

The Consumer's Guide to Hospice Care



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Has Your Doctor Recommended Hospice Care?

You've probably heard of hospice. But you may be unfamiliar with the details concerning this philosophy of medical care. If your physician has recommended hospice for you or a family member, you likely have lots of questions. Where is hospice? How does one enroll? How much does it cost? And perhaps...

What Is Hospice, Anyway?

Rather than a *place* to receive medical care, hospice is an approach to medical care for patients nearing the end of life. Its goal is to enhance the quality of life for patients with terminal illness. Hospice focuses on pain management and symptom relief, while addressing the patient's emotional, social and spiritual needs—as well as those of family members. Hospice lets patients and families share the end-of-life experience with dignity and, in most cases, in the comfort of their own homes.

Each person entering a hospice program gets an individualized care plan. This plan is developed by a team of professionals and volunteers working with the patient and family members. Depending on the patient's needs, the team may consist of the patient's primary care physician, a hospice physician (or medical director), nurses, home health aides, social workers, clergy, trained volunteers and speech, physical and occupational therapists.

Why Choose Hospice?

A patient with a life-limiting illness may reach a point where he or she no longer responds to treatments aimed at curing the disease. At that time, the physician may recommend a shift in focus from curing the disease to making the patient as comfortable as possible. This shift toward palliative care is “comfort-oriented” rather than “cure-oriented.” It is medical treatment that seeks to control symptoms and manage pain. When the physician's estimation of the patient's life expectancy is six months or less, hospice care often is the best option.

Although some hospice care is administered in assisted living facilities, nursing homes, hospice centers, and inpatient settings, approximately 80 to 90 percent of hospice services occur in the patient's own home. That's partly because advances in technology have made it possible to operate much medical equipment in a home setting. It's also because hospice team members and volunteers are available to provide services, as needed, including:

- Pain and symptom management
- Assistance with emotional, psychological, social and spiritual needs
- Drugs, medical supplies and equipment
- Training for family caregivers

- Speech, physical and occupational therapy
- Arrangements for respite care
- Bereavement counseling for surviving family members and friends
- Help with day-to-day chores and activities of daily living
- Experienced counsel for end-of-life decisions
- 24-hour on-call availability

The History of Hospice

Today, more than 3,000 hospice programs serve communities in the United States, Puerto Rico and Guam. In 2002 alone, hospice programs treated more than 885,000 dying Americans, according to the National Hospice and Palliative Care Organization, an industry trade group. Also according to that organization, about 70 percent of American hospice programs are not-for-profit, 27 percent are for-profit and 3 percent are government owned.

These hospices are patterned after the first modern program, St. Christopher's Hospice, which physician Dame Cicely Saunders established in the London suburbs in 1967. She adopted the word *hospice* to describe the program of specialized care for dying patients. The name derives from the Latin word for guesthouse, *hospitium*. In Medieval times, the word *hospice* referred to a sheltered rest stop—a place of comfort—for ill or tired travelers returning from religious pilgrimages. Modern hospice also offers comfort to those on a different kind of journey.

Dr. Saunders introduced her concept in the United States in a lecture to medical students, nurses, social workers and chaplains at Yale University in 1963. She returned to Yale as a visiting faculty member in 1965. Three years later, Florence Wald, dean of the Yale School of Nursing, took a sabbatical to work at St. Christopher's.

Interest in care for dying patients increased on both sides of the Atlantic in 1969, when Dr. Elizabeth Kubler-Ross published *On Death and Dying*, an international best-seller. The book defined five stages of dying gleaned from Dr. Kubler-Ross's interviews with more than 500 terminally ill patients. An important feature of the book was the author's recommendation that patients with terminal illness be allowed to participate in decisions about their medical treatment and be offered the choice of continuing treatment at home instead of in an institutional setting.

Three years later, Dr. Kubler-Ross told the U.S. Senate Special Committee on Aging, "We should not institutionalize people. We can give families more help with home care and visiting nurses, giving the families and the patients spiritual, emotional and financial help in order to facilitate the final care at home."

Unfortunately, subsequent legislation proposing federal funds for hospice programs failed.

