



Instructions: Legal and Medical Planning Resource

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Legal and Medical Planning Instructions

Legal and medical planning is about putting in place critical instructions that protect yourself and your family when something happens to you. This resource introduces and explains terms to prepare and prompt you to take action. Acting means assuring that legal documents and expressed medical wishes are in place so that your family and appointed agents know your wishes and can enforce them when you cannot make your own decisions. By executing and organizing the documents needed to manage your affairs, everything of practical and emotional value is kept secure and accessible in one place.

What are the basic components of an estate plan?

What's an estate?

An estate includes everything that belongs to you, from property and investments to your grandfather's watch, to your own body.

What are the legal documents that constitute a basic estate plan?

Estate plans are instructions that declare who gets what, who manages the distribution process, who cares for your kids, and who acts as your legal proxy. It also expresses your end of life wishes.

The key legal documents are:

1. **Will or Trust;** declaration of how to distribute your property and appoints:
 - A. Executor (will) or Trustee (trust)
 - B. Guardian for minor or incapacitated children
 - C. Custodian of finances for minor or incapacitated children
2. **Durable Power of Attorney (DPOA);** authorizes an agent to act on your behalf for:
 - A. Medical decisions
 - B. Financial decisions
3. **Living Will (aka Advance Directive)** states your end of life medical choices.

What do you need so that your estate plan is in order?

Unless you have already done so, you need to create the documents that formalize your wishes. Most important is that you authorize an agent with your durable power of attorney (DPOA). This and a living will can be accomplished online. It's best to consult an estate attorney regarding a will or trust, although online services are available. Even if your estate plan is complete, you may need to update it because life circumstances (birth, death, marriage, divorce, bought or sold property) and/or wishes have changed.

Why do you need a will or a trust and what is the difference between them?

What happens if you die without a will or trust?

If you die without a will or trust, state law, not you, determines who gets your property and a judge decides who cares for and has custody of your children. Your assets are frozen for as long as the probate court process takes--anywhere from months to years.

What's required for you to write a will?

A will (aka last will and testament) is simple enough to write by yourself but does not provide the advantages of a trust. You must be of sound mind, act without coercion, and revoke any prior wills or their amendments. Requirements vary by state, but often two people who do not stand to gain anything from your will must witness you signing it, although a notarized affidavit can simplify proving the validity of your will. Both a will and trust designate who you want to get what, who you appoint as legal guardian for minor or incapacitated children, who will administer finances for them, and who you select to execute your expressed wishes.

How do you set up a trust?

Depending on your circumstances and goals, there are many types of trust, some offering advantages over others. An irrevocable trust avoids taxes on the assets in the trust because they are owned by the trust, but you can not access those assets. A revocable living trust allows you to access the funds in the trust while you are alive but does not offer tax protection. Because there are many types of trust, it's either necessary to consult with an attorney or do your own research to determine the one that best fits your needs. Regardless of the trust you choose, a trust only works if you transfer ownership of your assets into the trust (funding the trust). Otherwise it's like a bank account without any money in it.

What are the advantages and disadvantages of a will?

A will is inexpensive, quick and easy. The disadvantages occur after you die. A will is a public document processed through probate court, governed by state law. The probate process can be lengthy, exasperating and expensive. Probate means "proof." The probate registrar has to prove your will is legally valid, document and oversee distribution of assets, ensure payment of debts, death taxes, appraisals, attorney, court, executor and administrative fees. The costs of the probate process eat away at the inherited sum (up to 10% of your estate's value). Assets that may be needed by your family are inaccessible for the duration of the probate process and creditors are paid ahead of family.

What are the advantages and disadvantages of a trust?

A trust is private, avoids probate, and ensures a more seamless transfer of assets. It designates who gets what, appoints a guardian for minor or incapacitated children and a custodian to manage their money. Trusts can provide flexibility in disbursing assets both before and after your death. While you are alive, you can be the trustee of a living or revocable trust, maintaining full ownership and control so you can do whatever you want with your money and assets. During your life, you can also appoint a trustee other than yourself. After you are gone, your named successor trustee(s) assumes ownership and control as outlined by your trust. The trust can specify how and when disbursements of assets are made, and provide tax advantages that result in savings that a will does not. The disadvantage of a trust is that it likely costs more in effort and attorney fees.

