

# End of Life Planning

The topic off End-of-Life-Planning is very broad and deep. I have researched over 250 pages of online resources as well as read several books. The information contained in the included documents are summaries and combinations of all of these resources. It is not my own original writing (for the most part). I am not an End-of-Life-Planning “expert.” I am also unable to take credit or responsibility for the accuracy of the included information. That said, I have done my best to find accurate sources without influence of advertising or monetary benefit. If you have additional questions or require additional assistance, I encourage you to contact a professional in the medical or end-of-life-planning field. I do hope you find the provided information useful and helpful for yourself and for your family.

## Contents:

- Resources

- Advance Directives

- Hospice

- Preferences

- Organization

- After a Person Dies

## End of Life Planning – Resources

### Resources used to create handouts:

<https://en.wikipedia.org/wiki/Hospice>

<https://hospicefoundation.org/Hospice-Care/Hospice-Services>

<https://myfamilydocuments.com/important-end-of-life-preferences-to-consider/>

<https://trustandwill.com/learn/what-to-do-when-someone-dies>

<https://www.aarp.org/caregiving/basics/info-2020/end-of-life-talk-care-talk.html>

<https://www.aarp.org/caregiving/health/info-2019/hospice-need-to-know.html>

<https://www.aarp.org/home-family/friends-family/info-2020/when-loved-one-dies-checklist.html>

<https://www.americanactionforum.org/insight/a-better-approach-for-end-of-life-planning/>

<https://www.cancer.gov/news-events/cancer-currents-blog/2015/end-of-life-communication>

<https://www.cancer.org/treatment/treatments-and-side-effects/planning-managing/advance-directives/faxs.html>

<https://www.cancer.org/treatment/treatments-and-side-effects/planning-managing/advance-directives/setting-up-a-good-adv-health-care-directive.html>

<https://www.cancer.org/treatment/treatments-and-side-effects/planning-managing/advance-directives/types-of-advance-health-care-directives.html>

<https://www.cancer.org/treatment/end-of-life-care/hospice-care/what-is-hospice-care.html>

<https://www.gwic.com/Education-Center/Grief-Support/Forms-you-need-to-complete-after-a-person-dies>

<https://www.healthline.com/health/what-is-an-advance-directive>

[https://www.hopkinsmedicine.org/patient\\_care/patients-visitors/patient-rights-records/advance-directives.html](https://www.hopkinsmedicine.org/patient_care/patients-visitors/patient-rights-records/advance-directives.html)

<https://www.kiplinger.com/retirement/estate-planning/605116/a-checklist-for-what-to-do-and-not-do-after-someone-dies>

<https://www.ncbi.nlm.nih.gov/books/NBK285676/>

<https://www.nia.nih.gov/health/providing-comfort-end-life>

<https://www.unitedway.org/my-smart-money/immediate-needs/a-family-member-has-died/immediate-steps-to-take-when-a-loved-one-dies>

<https://www.miemss.org/home/molst>

**Additional Resources:**

<b>Advance Directives</b> <a href="#">Advance Directive Overview</a> <a href="#">Advance Directive Presentation</a> <a href="#">Hospice Care</a> <a href="#">Palliative Care</a> <a href="#">Aging With Dignity</a> <a href="#">National Hospice and Palliative Care Organization</a> <a href="#">Your Voice Matters video</a> <a href="#">“Five Wishes” Advance Directive</a> <a href="#">Advance Directive Wallet Card</a> <a href="#">End of Life Issues (NIH)</a> <a href="#">National Institute on Aging Advance Care Planning</a>	<b>Other:</b> <a href="#">Planning a positive death experience for a loved one</a> <a href="#">How to help plan your own funeral</a> <a href="#">Tips for managing someone else's medical matters</a> <a href="#">My Family Documents</a> <a href="#">Important Documents, Life</a> <a href="#">Planning the Transition to End-of-Life Care in Advanced Cancer (PDQ®)–Patient Version</a> <a href="#">Video Eases End-of-Life Care Discussions</a> <a href="#">MOLST order form and video</a> <a href="#">Maryland Attorney General - Advance Directives</a> <a href="#">The Conversation Project</a> <a href="#">National Institutes of Aging: Getting Your Affairs in Order</a> <a href="https://www.americanactionforum.org/insight/a-better-approach-for-end-of-life-planning/#ixzz7qaGt6AEv">https://www.americanactionforum.org/insight/a-better-approach-for-end-of-life-planning/#ixzz7qaGt6AEv</a>
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<b>National Institute of Nursing Research</b> 301-496-0207 <a href="mailto:info@ninr.nih.gov">info@ninr.nih.gov</a> <a href="http://www.ninr.nih.gov/end-of-life">www.ninr.nih.gov/end-of-life</a>	<b>Hospice and Palliative Nurses Association</b> 412-787-9301 <a href="mailto:hpna@hpna.org">hpna@hpna.org</a> <a href="https://advancingexpertcare.org">https://advancingexpertcare.org</a>
<b>American Music Therapy Association</b> 301-589-3300 <a href="mailto:info@musictherapy.org">info@musictherapy.org</a> <a href="http://www.musictherapy.org">www.musictherapy.org</a>	<b>National Alliance for Caregiving</b> 301-718-8444 <a href="mailto:info@caregiving.org">info@caregiving.org</a> <a href="http://www.caregiving.org">www.caregiving.org</a>
<b>CaringBridge</b> 651-789-2300 <a href="mailto:customercare@caringbridge.org">customercare@caringbridge.org</a> <a href="http://www.caringbridge.org">www.caringbridge.org</a>	<b>What Matters Now</b> 877-365-5533 <a href="mailto:info@whatmattersnow.org">info@whatmattersnow.org</a> <a href="http://www.whatmattersnow.org">www.whatmattersnow.org</a>
<b>CaringInfo</b> National Hospice and Palliative Care Organization 800-658-8898 <a href="mailto:caringinfo@nhpco.org">caringinfo@nhpco.org</a> <a href="http://www.caringinfo.org">www.caringinfo.org</a>	<a href="#">What To Do After Someone Dies</a>

Note: Advance Directive information is available on MyChart. Click on the three horizontal lines icon for the Menu. Select “Questionnaires.” Scroll down to “Optional Questionnaires.” There you will find sections for “What matters most to you?” “Maryland Health Care Directives,” and “Life Issues that affect your health.” From there, you can follow the provided process for entering your desired information.

