



# Planning for End-of-Life Care

No one wants to think about losing a loved one, but having a plan in place can help reduce stress and anxiety for everyone involved. Understanding the care and support options that are available and putting plans in place ahead of time can allow the patient, their caregivers, and their healthcare team to be more in tune with each other. This document provides an outline of care considerations and resources for end-of-life planning.



## Palliative Care

Focused on improving the quality of life and providing an extra layer of support while **receiving disease-directed and curative treatments.**

Team-oriented approach to patient care. **Can be part of your healthcare team or a separate consulting service.**

Provides relief from physical symptoms including pain emotional stress, anxiety/ depression, spiritual distress. It is appropriate at any age and any stage of serious illness.



## Hospice Care

Focused on improving quality of life while prioritizing comfort over length of life. **Disease-directed treatments are discontinued.**

Team-oriented approach to patient care that **assumes primary role for healthcare.**

Minimizing medical interventions that do not improve comfort. Increased in home support for individual and families. **Typically started when comfort becomes the priority goal or when prognosis is expected to be 6 months or less.** Does not include medications or surgeries solely aimed at extending life, rehabilitation services, or clinical trials.

## Benefits of Palliative Care

- Can help people live better, and sometimes, longer with the ability to address the total suffering that people experience.
- Creates dedicated time and space to address symptoms and suffering.
- Ability to match treatment options to your goals.
- Palliative care specialist works together with your other doctors to create a comprehensive care plan.

## Considerations Before Enrolling in Palliative Care

- Can be another appointment which requires scheduling and transportation.
- Insurance covers palliative care as a consultation service (same as any other medical specialty), therefore, some patients may have a co-pay as they would for any medical specialist.
- Specialty palliative care may not be available where you live.

## Benefits of Hospice Care

- Continued hope for achieving goals of comfort, dignity, and safety by providing relief from suffering when life-prolonging treatments are painful or no longer helping.
- Decreases unhelpful medical interventions by focusing on comfort care.
- Care team provides support for loved ones and care partners.
- Increased in-home services.
- Bereavement services offered to family and care partners.

## Considerations Before Enrolling in Hospice Care

- Medications solely aimed at prolonging life will be discontinued.
- Rehabilitation services, surgeries, and equipment will not be covered by hospice. If someone has a second insurance, these services may be covered by this additional insurance (please check with your insurance first).
- Some hospice agencies may not be familiar with CPAP/BIPAP machines. You may need to have your healthcare team explain their management to the hospice team and not to discontinue their use.

## Additional Considerations for End-of-Life Care

There are special considerations for end-of-life care that are important to discuss with your healthcare provider and loved ones. It is important to make your wishes known so they can be carried out when the time is necessary. See below for a list of considerations that you may want to include in your planning:

### Breathing – tracheostomy / invasive ventilation

- Prolongs life
- Significant change in quality of life for the person and care partners
- Requires 1-2 care partners that can be available 24/7
- Speaking abilities may be limited
- Weakness progresses to immobility
- Feeding tube

### Feeding – feeding tubes (PEG)

- Can be placed through the skin - Percutaneous endoscopic gastrostomy (PEG)
- Extends life
- Improves hydration and minimizes weight loss
- Can make medication administration easier
- Decreases fatigue and stress around eating by mouth

### Resuscitation

- Includes chest compressions, shocks, medications, invasive ventilation
- Resuscitation orders refer only to when someone's heart stops and they need CPR, which include placement on a ventilator (or intubation). It does not impact any other medical decisions or care provided outside of this event.
- Do not resuscitate (DNR) tells emergency services and the healthcare teams that if and when someone dies (their heart stops), they do not want to receive chest compressions or shocks. They want to be allowed to die naturally at that time.
- Every person should consider their preferences surrounding resuscitation, which is also referred to as their code status. In the United States, the default is for everyone to receive resuscitation.

## Healthcare agent / power of attorney

- This is the person who will speak on your behalf if you cannot make a decision for yourself.
- This does not apply to any financial decisions. Solely medical.
- If you do not select an individual, medical decisions will defer to a healthcare surrogate.
- Selecting a healthcare power of attorney (HCPOA) can be done by picking the person who knows your wishes or can enact your wishes, then speaking to them, and lastly documenting this person.
- You should select a HCPOA as soon as possible and continue to keep them updated about your medical condition and medical wishes.
- Advance directives / living wills contain a place to document who is your HCPOA.

## Advance directives / living wills

- These are legal documents to tell people what you want for your medical care. Usually, it includes a place to name a healthcare agent/power of attorney
- It is ideal to complete these documents as soon as you can, and to keep them updated. Review these at least every year or any time there is a major medical event (like going to the hospital).
- Once these are completed, give a copy to your healthcare team, healthcare agent, and keep them on you and in your home in a place that is easy to find.
- To learn more about advanced care planning, visit the [National Institute on Aging](#). Additionally, [Caring Info](#) provides state by state advanced directive forms and [Altogether](#) provides personalized planning assistance.

## Legacy work

- This is to preserve your story and values. It is an opportunity to make connections and share precious moments with special people in your life
- Examples include – making a scrapbook, creating a video, writing letters to your loved ones, purchasing gifts, writing a poem or song, creating drawings, fingerprint or handwriting keepsakes.
- To create a photo book, you can visit [shutterfly](#) or [mixbooks](#). To create your own book or video, visit [Storyworth](#), [Every Story Media](#), or [Life Chronicles](#).

## Funeral Planning

- It is important to talk to your loved ones regarding your wishes for a funeral, memorial service and/or a final burial place. Consider costs, values, and other factors that may be important to you. Funeral homes and funeral planning services can offer pre-payment options and quotes for services.
- If you are pre-planning a funeral and plan to use life insurance to cover the cost, ask your funeral planning service about their policies on accepting life insurance. Some may ask that the entire payout be sent to them and they will offer your family a refund after your funeral is paid off.
- Selecting a final resting place is not one size fits all. Ask your advance planning service provider, medical professionals and/or social workers about options available in your state.
- [FuneralWise](#) is a helpful website to learn more about your options, including getting state assistance for funerals and/or burials.

## Insurance Options

- Some individuals may consider enrolling in a life insurance plan to ensure their family members will have funds to cover the cost of a funeral, burial, and other related expenses. Rates for life insurance can vary based on the insurer's qualifications for age, health, lifestyle and weight. Generally, it is advised to enroll earlier in life to secure a better rate.
- There are a number of supplemental insurance plans including long term care insurance, burial insurance and more that can ensure your final expenses are covered.
- Speak with an insurance agent or your employer's HR (Human Resources) department to see which insurance options are available to you.

**Be sure to contact the MDA Resource Center at 833-ASK-MDA1 (275-6321) or [ResourceCenter@mdausa.org](mailto:ResourceCenter@mdausa.org) for additional support and assistance.**

## Acknowledgments

This resource was developed with the expertise and knowledge of Dr. Ambereen K. Mehta MD, MPH, FAAHPM of John Hopkins School of Medicine.

This resource is meant to inform and educate the community. The information presented is not intended to replace discussions with medical, financial, or employment specialists, and it should not be considered financial, medical, or legal advice. Please consult with your healthcare provider, employment specialist, or legal advisor for information specific to you.