What is the value of video recording explanations of your will or trust?

Articulating your decisions in a video demonstrates competency and reinforces credibility. Being seen and heard can relay the basis and nuance of your decisions. If someone contests your decisions, there is evidence of your clear intent. Although video recordings are not legally valid without written documents, they are invaluable in helping to clarify, amplify, and explain what is written.

Why do you need an agent and what purposes do agents serve?

What are the criteria for selecting the person with your power of attorney?

Your POA, also referred to as your agent, must be 18 years or older, agree to serve in this role, and be willing to carry out your expressed instructions, acting as your surrogate or proxy. Confidence in your agent's judgment and competency is crucial. Do you trust this person with your life, with your money, and with your best interests at heart? In order to appoint an agent, you must be of sound mind. If you become incapacitated, or mentally incompetent, the POA is void unless you have a Durable POA.

What does "durable" mean in the context of a power of attorney (POA)?

A durable power of attorney permits an agent to act on your behalf if you become mentally incapacitated. Without this, your POA may be invalid. If your state allows durable powers of attorney (DPOA), it offers protection if you should become unable to think and act for yourself. A durable power of attorney goes into immediate effect, so it is crucial for you to trust the person you appoint.

What happens without a durable power of attorney (DPOA) for financial matters?

If you don't have a durable power of attorney, there will be no one to act as your agent. If you become mentally or physically incapacitated, the court imposes a conservator or guardian, appointing a stranger to act on your behalf, usually paid for by your estate.

How many agents should you appoint?

You may appoint a single person as your agent in multiple roles if he or she is able, available, and accepts the role. You may appoint multiple agents in a single role, as long as they agree with each other. Often there is a different DPOA for health than for finance, and a different person appointed as a child's guardian than the custodian who manages the money. It's necessary to select alternates as backups in case your appointed agent is unable or unavailable to serve. Choose at least two alternates for: guardian for children, custodian for their finances, durable power of attorney for health, durable power of attorney for finance, executor (will) or trustee (trust).

Who should appoint a guardian for underage or incapacitated children?

All parents with minor or incapacitated children should appoint a guardian. No one wants to imagine that replacing yourself as a parent will ever be necessary, but just in case, protect your children by choosing carefully. You can update your choices if they change over time.

What are the criteria for designating a guardian(s) for your children?

Your children's guardians are ideally stable, mature, capable of assuming this role, and know and care about your children. Can they provide the support and comfort your children need? Are their values, practices and parenting style acceptable? Are their financial resources adequate or must you provide them with funds? If you appoint a couple, designate who keeps the children in case they separate.

Is there anything in addition to these legal documents that needs to be done, and why?

Completing all of the items on the Essential Documents Checklist helps people assuming responsibility for you do their job. For example, they might need to know who to contact in an emergency, your medical insurance data, how to access your accounts to pay your bills, or your passwords that unlock your electronic medical records. Having this plus your estate plan securely stored and accessible online spares them days or weeks of rummaging through a mess of papers, lessening the anxiety and stress that comes from chaos and confusion.

Living Will: End of Life Choices

It's natural for people to feel unsure about how to enter end of life territory. It's hard to know how to prepare for terrain you've never navigated before, and easy to procrastinate. But it's important to make medical choices while you are healthy and feeling good. The following series of questions and answers leads you through a process to help you imagine, explore, and express your wishes. While loss, grief, and dying are inevitable, advance planning improves the likelihood that you will live your life on your own terms until the very end, according to your own priorities and values. Making your wishes clear spares those who love you the anguish and regret of not knowing what you would have wanted.

What do you need to know about the legality of end of life instructions?

What is a living will? What is an advance health care directive?

Unlike a will that dispenses property after death, a living will governs your care while you are alive. Living wills originated in the 1970s to give people the right to refuse or accept life-sustaining medical practices. In 1990, the Patient Self-Determination Act mandated that medical institutions must inform people of these rights. In some states, an advance directive combines the living will and power of attorney for health care. In other states, an advance directive is a synonym for a living will.

When does a living will go into effect?