## End of Life Planning – Advance Directive

Note: The information here focuses only on adults. For children, a separate discussion would be necessary as causes of death and wishes often differ from adults.

### **Overview**

No one really wants to talk about death, but it is the one thing we will all have in common. Whether we discuss it or not, it will come. Death comes in three major ways, though each of us will experience it differently.

- Sudden, serious accident or unexpected cause. Death occurs within minutes or months. The person is usually not able to consult on their wishes.
- Health conditions that deteriorate (such as diabetes or congestive heart failure). Death occurs over years and may accelerate quickly near the end. These conditions come in two main forms: those that affect mostly the body and those that affect mostly the mind. By the time many people realize their condition is leading to death, they may not be able to communicate their care wishes.
- Steady decline from a progressive disease (such as cancer). Death occurs within days to years. People will often be capable of discussing their wishes, but may not want to.

To a patient or family, these categories may appear to overlap. A person dying suddenly from an unexpected cause may have had serious underlying health problems; someone experiencing a steady decline may also enjoy many good days; and a person with a generally slow decline may suffer a sudden steep deterioration in health status.

The obvious response, is to discuss our end-of-life desires sooner, when you are relatively healthy, rather than when it is even more stressful or too late.

Finish this sentence: “What matters to me at the end of life is ...” Sharing a “what matters to me” statement with your family can help them communicate to your doctors what is most important to you and what treatments are, and are not, worth pursuing.

### **What Is an Advance Directive?**

State and federal laws give you the right to make many health care decisions in advance so that your wishes can be honored in the event you can’t express them. It is your right, as a competent adult to decide whether to accept, reject, or discontinue medical treatment for yourself.

An advance directive, sometimes called a "living will," is a written document that establishes a legally binding outline of your healthcare wishes. It tells your health care providers who should speak for you and what medical decisions they should make if you become unable to speak for yourself. Even though these situations can be uncomfortable to think about, planning in advance offers you and your family members peace of mind and helps eliminate confusion in a difficult time.

You can change or revoke your advance directive if your health situation evolves. Advance directives can include instructions on preferences for hospital and home care, desired or undesired medical procedures, and much more.

Do not lock your advance directive in a place that only you can open. Let your loved ones know where your original copies are. Be sure your health care team has your advance directive in their records. You may also keep copies of your advance directive in easy-to-find places so that someone else can find it if you are in the hospital and need it. You might also give a copy to your attorney and be sure your family knows exactly who has it.

### **Who needs an Advance Directive?**

Any adult who will eventually die and who has anything to say about how that is managed should have an Advance Directive. While we may all hope to remain healthy as we get older, a medical emergency that leaves you unable to make your own healthcare decisions could happen at any time. An advance directive helps ensure you and your family are prepared for this situation.

### **What is contained in an Advance Directive?**

An advance directive includes two primary documents: a Living Will and a Healthcare Power of Attorney.

- A Living Will is a written document that specifies what medical treatment you would or would not want in the event you are in a terminal condition or a persistent vegetative state. A terminal condition is an incurable, irreversible medical condition in an advanced state caused by injury, disease, or physical illness, which will, in the opinion of the attending physician, to a reasonable degree of medical certainty, result in death regardless of the continued application of life-sustaining treatment. A Living Will only goes into effect if certain criteria are met.
- A healthcare power of attorney (durable power of attorney for health care decisions) is a document that designates a trusted person (agent) you select to make medical decisions for you and speak on your behalf if you are unable to do so yourself. This document also only goes into effect under certain circumstances, designated by you.

The appointed health care agent has broader power to execute your wishes than can be provided under a living will, so you will want to select your agent carefully to make sure your agent knows and will follow your wishes.

### **Creating an Advance Directive**

Each state has its own laws about advance directives. You can choose to use a lawyer or estate planner to help you create an advance directive, but you don't have to. Many people choose to create an advance directive on their own.

Your advance directive will be legally binding as long as you sign it with either two adult witnesses (not designated as your proxy in a healthcare power of attorney) or in front of a notary.

### **Advance Directive vs DNR**

DNR stands for "do not resuscitate." A DNR order is a document that tells doctors, nurses, paramedics, and other medical professionals that you do not want CPR or other lifesaving measures performed if your heart stops or if you stop breathing. That might sound a lot like a living will, but there are some differences. A DNR is signed off on by a physician. This means that the DNR is a medical order. It gives instructions to emergency medical personnel and tells them not to perform lifesaving care. Without a DNR, paramedics and other first responders will always attempt CPR and other lifesaving care when responding to an event such as a heart attack. If you wish to include a DNR as part of your Advance Directive, talk with your doctor so they can sign the form. A DNR is not official without a doctor's signature.

