can change your mind, revise & update or even revoke (cancel) your planning documents as your health needs and choices change, for as long as you are competent.
- Be sure to share revised copies with the people on your list who have your documents.

- Review your advance directive regularly and update documents as needed. Changes in your life such as a divorce, death of a loved one, change in employment (including retirement), moving, or new state laws, may all affect your decisions. You should also update your documents if there are any changes to your health, such as a disease diagnosis. Everyone should update their plans at least once each year. Consider choosing a date every year — like New Year's Day — to revisit your advance directive.

Store documents & make them easily accessible

- Keep your original documents and copies in a personal file you can easily retrieve in an emergency.
- If you have a Portable Order for Life-Sustaining Treatment (POLST) or a Comfort Care/Do Not Resuscitate Order (CC/DNR), keep a copy visible for Emergency Medical Personnel to find as soon as they enter the place where you reside. Keep a copy of your Health Care Proxy with these documents. Consider putting a File of Life on your refrigerator for emergency personnel

Remember that while you are alive, awake, and aware, you have agency to guide the ending of your life story. As the following video from Compassion & Choices reminds us, ***This is your show***.