Living wills take effect only when you are terminally ill, permanently unconscious, or unable to make or express your medical wishes. Exact criteria vary by state, but in general "terminal" means an irreversible condition (injury, disease, or illness) without cure that will result in death in the near future. Without a designated agent (POA), one or two physicians must certify that a person is terminal and cannot communicate, or a court must declare incompetency.

Is a living will a guarantee that your wishes will be honored?

Unfortunately not, but it is a necessary first step. Because living wills tend not to be specific to the person, condition, or circumstance, medical personnel may fail to correctly interpret or apply their provisions. Without direct oral or written instruction, paramedics must by law provide life support. People are often unable to formulate thoughts, speak, or provide the paramedic with a document. Dr Ken Murray tells 78-year-old Jack's story: after 15 major procedures, he never wanted to be on life support again. But Jack suffered a massive stroke, arriving to the ER unconscious, without his wife or documents. He was resuscitated and placed on life support--his worst nightmare. After Dr Murray arrived and spoke to Jack's wife, he disconnected life support and they sat with Jack until he died two hours later. Even

with his wishes documented, Jack hadn't died as he'd wished. But because his wife had Jack's POA and Dr Murray had a copy of his living will, his wishes were at least honored belatedly, saving Jack more unwanted time on life support.

If you have a living will, must you select a durable power of attorney for health care?

Absolutely yes. Living wills are important guides for agents, family and caregivers. But invariably unanticipated conditions arise, requiring that someone you trust with your life be able to make decisions on the spot and interpret how or when to apply your expressed wishes. Whereas living wills apply only to terminal situations, if you are incapacitated for any reason, the person with your durable power of attorney can speak and make decisions for you.

What are the criteria for selecting your durable power of attorney for health care?

Your agent must be over 18, understand your choices, and be willing to implement them. This person should be accessible, know you well, and be a vigorous advocate. You must trust your agent's judgment to act in your best interest.

What is the advantage of video recording end of life choices?

It's ideal for you to capture your thoughts, feelings, and fears on video, documenting them for your agent, family and physician to hear. Make clear that your appointed agent has the ultimate authority to interpret your wishes and act decisively for you. Video recording is evidence of your conviction and competence. You can persuasively convey your reasoning, reinforcing your written communication. This is of particular use if there are conflicting interpretations within the family about your wishes. You can either speak at length or be brief. For example, "I want to be kept alive. End of story." Or "If I don't know who you are or how to use a spoon, I don't want to be given food and fluid."

Why is it important to make end of life decisions now?

When is the right time to make end of life decisions?

In short, right now. The Institute of Medicine's 2014 Report on Dying in America says, "Most people nearing the end of life are not physically, mentally, or cognitively able to make their own decisions about treatment. As a result, advance care planning is essential to ensure that people receive care that reflects their values, goals, and informed preferences."

What is at risk if you do not make these decisions in advance?

Most people want to die in comfort at home. But without forethought, conversation, and a plan, 75% die in the hospital, often hooked up to machines--exactly what they didn't want. Dr. Ira Byock tells us, "Families cannot imagine there could be anything worse than their loved one dying. But in fact, there are things worse. It's having someone you love die badly."

Why should you fill out a living will when you are young?

Life-threatening accidents and illness happen at any age. We cannot predict, but we can prepare a plan. You can always change your mind later, but it's crucial to make treatment choices before a medical crisis occurs. Terry Schiavo was only 27-years-old when she fell into a coma in 1990. Eight years later her family had to bring their case to court to request that she be removed from life support. After another seven years, their request was honored. If Terry had documented her wishes, she and her family would have been spared 15 years of pain and suffering. It is prudent for anyone 18 or older to have appointed a durable power of attorney for health care as well as a living will.

What are the economic impacts of not doing advance medical planning?

There are about 50 million Baby Boomers entering their elder years. A staggering 25% of medical expense over a lifetime occurs in the last 2 months of life. This accounts for more than the entire \$50 billion 2008 education budget to briefly postpone death. One in every five people die in the ICU at a cost of \$10,000 a day, frequently without real benefits. A month in the ICU costs \$300,000, and two months costs \$600,000. People in the ICU are often not conscious and experiencing a poor quality of life without a chance of recovery. The impact of not engaging in advance medical planning as a society risks bankrupting our children and grandchildren.