### **DNR vs MOLST**

Effective January 1, 2013, the Maryland Order for Life Sustaining Treatment (MOLST) form replaces the EMS/DNR form. Prior EMS/DNR forms are still valid and will be honored by emergency medical services (EMS) clinicians. MOLST is a portable and enduring medical order form covering options for cardiopulmonary resuscitation and other life-sustaining treatments. The medical orders are based on a patient's wishes about medical treatments. The MOLST order form:

- Consolidates important information into orders that are valid across the continuum of care
- Standardizes definitions
- Reminds patients and clinicians of available treatment options
- Increases the likelihood that a patient's wishes regarding life-sustaining treatments are honored throughout the health care system

The order form must be signed by a doctor, nurse practitioner, or physician assistant. The MOLST form is valid across the continuum of care, and is to be honored by

physicians, nurses, and other health care providers, as well as EMS clinicians. In the absence of a valid MOLST form or EMS/DNR Order, patients calling for ambulance service who are unable to communicate their health care wishes will receive restorative interventions under the statewide *Maryland Medical Protocols for EMS Clinicians*.

### **POLST (Physician Orders for Life-Sustaining Treatment)**

A POLST form (similar to the Maryland MOLST) also helps describe your wishes for health care, but it is not an advance directive. A POLST form has a set of specific medical orders that a seriously ill person can complete and ask their health care provider to sign. A POLST form addresses your wishes in an emergency.

### **Organ and tissue donation**

Organ and tissue donation can be included in your advance directive. Many states also provide organ donor cards or add notations to your driver's license

### **Making things Official**

Once you've completed an advance directive, tell your health care provider and close family or friends about your decisions and give them a copy. Of course, be sure to share your wishes and copies of your Advance Directive with the person you designate as your Medical Power of Attorney agent.

### **Interesting Facts**

- Assigning durable power of attorney was associated with lower chances of patients dying in the hospital rather than in a hospice facility or their own home.
- If a patient's treatment preferences have not been communicated explicitly, either through writing or discussions, then surrogates "may default to providing all care possible instead of limiting potentially intensive, life-prolonging care." Friends and family members are notoriously unable to accurately predict what level of care the patient would prefer, consistently allowing more medical interventions than the patient or even they themselves would want.
- Palliative care has been associated with a higher quality of life, as measured by indicators that include information and communication, access to home care, emotional and spiritual support, well-being and dignity, care at time of death, and a lighter symptom burden. Some evidence suggests that on average, palliative care patients (including hospice patients) may live longer than similarly ill patients receiving usual care.
- Three in 10 U.S. adults are family caregivers.
- Care coordination, including communication among all providers and between providers and the patient and family, is especially crucial because care near the end

of life can involve many health professionals, multiple chronic conditions, and rapidly emerging complex problems with medical and social dimensions.

- Patients often experience multiple transitions near the end of life, including high rates of apparently preventable hospitalizations, and they suffer the consequences of the resultant discontinuities in care. Medication errors, disruptions in care planning, and failures to coordinate care all are implicated in poorly managed transitions between care settings, including between hospitals and nursing homes or private homes. Try to assign a particular person to be the point of contact for all providers.

## **Frequently Asked Questions**

### **Is an Advanced Directive required?**

No, but it is a good way to make your wishes regarding your medical treatment known, to reduce confusion among your family and your caregivers, and to have your wishes honored.

### **Who can be your health care agent?**

Generally, your agent may be any competent adult other than an employee, owner, or operator of the health care facility where you are being treated. Legally, you can designate multiple health care agents, but it is recommended that only one agent receives the durable power of attorney. You can also name an alternate agent who would take on the responsibilities of your primary agent if he or she resigns or is otherwise unable to fulfill their duties.

### **When does my Advance directive go into Effect?**

Before your health care team uses your living will to guide medical decisions, two physicians must confirm that you are unable to make your own medical decisions and you are in a medical condition that is specified by your state law as terminal illness or permanent unconsciousness.

### **What is life-sustaining treatment?**

In most cases, life-sustaining medical treatment is any medical intervention, medication, or anything mechanical or artificial that sustains or restores that would prolong the dying process for a terminally ill patient. These may include but are not limited to:

- CPR (cardiopulmonary resuscitation) including use of an AED (automated external defibrillator)
- Breathing machines
- Medications such as antibiotics
- Nutrition and hydration (food and liquids) given through feeding tubes or IVs
- Kidney dialysis



- If you want treatment for pain, nausea, or other symptoms, even if you can't make other decisions (this may be called comfort care or palliative care).
- medicines to make your heart work,
- certain surgical procedures.

If I chose to no longer medically fight a terminal disease, does that mean I receive no more medical care?

Choosing not to have aggressive medical treatment is different from refusing all medical care. A person can still get treatments such as antibiotics, food, pain medicines, or other treatments. It is just that the goal of treatment becomes comfort rather than cure.

Will all of my wishes be followed?

In most cases, your caregivers will do their best to carry out your wishes. However, there may be some special circumstances, such as:

- If a disagreement arises between equal ranking decision-makers regarding your medical treatment, your physician may consult the hospital's Patient Care Advisory Council.
- If your physician believes that an instruction to withhold or withdraw life-sustaining procedures from you is inconsistent with generally accepted standards of patient care, the physician may consult the hospital's Patient Care Advisory Committee or file a petition in court.
- A physician doesn't have to provide treatment he or she believes to be medically ineffective or ethically inappropriate. In cases when such treatment is requested by a patient or those making decisions on the patient's behalf, the physician must offer them an option to request a transfer to another physician and, if desired, assist with the transfer. Pending the transfer, the physician must comply with the request for treatment if failure to comply would result in the death of a patient.
- When the decision is against the health care institution's policy.

Will my advance directive be used if I am taken to the emergency room?