However, with funding from the National Cancer Institute (NCI), The Connecticut Hospice Inc., in Branford, Connecticut, opened in 1974. The funding covered the first three years of operation, so the program could serve as a national demonstration center. Between 1978 and 1980, the NCI supported additional hospices.

Because of the initial support of the NCI, many people today mistakenly think that hospice programs support only cancer patients. In fact, hospice is available to patients of any age, race or religion with any illness. Today, about 70 percent of hospice patients have cancer. Other frequent diagnoses include Alzheimer's, Parkinson's, emphysema and AIDS, as well as infectious and parasitic diseases and diseases of the circulatory, nervous and respiratory systems.

Between 1978 and 1986 such government entities as the U.S. Department of Health, Education, and Welfare and the Health Care Financing Administration conducted studies, investigations and demonstration programs to evaluate the feasibility of paying for hospice care and to develop standards for hospice accreditation.

In 1986, the U.S. Congress made hospice care a permanent Medicare benefit. Congress also gave states the option of adding hospice benefits to Medicaid programs. In 1991 Congress added hospice to benefits for military patients, as well as those covered by CHAMPUS, the health benefits program for retired military personnel and dependents of active duty, retired and deceased military personnel.

In addition to these programs, many Health Management Organizations (HMOs) and managed care organizations (MCOs) cover hospice care for patients not eligible for Medicare, Medicaid or CHAMPUS benefits. Additional funding for hospice comes from community contributions, memorial donations and foundation gifts, so some hospice programs use a sliding fee scale based on a patient's ability to pay for those without such benefit packages.

Living Well

Patients and families who face a terminal illness may at first focus on the impending loss of life. However, hospice programs encourage them to make the most of living and enjoying what may be the patient's last months. Staying in the home lets patients reunite with friends and family members. It gives everyone a chance to reminisce and laugh together, despite the sadness, anger and pain that often accompany death. Hospice lets patients *live* until they die—enjoying life to its fullest potential.

Levels of Care And Medicare Eligibility Requirements

Medicare pays a great deal of the services provided by hospice throughout the country. In order to be eligible, a patient must be covered under Medicare Part A and must also have certification from a physician that the patient's life expectancy is six months or less, assuming the illness runs its normal course. There is a great deal of confusion about the six month standard. It does not mean that the patient will lose his or her hospice benefits after six months. Instead, it simply means that in order to be eligible, there must be a six-month life expectancy. After the initial period of certification, however, the patient can have an unlimited number of additional sixty-day periods. So long as the individual continues to have a life expectancy of six months or less, hospice can go on indefinitely.

To enroll in hospice, the patient must sign a statement electing the hospice benefit. This is perhaps the most difficult step for many families to take, since this election shifts the course of treatment from curative (i.e. intending to help the patient get better) to palliative (i.e. treating the pain, but not trying to cure the illness). Many patients worry that by electing the palliative (pain reducing) course of treatment, they are locking themselves into something that cannot be changed. That is not correct. The election from hospice to non-hospice to hospice care can be made as frequently as the patient desires.

A great benefit of hospice care is that medication related to the terminal illness is covered with a maximum co-pay of five dollars per prescription. In this day and age of spiraling medication costs, this benefit alone can save families a tremendous amount of money. In addition, the new Medicare law added another valuable hospice benefit. Under the law, patients can have a one-time educational consultation by a hospice physician to the terminally ill patient, even when that patient is not yet in hospice. The consultation could occur in a care facility or at home, and should also include a pain assessment, along with counseling on care options and advance planning.

The question frequently arises...does hospice pay for nursing home care? If the patient is a nursing home resident, there will be hospice benefits available, much like if the resident were at home. The Medicare hospice benefit will not cover the costs of room and board at the nursing facility. It will, however, continue to cover the types of services mentioned earlier.

What if the patient is not eligible for Medicare Part A? Are there other ways to pay?