What are key challenges in end of life decision-making and what might help?

How have advances in medical care made end of life decisions harder?

In her book 'Ordinary Medicine,' Sharon Kaufman examines the question, "Will treatment prolong the patient's life or simply prolong an unwanted kind of dying?" Dr. Atul Gawande, author of 'Being Mortal,' says dying used to be brief, but now with technology sustaining our organs, the definition of dying is fuzzy. He had a patient in her 60s with an obstruction that ruptured her bowel, triggering a heart attack that led to septic shock and renal failure. Gawande repaired her bowel and the cardiologist stented her coronary arteries. She was put on dialysis, a ventilator, and intravenous feeding for a few weeks. Then gangrene threatened her foot. Was she dying? Yes, because multiple systems were failing and she would never recover. But no, because with dialysis, a tracheotomy, and amputation of her foot, she would survive--if only for a bit. Medical advances can sometimes extend life that, in retrospect, prolongs an unwanted kind of dying.

What difference do conversations make?

It turns out, they make a profound difference. Gawande reports on a community in La Crosse, Wisconsin in which the elderly are hospitalized 50% less than the national average, and life expectancy is one whole year longer. Why? Simply because it became routine for those being admitted to medical facilities to discuss and answer four questions with their doctor:

- Do you want to be resuscitated if your heart stops?
- Do you want aggressive treatments such as intubation and mechanical ventilation?
- Do you want antibiotics?
- Do you want tube or intravenous feeding if you can't eat on your own?

Why is the timing of end of life conversations so important?

Another big difference in La Crosse, Wisconsin was that doctors, patients and family had discussions about end of life choices before people were in the ICU, before the family was overwhelmed by fear in the midst of a crisis. Patients suffered less, were physically abler, interacted longer, and tended to die in peace, sparing their family agony and depression. Doctors allotted time to listen to broad concerns (about death, suffering, family, finances), and helped people focus and assess their priorities.

What do you need to do so that your doctor can best help you make decisions?

Doctors are trained to be guided by what patients are ready to hear. They will tell you what medical options are available. But unless you ask, doctors may not fully explain the benefits vs the trade-offs, and they may not discuss whether treatment will be useful or futile. Useful care contributes to duration and quality of life. Futile care prolongs dying and unnecessary suffering. Frank, probing dialogue may help you determine whether to accept or refuse treatment

Can you change your mind about the decisions you make?

Absolutely yes. As long as you can communicate, you can alter or reverse any decision. Your expressed wishes are not carved in stone; they are your best guess about what you imagine you would prefer. It's difficult to be absolute about a future you cannot know. For example, Michael had a progressive degenerative disease and appropriately kept changing his mind. First he thought he'd refuse food and water when he could no longer speak, but when that happened, he wrote on a board. Then he thought he'd want his life to end if he couldn't walk, but he was given a scooter, then a wheelchair. When he couldn't eat, he sipped smoothies. By the time he could no longer swallow, his body was failing on its own, he lost his appetite, and his life ended, naturally. He altered his expectations along the way, yet fulfilled his wish to avoid being sedated on a ventilator, being fed by a tube, or dying in a hospital. Alice, on the other hand, signed up with hospice thinking she wanted to be at home, but instead found that she felt safer and more comfortable in the hospital. You get to decide.

How to decide when to pursue interventions: useful versus futile care

What criteria resonate with you for making medical decisions?

Would you opt to pursue treatment that provides you with acceptable quality time and opt to refuse treatment that doesn't? Some prefer to refuse apparently hopeless interventions before degeneration and diminished capacity rob them of their choice. Others heroically endure what appears to be pointless treatment and poor quality of life because it is preferable to giving up hope. For others, religious values or the fear of death is so great that voluntary surrender is not an option. How do you feel?

What happens to most people with a fatal disease?

Hospice nurse Sarah Creed tells author Gawande that although people know their illness is fatal, only about 25% acknowledge they are dying, and most feel abandoned by doctors who say there's nothing more they can do. She says that 99% understand they're dying, but 100% hope they're not. They still want to beat their disease. It's hard to "give up" and refuse interventions, even futile ones.