Your advance directive is valid in an emergency room only if the health care providers there know about it. In serious emergency situations, it may not be possible for health care workers to know that you have an advance directive before emergency medical care is given.

**Takeaway**

An advance directive can help ensure you get the short- or long-term medical care you desire even if you are unable to communicate for yourself at the time. You can also include a power of attorney and give them the authority to speak for you when you're unable to make your own choices.

# End of Life Planning - Hospice

The goal of Hospice is to prioritize a person's quality of life — emotional, physical and spiritual comfort, according to their individual wishes.

## **What Hospice IS and what it is NOT**

### **Hospice IS:**

- An interdisciplinary team of professionals trained to address physical, emotional, and spiritual needs of the person
- Specialty care that is person-centered, stressing coordination of care, clarification of goals of care, and communication.
- Provided primarily where a person already lives.

### **Hospice is NOT**

- Focused on curative therapies or medical intervention designed to prolong life.
- A replacement for nursing home care or other residential care.
- 24/7 care, in the majority of cases.
- Care that hastens death.

## **When is it time for hospice?**

A person does not have to be bedridden or in their final days of life to receive hospice care. It is most beneficial when the patient and family can receive care early. It can be used for months, as long as medical eligibility is met. To be eligible for hospice care, a doctor must certify that a patient meets both of these requirements:

- A fatal medical condition for which the patient is not seeking curative treatment
- An expected prognosis of six months or less

Hospice should be considered when:

- There is a significant decline in physical and/or cognitive status despite medical treatment.
- The goal is to live more comfortably and forego the often physically debilitating treatments that have been unsuccessful in curing or halting a life-threatening illness.

## **When Hospice Care Begins**

Typically, a family member serves as the primary caregiver and helps make decisions for the loved one when appropriate. Hospice workers provide support by:

- Assisting the patient and family members with the emotional, psychosocial and spiritual aspects of dying
- Having a hospice doctor make house calls or driving the patient to doctors' appointments
- Coordinating and supervising all care 7 days a week, 24 hours a day.
- Helping with bathing and dressing, chores, food preparation and laundry
- Instructing family on how to care for the loved one
- Providing general companionship, which can give a family caregiver time to run quick errands or do other work around the house
- Providing counseling for surviving family and friends.

## **What is Palliative care?**

Palliative care may also be called supportive care, symptom management, or comfort care. Palliative care looks at how the illness is affecting the whole person and helps to relieve symptoms, pain, and stress. It gives patients options and their care. The specialized professionals who are part of the palliative care team can help provide the patient options to enable them and their caregivers to take part in managing mental, physical, emotional, social, and spiritual issues that may come up.

Hospice Care	vs	Palliative Care
offered and provided for patients during their last phase of an incurable illness or near the end of life		offered and provided at any stage of a serious illness
provided when there is no active or curative treatment being given for the serious illness		can be provided while the patient is receiving active treatment
care team coordinates the majority of care for a patient, and communicates with the patient's medical care team		care team is separate from the patient's medical care team that's giving and managing treatment for the illness, but communicates with the medical care

## End of Life Planning – Preferences

Planning your final days is never easy, but it is an invaluable gift to your loved ones. Studies show that when there is a meaningful conversation about end-of-life choices, survivors report feeling less guilt and less depression and having an easier process of grieving. And thinking through these issues before a medical crisis — at the kitchen table rather than in the intensive care unit — will help you and your loved ones make decisions based on what you value most, without the influence of stress and fear.

Official Advance Directive forms available have a set list of questions for you to answer. You may want to communicate your wishes in more detail. You can include those at the end of your Advance Directive or write up separate Advance Health Care Instructions. Health care instructions allow you to specify what treatment you want or do not want in the event you are in a terminal condition, persistent vegetative state or end-stage condition, and to express other health care decisions, such as a do not resuscitate (DNR) orders, organ and tissue donation and special instructions for dialysis, and blood transfusions.

Is there a specific treatment you DO want? Be sure to specify it.

Do you have specific requests for your care if you are experiencing an acute episode of an illness (versus a life-ending event)? How might this differ from long-term care desires?

Below, along with information, are questions posed for you to think about, discuss with loved ones, and eventually, answer. This list of questions is not all-encompassing. It is meant to help you begin to think about what choices you want to make regarding your care. (All of these are “if possible”)

### **Practical tasks**

If you are responsible for caring for dependent children, pets, plants, or other important things in your life, consider designating someone ahead of time to continue caring for those things after you have gone.

Are there certain people you want notified of your illness? Make a list of names and their contact information. Are there people you do not want notified?

If you are concerned with your caregivers becoming overwhelmed, make a list of others who you think might be able to help.

### **What is end-of-life care?**

End-of-life care is the term used to describe the support and medical care given during the time surrounding death. This type of care does not happen only in the moments before breathing ceases and the heart stops beating. People often live with one or more chronic illness and need significant care for days, weeks, and even months before death. Generally speaking, people who are dying need care in four areas: physical comfort, mental and emotional needs, spiritual needs, and practical tasks. Of course, the family of the dying person needs support as well, with practical tasks and emotional distress.

### **Providing physical comfort**

Discomfort during the dying process can come from a variety of sources. Depending on the cause of the discomfort, there are things you or a health care provider can do to help make the dying person more comfortable.

Do you want to get potentially life-saving treatment indefinitely, no matter how uncomfortable it gets, or is quality of life more important than quantity?

When would it be OK to shift focus from curing an illness to comfort care alone?

Pain is easier to prevent than to relieve, and severe pain is hard to manage. How do you want pain (if any) managed? Some pain medications also have side effects. Ask your health care agent to talk with your health care team about benefits and drawbacks of pain medications.

