

Chapter 7

Planning for the Future

In this chapter:

- Advance Care Planning
- Personal Business
- Estate Planning

Most people don't like to discuss their wishes for what will happen at the end stages of their life or directly after death. But there are many important decisions, including what types of health care are wanted toward the end of life, or what will happen to one's assets when one dies. **This chapter introduces some of the most important plans for you to help your loved one make, including plans for advanced care, financial plans, and estate plans.**



Advance Care Planning

Part of helping someone live well with a serious illness involves accommodating his or her needs as the illness progresses.

Although you may be dealing with adjustments to daily living, it is important that you and your loved one talk in advance about his or her beliefs, values, and wishes for end-of-life care.

If you wait until your loved one is badly debilitated before getting these affairs in order, it may be too late for him or her to express requests, make rational decisions, and sign important documents.

Advance care planning (for yourself as well as your loved one) includes:

- Learning what life-sustaining treatments are available (artificial nutrition and hydration, extended mechanical ventilators, resuscitation, etc.)
- Deciding what medical treatments your loved one would want if his or her cancer becomes life-threatening
- Communicating with your loved one about his or her personal values and spiritual beliefs about death and dying
- Deciding who your loved one would want to speak for him or her and make decisions about his or her care if unable to do so for him or herself
- Preparing legal documentation of your loved one's end-of-life preferences (Advance Directives) and giving copies to health care providers

Advance Directives are a set of documents that allow your loved one to identify his or her wishes for care at the end stages of life, in the case he or she is not able to do so at the necessary time — specifically a *living will* and a *durable power of attorney*. Once the Advance Directives are completely filled out, they should

be signed, dated, and copies should be kept at home and also included in the patient's medical records. Once they are signed they become legal, official forms. These documents may vary by the state you live in, and you can obtain your state's version from your doctor, legal offices, or state departments.

Living Will

A living will is the part of the advance directives that document the patient's wishes about the medical care that he or she wants at the end of life. These written instructions are used if the patient is physically or mentally unable to communicate wishes at the time. This document is extremely valuable because it protects a patient's rights to accept or refuse care, and it removes the burden of life-or-death decisions from family members or the medical team. It is important to know that someone can decide to refuse "aggressive medical treatment to attempt to cure a disease" but not refuse all medical care. In other words, the patient can specify not to be kept alive artificially, but to be provided with comfort care (pain medication).

Typical information included in a living will:

- DNR (do not resuscitate) orders — instructions to refuse CPR if breathing or heartbeat stops
- Choices about artificial hydration and nutrition
- Choices about life-sustaining equipment (ventilators, respirators)
- Choices about comfort care (pain medications)
- Instructions about being an organ and tissue donor

Durable Power of Attorney (Health Care Proxy)

The durable power of attorney is the part of the advance directive that names a patient's health care proxy. A health care proxy is who the patient

designates to make decisions regarding end-of-life care if the patient is unable to do so.

Typically this is someone who the patient knows well, and trusts will make decisions that represent the patient's wishes in case they are not well stated. The health care proxy is often a spouse or relative of the patient. The patient should make sure to ask this person if he or she agrees to be the health care proxy, and if so, the person designated must sign the form.

Hospice

Hospice is a model of care that emphasizes comfort and management of pain and symptoms, when an illness is expected to lead to death within six months and curing it is not an option. It is appropriate for you, as the caregiver, to discuss hospice with the medical team and your loved one at any time when facing a potentially life-limiting illness. Ultimately, however, your loved one will make the final decision about starting hospice care. If the disease goes into remission or a cure becomes available, a patient can stop hospice and begin aggressive curative attempts again.

If a patient decides to begin hospice care, he or she can be admitted to an in-patient hospice center or remain at home and have regular visits from the hospice staff. Hospice care is comprehensive and includes physical, psychological and spiritual care to address issues such as pain management, adjusting the home to meet the patient's needs, providing necessary medical equipment, and counseling and grief services for the patient and family. Most insurance companies cover hospice care, and it is covered by Medicare nationwide. Speak with your insurance carrier to determine your loved one's coverage and co-pay. If coverage is unavailable, the hospice team may be able to use community or foundation funds to provide services¹.

Personal Business

In addition to the difficult decisions involving physical, emotional and spiritual care at the end of life, most people have personal business that will require management by someone who can be trusted. Naming someone to take charge of financial affairs is called *durable power of attorney for finances*. This is separate from the advance directive described above, but a patient may choose the same person.

Some financial institutions may only recognize the persons named on an account to make decisions about it, so it's important to not wait until the patient is too ill to make changes or add a secondary name on an account. The same goes for other financial assets and legally binding documents such as investments, properties, and car titles. **Adjusting the information on important documents before the patient becomes too ill may prevent years of legal battles and financial burdens.** The following is a list of important topics to become familiar with. If you need to learn more about these you can meet with an associate at your bank, seek advice from a legal service, call your hospital to speak with Patient Relations or a Social Worker, or search the Internet.

- **Bank Accounts** — Pay-On-Death beneficiary designations; do you need to add co-signers?
- **Safe Deposit Boxes** — where are the keys? Who are the co-signers?
- **Life Insurance Policies** — who are the beneficiaries? Do they need amending?
- **Health Insurance Policies** — where are membership cards? What are the ID numbers?
- **Durable Power of Attorney for Health Care** — has this been signed? where is original? Do health care providers have copies?

- **Durable Power of Attorney for Finance** — who has been designated? What is their contact information?
- **Will and/or Living Trust** — Where are they? What attorney drafted them?
- **Deeds/Property Titles** — Who has ownership of the property? Does “tenancy” need to be designated?
- **Stocks/Bonds** — Who are the beneficiaries? Do they need to be amended?
- **Birth Certificate** — Know where your loved one was born in case you need to order one.
- **Military Papers** — If applicable, where are the discharge papers?
- **Social Security Papers** — Where are these documents?
- **Benefits Forms** — Have copies of all forms (SSI, SSDI, GA, MediCal, Food Stamps, etc.)
- **Loan Papers** — Keep payment contracts and credit card statements organized.
- **Vehicle Registrations** — Who is listed as the owner and where is the certificate?
- **Income Tax Returns** — Keep returns for the last five years and the accountant’s contact information.
- **Funeral Instructions** — Is there a contract with a funeral home? Are wishes written down?

Estate Planning

Many people have things that they want to leave for their loved ones to remember them by — some form of a legacy — usually identified in a will. These inheritances can be in the form of financial gifts, family heirlooms, objects of sentimental importance, or even personal memoirs. Helping prepare a legacy with your loved one is a way to bring you closer by providing support that they may not know to ask for.

If your loved one does not specify who is to inherit his or her belongings, each state has a formula that will disperse property out to your next of kin after a lengthy and costly process. If a person dies *intestate* (without a formal will) the state takes control of the property, determines the legal nearest blood relatives and disburses the estate to them. Many times property is sold, all the expenses are paid and what is left goes to the heirs.

There are many issues involved in estate planning that you should be aware of. The best way to become educated on these topics is to seek legal advice or refer to a social worker at the hospital for references. The Internet can be very helpful because it will lead you to many resources and references, but make sure that the information has been written by a legitimate source such as a government or nationally known organization. Also, guarantee that the information you read is current and relevant to the state you live in.

¹ Hospice Net, www.hospicenet.org, retrieved 2007.