How do patients' families unwittingly end up inviting futile care?

Family conversations before a crisis can avert interventions for a grievously ill person near the end of life. Dr Ken Murray says such interventions often 'buy misery.' He warns, "Imagine a scenario in which someone has lost consciousness and been admitted to an emergency room. As is so often the case, no one has made a plan for this situation, and shocked and scared family members find themselves caught up in a maze of choices...When doctors ask if they want "everything" done, they answer yes. Then the nightmare begins. Sometimes, a family really means... do everything that's reasonable. The problem is that they may not know what's reasonable, nor, in their confusion and sorrow, will they ask... or hear what a physician may be telling them...Doctors told to do 'everything' will do it, whether it is reasonable or not."

When do some physicians advise halting lifesaving efforts?

Doctors who have repeatedly witnessed the limits of medicine can help families realize when there's nothing they can do that will be of true benefit. Dr. Jessica Nutik Zitter, both an ICU and palliative physician, tells a story about it being time to remove three of her patients from a breathing machine, shifting the course of their care. She had to tell families that their loved one had begun to die. Their response was disbelief, "Can't you do a surgery to fix it? Could there be a miracle?" She needed to explain that their loved ones' brains were so damaged that they would not speak, eat, or hug again, and that a series of fatal infections were likely next. Knowing that there's nothing useful that can be done, she says, helps families choose a more peaceful ending for those they love.

What is an acceptable and unacceptable quality of life to you?

Only you can define an acceptable quality of life. Your definition guides the evaluation of whether a medical intervention is useful or futile. Useful is what delivers an acceptable quality of life, and futile is what doesn't. One person is willing to be hospitalized for days, weeks, months without hope for recovery, subjected to tests and treatments that cause distress, while another feels unwilling. One person can tolerate the idea of an ongoing loss of the capacity to communicate, move, or be conscious, and another finds this intolerable. What would you want? Do you draw a line in the sand? If so, where is it? What if your body is fine but you don't recognize your family? What if you feel no hunger, cannot ask to be fed, nor feed yourself? What if you will never wake up? By imagining different circumstances and recording your attitudes and feelings, you begin to know your wishes, the first step toward making them clear to others.

How do you go about beginning the process of making end of life decisions?

Start a conversation with friends and family about what matters most. Connect with your worries, fears, and deepest desires about how you want to live the last period of your life. Become clear about your priorities. Develop criteria. Asking others how they feel may help. Where, when and with whom can you begin this conversation? Tell those you trust that you need their help and schedule a time to both write and video record your end of life wishes. Do your best to avoid making these decisions in the emotional heat of a crisis. Do your best to make your wishes known ahead of that time.

What is especially challenging about dementia in end of life decision-making?

Who has dementia, and what does this cost our society?

According to the Alzheimer's Association, there are 5.4 million Americans living with dementia in 2016. Most are over age 75, while 11% are younger. One out of every nine people age 65 and older has dementia, and one in every three people over 85. This costs \$236 billion, \$160 billion of which is paid for by Medicare and Medicaid. Of all Medicare spending, 20% is spent on dementia.

What are the human costs for family members when a loved one has dementia?

Someone else has to decide and do everything. People can be physically healthy, living for decades without the capacity to care for themselves. Some are sweet and loving, others irritable, agitated, anxious, and hostile. Over 15 million family and friends are caregivers, many elderly themselves, while some are children. Caregivers perform a demanding, relentless, exhausting, unpaid job everyday with helpless people who are unable to be cooperative. This takes a toll on the caregivers who get no recognition, reciprocity, or time to rest, putting their own health at risk.

How is dementia different than just the natural aging process?

With a medical problem, your body fails, but you're still yourself, with the capacity to be self-aware, expressive and responsive. With dementia, those capacities fade. Severe dementia is not simply forgetting where you put your keys, it's a progressive disease with profound losses. It might begin with difficulty tracking and remembering, progressing to motor losses, then the inability to control bodily functions, and finally into loss of capacity to communicate and know who or where you are.

How are decisions about dementia different than other end of life choices?