Shortness of breath or the feeling that breathing is difficult is a common experience at the end of life. Some ways to ease breathing are raising the head of the bed, opening a window, using a humidifier, or using a fan to circulate air in the room, rolling the person on their side, as well as some medications. What might you find comforting to ease your breathing?

Skin problems can be very uncomfortable for someone when they are dying. Do you have a favorite lotion or moisturizer or lip balm? Might you enjoy a damp cloth over your eyes, ears, or around your neck?

Nausea, vomiting, constipation, and loss of appetite are common issues at the end of life. Swallowing may also be a problem. The causes and treatments for these symptoms

vary, so talk to a doctor or nurse about what you are seeing. What are some of your favorite foods? Would you prefer to try to eat with your fingers rather than with a utensil? Be sure to let your healthcare agent know if you want to be allowed to not eat.

Fatigue is common near the end of life. Would you prefer to sit in the shower or try a sponge bath? Do you prefer to lie down, be propped in a bed, or sit in a recliner?

### **Relieving Mental and Emotional Distress**

End-of-life care can also include helping the dying person manage mental and emotional distress. Someone who is alert near the end of life might understandably feel depressed or anxious.

Would you like to speak to someone about your feelings? Would you like that person to be a friend or a professional?

Are you open to medication to help relieve anxiety or depression?

Would you be soothed by listening to music? If so, what music would you prefer?

Would you like to have someone read to you? If so, what (poetry, humor, the Bible)?

Would you like lots of company or few visitors with some solitude?

### **Issues surrounding PROGNOSIS**

The problem of prognosis—establishing the life expectancy of a patient with an advanced serious illness or medical condition who is likely approaching death—is important for several reasons. A patient's prognosis

- has important personal implications, affecting the patient's state of mind and decisions about how to spend the next several weeks or months and the family's support for the patient
- has family caregiver implications, affecting family caregivers' understanding of what will be expected of them and for how long
- has clinical implications, affecting decisions about treatment of the illness and of comorbid conditions, and referrals to hospice and social services

Predicting prognosis is easier for some conditions than others and can be complicated by the person's age and other underlying medical conditions. Necessary care with change as the person's condition deteriorates.

As a patient, how much do you want to know about your condition? Just the basics? All the details? Something in between?

Do you want to be told your prognosis? How much time you might have remaining? What might be involved? What you might experience?

Other than yourself, who do you want to be told of your prognosis?

How much information should your doctors share with your loved ones?

### **Spiritual needs**

Spiritual needs may include finding meaning in one's life, ending disagreements with others, or making peace with life circumstances.

Do you want people to pray with you? Do you want visits from a clergy member?

Do you want visits from specific family members or friends? (How about people you may NOT want to see?)

Do you want to always have someone in the room or be left alone sometimes?

### **Practical Tasks**

Where would you like to die? Would you prefer to stay at home? In a hospital? In a nursing home or hospice care facility?

Who would you prefer to be your primary caregiver(s)? If you are confused, who might be the most successful at keeping you calm?

Who would you like with you when you die?

Are there financial affairs you want to get in order? Family tensions you are concerned about?

Whom do you want (or not want) to be involved in your care and in making decisions on your behalf?

Would you prefer to be actively involved in care decisions or to have your doctors do what they think is best?

If you can no longer perform tasks of daily living for yourself, who would you prefer to have perform them? Bathing? House cleaning? Cooking? Laundry? Paying bills?

Are there important milestones you would like to be there for (the birth of a grandchild, your 80th birthday)?

### **Funeral Preferences**

Tradition? Cheerful?

Funeral home? Place of worship?

Flowers? Donations to a specific organization?

Specific passages or poetry to be read? Music?

People to eulogize you?

Photos of yourself that you particularly like or dislike?

What to include in an obituary / write your own obituary?

Pay for funeral in advance?

What should happen to your body? Casket and burial? Cremation? Urn or scattering of ashes? Be turned into jewelry or a paperweight? Green burial? Where to be buried? Grave marker?

Donate your organs and tissues to those in need of transplants or other life-saving treatments or research?



## End of Life Planning – Organization

Organizing paperwork is one way to make things easier on those around you when you are unable to do everything yourself. The basic categories of things to organize is below.

1. Current Information and Responsibilities
2. Personal
3. Financial
4. Property
5. Work History
6. Insurance
7. End of Life and Death Related
8. Digital Estate

Choose what you wish to include in each category, place it in a central location, and let your loved ones or financial and health agents (proxies) know where the information is location and how to access it.

## **Current Information and Responsibilities (I am Still Here)**

1. All legal names used
2. Current and previous Addresses
3. Current and previous Landline Phone number
4. Cell phone number
5. Birthplace
6. Locations for all documents including living will
7. Any medical implant information
8. Hospital insurance information
9. Rx benefits information
10. Vaccination records
11. Primary Care physician name and contact information
12. Other healthcare providers name and contact information
13. Medical conditions, blood type, allergies, current medications, medical history information
14. Healthcare power of attorney paperwork and name and contact information for (proxy) agent
15. Organ donation requests
16. Dependent information:
  - a. Name
  - b. Relationship
  - c. Contacts
  - d. Original birth certificate
  - e. Caregiving, custody, or guarding information
20. Pet information:
  - a. Type
  - b. Name
  - c. Description
  - d. Age (birth date)
  - e. License/ID number
  - f. Microchip info
  - g. Health information
  - h. Vet name and contract
  - i. Guardian name and contact
  - j. Care and guardianship instructions
21. Miscellaneous Information: If I am unable to communicate, this is what I would like my caregivers to know