End of life decisions usually take effect when the body breaks down and natural death is imminent. With dementia, the body outlives the mind's capacity to remain competent. Dementia doesn't happen all at once. When you reach the tipping point of diminished capacity, the power to speak for yourself is eclipsed. Now is the time to weigh how much of your mind you're willing to lose before you may prefer to exit life altogether. Do you have an exit point? What are your wishes if you reach what you define as your own exit point?

What is useful to know about life-sustaining treatment decisions?

What is Basic Life Support (BLS)? What are the benefits and risks?

Basic Life Support includes CPR (chest compression for cardiopulmonary resuscitation); intubation (an airway tube inserted into the throat); ventilation (attached to a breathing machine); defibrillation (an electroshock that restarts the heart); heart stimulating drugs; and artificial hydration and nutrition (fluids and food delivered by tubes). Without basic life support, survival is at risk. With it, when neither recovery nor a satisfactory quality of life are achievable, there may be the unnecessary suffering of a prolonged dying process.

What is a DNR (Do Not Resuscitate) order?

A DNR means that if your heart or breathing stop in the hospital, you request nothing be done. This is common for people who determine that life-saving measures are futile because they have an irreversible condition without a chance for meaningful recovery, or that resuscitation will do more harm than good by causing unnecessary suffering and an unacceptable quality of life.

What are Physician Orders for Life Sustaining Treatment (POLST)?

POLST is a set of specific orders for or against life support, discussed with and signed by your physician, kept by you. Because it's "doctor's orders," it is easily understood in hospitals. Not all states offer this, but if they do names vary, such as: Medical Orders on Scope of Treatment (MOST), Medical Orders for Life-Sustaining Treatment (MOLST), Physician's Orders on Scope of Treatment (POST), Transportable Physician Orders for Patient Preferences (TPOPP).

Why must POLST or DNR be posted within view or worn as a bracelet?

If a POLST or DNR is not immediately seen by first responders (EMTs, paramedics, fire, police, ER docs) it will likely be ignored. Keep instructions in a place where they can be easily reached and seen.

Without food or fluids, how long is life sustained?

At the final stage of life, you naturally lose your sense of hunger and thirst as your body loses its self-sustaining capacity. This occurs as part of a self-protective process when your body is beginning to shut down--an empty stomach and natural dehydration put less strain on the heart, and produce less of the secretions that lead to lung congestion, swelling, and nausea. Feeding and hydration that you don't want, and are unable to handle, can cause discomfort and therefore be inappropriate. The stomach becomes bloated and fluid collects where it doesn't belong. With absolutely no fluid or food, life ends within 5 to 21 days. This is one of many ways that the body naturally ends its life.

Would you ever want to allow a natural death?

The right to refuse food and fluid is protected by law. If you were to have an advanced terminal illness, be in an irreversible unconscious state, or have severe advanced dementia, and if you either did not or were unable to request food or drink, under what conditions, if any, can you anticipate choosing to allow a natural death? If you contract pneumonia or a urinary tract infection, under what conditions, if any, do you anticipate choosing to refuse antibiotics? Many hospitals have an order called 'Allow Natural Death' that permits patients to request all life-sustaining measures be withheld.

Where do you want to be during the last period of your life?

What are the advantages of hospice care at the end of life?

Hospice enables those with six-months or less life expectancy to remain in their home with supportive medical and social services. The focus is solely on comfort and living life fully, up to the last minute. Hospice guides a family through this time with loved ones, both practically and emotionally. People are accepted into hospice by physician referral.

Do people who sign up for hospice die more quickly than those in a hospital?

Actually, it's just the opposite. The Institute of Medicine's 2014 Report on Dying in America concludes hospice patients often live longer on average with a better quality of life, greater emotional and spiritual support, well-being, and dignity.

Why don't more people choose hospice care?

Many people equate the word 'hospice' with death, and people are afraid to lose hope or admit that death is near. In fact, hospice does mean death is close and some people are just not ready to deal with that. Another reason is that families may feel unqualified to care for loved ones at home. People often choose hospice too late to benefit fully, waiting until the last few days. When people enroll earlier, staff get to know the patient and family and are better able to help. On the other hand, sometimes hospice just isn't an option because people require full-time hospital care.

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