## Personal

1. Original documents:
  - a. Birth certificate
  - b. Birth certificates for all children
  - c. Death certificates for all previously-deceased family members
  - d. Social security card ([www.ssa.gov](http://www.ssa.gov) for replacement)
  - e. Citizenship papers
  - f. Marriage certificate for all marriages
  - g. Divorce certificate for all divorces
  - h. Death certificates for any pre-deceased spouses
  - i. Discharge papers from military
2. Copy of Drivers' license
3. Copy or original Passport or its location
4. Keys: For everything in your home that has a key, make a key label. If possible, attached the label to an extra copy of the key. Place all key labels and keys into a bag and keep with paperwork. If only the key label is there, survivors know to look for a key. Think home(s) with address and access information, file cabinets, locked boxes, storage units, tool chests, sheds, safety deposit boxes, PO box)
5. Guardianship wishes for dependent children and pets
6. People who have access to this information: Name, contact
7. Information on dependents: personal documents, doctor, allergies, meds list, activities, special needs
8. Family tree / relationship information
9. Photos and memorabilia: what, why it is important to you, where it is located
10. Any other miscellaneous notes
11. Personal wishes (Healthcare instructions not included in your Advance Directive)
12. Last words (signed and dated)

## Financial

1. Assets (Account information for all)
  - a. Brokerage, bank accounts, credit union accounts
  - b. Investments: stocks, bonds, funds, share certificates, IRAs, 401(k)s
  - c. Retirement accounts: location, account number, contact, online access, notes
  - d. College savings
  - e. Digital assets
  - f. Recurring income: inheritances, trusts, child support, spousal support, disability, unemployment, severance pay: source of income, amount, notes
  - g. Money owed to me: personal loans, judgments, possessions, other
  - h. Insurance or money for funeral / burial expenses
2. Liabilities (Account information for all)
  - a. Credit card accounts (store credit cards, too), debit, and ATM accounts: type of card, PIN, password, rewards, location of cards
  - b. Records of debts with payoff status and paperwork such as: Mortgage, Home equity loan, auto loan, student loan, judgments (current and past, with any proof-of-payoff documentation)
  - c. Utilities (electric, water, sewer, gas, oil, trash, lawn services, solar, internet, landline telephone, cell phone, TV, streaming services, HOA)
  - d. Other bills (medical, storage unit, safety deposit box with business name and location, number, location of key, contents)
  - e. Autopay accounts: account name, username, password, amount, date of payment
3. Other
  - a. Online trading and money moving accounts: (E-trade, Venmo, Apple Pay, PayPal including account name, how to access, username / password, any regular payments or credits)
  - b. Subscriptions / charities: newspapers, magazines (paper and online), meal kit deliveries, pet food deliveries, clothing subscriptions, gyms, clubs/lodges, big box, airline mileage, loyalty programs (name, contact information, notes)
  - c. Memberships / Licenses: name of organization, description, position, contact, membership number
  - g. Most recent (2 years) state and federal income tax return with tax return software login information, state revenue service login, IRS login information
  - h. Copies of recent credit reports from Equifax, Experian, and Transunion
  - i. Social security card, statement, login information, where payment depo, benefits you manage for a minor or spouse, location of paperwork, notes
  - j. Name and contact information for your attorney, CPA, advisor or stock broker, insurance agent(s), executor, financial power of attorney

- k. Present and past legal background: prenuptial, adoption records, patent/trademark/copyright property, lawsuits, judgements, ID theft, bankruptcies, inheritances, LLC, corporations, partnerships

## **Property**

1. Deed of cemetery plot or proof of ownership.
2. Deeds for all property owned: location, co-owners, location of keys, documents, what is included (furnishings, possessions), home security system, access information
3. Rental agreement for all property being rented: property owner and contact information, location, co-owners, location of keys, documents, what is included (furnishings, possessions, amenities), home security system, access information, location and dates of lease
4. Commercial Property information
5. Ownership Title documents for all vehicles: Vehicle year, model, make, color, vin or id, location of title or lease, key location, notes
6. Inventory of all assets (house, car, personal property, furniture, jewelry with a description of the item, location, notes on when it was purchased, where, and for how much, and instructions on who you want to receive the item)
7. Appraisals for any items you own
8. Firearms: location, reg information, permit information, access codes
9. Storage units: location, company name, contact, unit number, location of key, contents
10. Safe: location, keys, combo, contents
11. Hidden valuables: location, items, who should take possession
12. Garage code or location of access key
13. Utility shutoff locations in the house
14. List of major maintenance and repairs on home, description, company, receipts, other home information like electric panel map, blueprints, surveys
15. Home inventory with date (include serial numbers, model numbers, and receipts if possible)
16. Vehicle maintenance information, roadside assistance, warrantee information, contents of vehicle, ownership, insurance, keys, toll passes. Satellite radio
17. Purchase documents, appraisals, insurance policies, licenses
18. List of items or files you DO NOT want next of kin to go through, who should, location, access
19. Location of cash

## Work History

1. List of current and all former employers:
  - a. Employer name
  - b. Address
  - c. Telephone
  - d. Web site
  - e. Most recent manager name and email
  - f. Most recent position/title
  - g. HR Contact
  - h. Start date and end date
  - i. Employment contracts
  - j. Benefit documents, bonus information, stocks, vesting, life insurance policy with account information
  - k. Information about retirement benefits/pension plans with account information
  - l. Credit unions with account information
  - m. Union death benefits with account information
2. Any copies of current or previous resumes or CVs
3. Work emails and passwords
4. Education and career accomplishments:
  - a. High school and college test scores, transcripts, and diplomas
  - b. Fraternity or sorority memberships
  - c. Publications or articles
  - d. Resumes
  - e. Recommendation letters
  - f. Certificates and Licenses
  - g. Union or professional organization memberships

Note: If you own(ed) your own company, include all financial information (suggestions listed above) for the business. Also include businesses name, location, contacts, landlords with contacts, keys and lease locations, employees with contacts along with contact information on who is next in line to run the company and take care of its finances.

## Insurance

1. For all types of insurance (life, health, dental, eye, disability, homeowners/rental, auto or other vehicle, renters, storage, health savings account, Medicare/Medicaid, dental, vision, long term care, umbrella, job loss, annuity, pet insurance):
  - a. Type of Account
  - b. Account number
  - c. Group Number
  - d. Any other ID numbers
  - e. Company name
  - f. Address
  - g. Telephone
  - h. Specific contact
  - i. Amount or Contract
  - j. Web address
  - k. Agent name and contact
  - l. Copy of policy
  - m. Beneficiary
  - n. Location of papers



## **End of Life and Death Related**

1. A copy of your Advance Directive (Living Will)
2. A copy of any other End-of-Life-related wishes.
3. Wishes pertaining to organ donation (transplant, science or research)
4. Funeral plans / wishes
  - a. funeral home /director/ company
  - b. service (funeral, religious group) will be
  - c. whether to cremate or bury, where the body or ashes will be interred , kept, or scattered and what type of casket, tombstone, or urn to order
  - d. List of possible people to eulogize you.
  - e. Pre-written obituary or information to include
5. A copy of your Will with name and contact information for the Executor of your Will
6. Name and contact information for your trust or estate attorney.
7. List of beneficiaries and trustees with contact information
8. Information pertaining to filing claims for pension plans, credit unions, and union death benefits
9. People to contact upon your death, with contact information:
  - a. Family members
  - b. Friends
  - c. Coworkers / Employer / Professional relationships / Business contacts
  - d. Frequent acquaintances
  - e. The military unit to which you were assigned
  - f. Your community of faith
  - g. Any organizations to which you belonged that played a significant role your life
  - h. Old friends whom they may not communicate with anymore
10. Wishes for how to let people know of your death

## **Digital Estate**

This includes every online account you have set up. Try to include all, but at least include those with recurrent membership or subscription fees and those which have your credit card number. Suggestions include:

1. Social media accounts and passwords
2. Email accounts and passwords (work and personal)
3. Phone password or PIN, also for tablets, computers, etc.
4. Voicemail password
5. Food Ordering Apps
6. Ride Ordering Apps

Information to include for each:

- Web Site Name or App Name
- Web address or bookmark
- Type of Web Site
- Account Name / Username
- Password
- Other PIN or ID information

When I suggest including “information” about something, these are items you might consider supplying. Creating a master “table” and using it for each item is an easy way to be sure you have all information included.

Type of Information	
Name of Company or Contact	
Name(s) on Account	
Account Number	
Policy Number	
Web site address	
Contact address	
Contact phone numbers	
Login Name / Password / PIN	
Other login information	
Personal or Customer support email address	
Any support-related telephone numbers	
Date of account opening / closing	
Account Beneficiary	
Dates of initiation	
Notes / Description	

# After a Person Dies

## To Do Immediately After Someone Dies

1. Get a legal pronouncement of death
2. Inform the person pronouncing death if the deceased person's organs are to be donated.
3. Try to inform the following people, in this order, if possible:
  - All family members
  - Friends
  - Coworkers
  - Employer
  - Frequent acquaintances
  - Professional relationships
  - Old friends whom they may not communicate with anymore
  - The military unit to which they are or were assigned, if applicable
  - The individual's community of faith
  - Any organizations to which the person belonged that played a significant role in his or her life.

After you get in touch with immediate family, friends and acquaintances, the more formal calls will need to be made. This includes telling anyone who would need to know about the death for either financial or business purposes.

4. Find out about existing funeral and burial plans. Make arrangements for the body. Find where the deceased person has left important paperwork. Some of the items you will need to find are:
  - a. The will
  - b. Records of accounts—these can be most recent statements from banks or credit unions, retirement accounts, and investments; look for beneficiary designations
  - c. Records of debts—these can be the most recent credit card, mortgage, auto loan, student loan, or any other kind of debt statements
  - d. Copies of all insurance policies—life, health, disability, homeowners, auto, and any others
  - e. Identification documents
  - f. Marriage and birth certificates
  - g. Tax returns from the last two years
5. Provide care for children and pets. The children and pets will be grieving, so be sure they are with someone who can comfort them.



## **To Do Within a Few Days of Death**

1. Make funeral and burial or cremation arrangements. Be sure friends and family are informed of the time, date, location, etc.
2. Get help with the funeral. Line up relatives and friends to be pallbearers, to eulogize, to plan the service, to keep a list of well-wishers, to write thank-you notes and to arrange the post-funeral gathering.
3. Get a friend or relative to write an obituary.
4. Secure the property. Lock up the deceased's home and vehicles. Ask a friend or relative to water the plants, get the mail and throw out the food in the refrigerator. If there are valuables, such as jewelry or cash, in the home, lock them up.
5. Forward mail. Go to the post office and put in a forwarding order to send the mail to yourself or whoever is working with you to see to the immediate affairs.
6. Request certified copies of the death certificate. A death certificate serves as a proof of death. Your funeral home will usually process the request for you. It is needed in order to settle debts and close various accounts. It is advised to order 10-15 copies of a death certificate to be sure you have enough for all tasks.
7. Notify the Social Security Administration. Typically, the funeral home will report the person's death to Social Security. In that case, you will only need to give the funeral home the deceased person's Social Security number. If that is not your situation and you need to report a death, call 800-772-1213 or contact your local Social Security office to learn which forms will need to be completed.
8. Notify your family member's employer. Ask for information about benefits and any paychecks that may be due. Also inquire about whether there is a company-wide life insurance policy.
9. Find the will and the executor

## **To Do within Two Weeks of Death**

1. Submit insurance claim forms. To claim Term-Life or Final Expense insurance benefits, contact the deceased's local insurance agent or visit the company's website to obtain claim forms. If the deceased served in the military, a copy of his or her discharge certificate will be needed to prove service and to attain veteran benefits. Visit [archives.gov](https://archives.gov) to seek a veteran's discharge certificate.
2. File claims for pension plans, credit unions, and union death benefits. If the deceased was still working at the time of death, contact the employer to learn about pension plans, credit unions, union death benefits, and survivorship pension.
3. Contact financial advisers and stockbrokers.
4. Pay outstanding bills and cancel accounts. Monthly bills must be paid. In addition, if you or others will need to occupy the property for some time, be sure that utilities

like electricity and water remain functional. Inform the billing companies of the person's death in order to stop future billings.

5. Meet with a trusts and estates attorney. While you don't need an attorney to settle an estate, having one makes things easier. If the estate is worth more than \$50,000, hire a lawyer to help navigate the process and distribute assets. The executor should pick the attorney.
6. Take the will to probate. Probate is the legal process of executing a will. You'll need to do this at a county or city probate court office. Probate court makes sure that the person's debts and liabilities are paid and that the remaining assets are transferred to the beneficiaries.
7. Obtain letters of "administration," "representation," or "testamentary." These come from probate court and give you the authority to settle the business of the person who died. If there is a will, the executor of the will must get a letter of testamentary. If you are the spouse, partner, or next of kin of someone that died without a will, you can get a letter of administration or representation from the probate court that will allow you to settle their affairs.
8. Make an inventory of all assets. Laws vary by state, but the probate process usually starts with an inventory of all assets (bank accounts, house, car, brokerage account, personal property, furniture, jewelry, etc.), which will need to be filed in the court. For the physical items in the household, consider hiring an appraiser. Part of the work of making that inventory of assets is finding them all. The task, called marshaling the assets, can be a big job. Comb your family member's tax returns, mail, email, brokerage and bank accounts, deeds and titles to find assets. Don't leave any safe-deposit box or filing cabinet unopened. If you still think there are things you have not found, there are search firms that will help you track down assets in exchange for a cut.

## **What to do Next**

Make a list of bills. Share the list with the executor so that important expenses like the mortgage, taxes and utilities are taken care of while the estate is settled.

Cancel services no longer needed. These include cellphone, streaming services, cable and internet.

1. Reconcile bank accounts. If the accounts are held jointly with you or are in a living trust, you can use the accounts. If not, the accounts are off limits until the estate has been settled in court.

2. Settle Ownership of Property. Investment accounts, bank accounts, property, land, vehicles, and other assets will need to have ownership changed by the beneficiary.
3. File final income tax returns. Even after someone has died, his or her taxes for the year will be due, and a final tax return will need to be filed. The IRS provides a list of forms and instructions on its website to walk you through the process. Contact the deceased person's CPA, if they had one.
4. Cancel driver's license. This removes the deceased's name from the records of the department of motor vehicles and prevents identity theft. Keep a copy of the canceled driver's license in your records. You may need it to close or access accounts that belonged to the deceased.
5. Close credit card accounts. Contact customer service and tell the representative that you're closing the account on behalf of a deceased relative who had a sole account. You'll need a copy of the death certificate to do this, too. Keep records of accounts you close and inform the executor of any outstanding balances on the cards.  
NOTE: If the credit card account is shared with another person who intends to keep using it, keep the account open but notify the issuing bank your relative has died so the deceased's name can be removed from the account. Destroy any cards with their name on them to prevent theft and identity fraud.
6. Terminate insurance policies. Contact providers to end coverage for the deceased on home, auto and health insurance policies, and ask that any unused premium be returned.
7. Delete or memorialize social media accounts. You can delete social media accounts, but some survivors choose to turn them into a memorial for their loved one instead.
8. Close email accounts. To prevent identity theft and fraud, shut down the deceased's email account.
9. Update voter registration. Contact your state or county directly to find out how to remove your dead relative from the voting rolls.
10. Opt out of prescreened offers and direct marketing. This may prevent unwanted offers or mail from ending up in the wrong hands.
  - To opt out of prescreened offers permanently, visit [www.optoutprescreen.com](http://www.optoutprescreen.com).
  - To prevent unwanted calls, contact the National Do Not Call at [www.donotcall.gov](http://www.donotcall.gov), or call 1-888-382-1222
  - To prevent unwanted offers via the mail, contact the Direct Marketing Association's (DMA) Mail Preference Service (MPS) at [www.dmachoice.org](http://www.dmachoice.org).

### **Particularly for Spouses**

1. Change account titles, file beneficiary paperwork for IRAs, 401k(s), etc.



2. Retitle any assets. Any assets (real estate, vehicles, etc.) in your spouse's name or jointly owned should be retitled to your own name.
3. Update your own estate plan. If your spouse was your beneficiary, then you'll need to update all of your accounts, insurance policies, estate documents, etc. in order to reflect your new beneficiaries.

### **Things You Should NOT Do After Someone Dies**

1. Don't make big decisions that you are not required to make.
2. Don't make major purchases.
3. Don't be quick to give away money, or "stuff."