In addition to Medicare, there are many ways that hospice care may be paid for. Often, Health Maintenance Organizations (HMOs) and managed care organizations cover the cost of hospice care. Military patients as well as those covered by CHAMPUS (the health benefits program for retired military personnel and dependents) will frequently be covered for the cost of hospice. Additional funding for hospice also comes from

community contributions, memorial donations and foundation gifts. Many hospice programs also use a sliding-fee scale, based on a patient's ability to pay for services when insurance and other benefit programs are not available.

I've Elected To Enroll In Hospice. Are There Other Steps I Should Take?

Once the decision is made to move from curative medical care to hospice care, patients often begin to wonder if there are additional steps they should take. And while hospice treatment, in some cases, can go on for years, in reality, the patient is dealing with a terminal illness, and they need to get their affairs in order.

There are steps which should be taken. Some of the recommended steps should be taken by everyone, while others may or may not be necessary, depending upon your particular situation.

Among those things which are appropriate for everyone, probably the most important is for you to have the right powers of attorney in place.

A **power of attorney** is a document that gives someone the legal authority to make decisions for you if you cannot make decisions for yourself at some time. There are powers of attorney for *financial matters* and *health care* issues.

The **healthcare power of attorney** allows someone to make decisions for you (when you can't) concerning doctors, hospitals, medication and so on. People often wonder..."My husband and I have been married for 40 years, can't I just make decisions for him?" Unfortunately, the law presumes that, no matter how long you've been married, or no matter how close you are to your loved one, if you have not given them authority to act for you under a proper power of attorney, then you must have meant **not** to give them permission to act for you.

Parents are the legal guardians of their minor children, and decisions which need to be made up until the child turns 18 can legally be made by the parent. Once that child is no longer a minor, however, after age 18...then the parent loses the legal authority to make those decisions. In addition, if your parent or spouse or child over age 18 has not given you specific authority to make decisions for him or her, then the law presumes that they must have meant not to give you such authority. And that means you will not be able to make decisions for them.

Having powers of attorney in place is crucial where someone is on hospice, since their health may deteriorate to the point where they can no longer communicate their wishes. If that's the case, then perhaps at the most critical time, without a proper power of attorney in place, you will not be able to make legal, financial, and even life and death decisions for your loved one.

What's more, if your loved one loses the ability to give you authority under a power of attorney, (i.e. if he can no longer understand and sign the documents) and then decisions need to be made, you will have to go to court and begin a costly legal process to be named their guardian.

From my experience as an elder law attorney who has helped thousands of families, the reason why people don't have powers of attorney in place is not because they didn't want someone to manage things for them...oftentimes it's simply that they didn't know they needed these documents. It comes as a shock when I tell them that, since this was never put in writing, they have no legal authority to make decisions for their spouse or parents.

The other type of power of attorney is a **financial power of attorney**. This document covers a whole host of situations, from handling real estate, to dealing with bank accounts, to paying taxes, to almost anything you can think of, from a financial standpoint. It is crucial that you have the appropriate financial power of attorney in place.

Having the appropriate financial and health care powers of attorney in place is the critical first step. Next, depending upon the specific situation, other legal issues related to end-of-life planning may arise. After executing durable powers of attorney for finances, health care, and a health-care treatment directive (i.e. a living will), you and your family may need to consider other legal planning.

Revising wills and trusts: Whenever a "major life event" occurs, attorneys recommend that you review your wills and trusts. Your current legal documents may no longer be appropriate. You may want to make changes that reflect the new circumstances. Having a life-threatening illness is a "major life event" worthy of review. The plans that were put into place when everyone was healthy may no longer be appropriate.

For instance, many clients set up what we call "sweetheart wills" in which each spouse leaves everything to the other, and then at the death of the second spouse, to the children. That may be exactly the wrong way to set things up now, given one spouse's illness. It may be that things can be arranged in a better fashion so that if the "healthy spouse" passes away first, the assets can be put into a trust to benefit the spouse who is on hospice...or perhaps the assets should be passed on down to the children to protect those assets from Medicaid. This is where specific legal planning with an attorney experienced in dealing with patients on hospice is critical.

Changing property titles: The way in which your real estate is titled can be critically important. In some cases, if things aren't handled properly now, then dealing with the property later on could require going to court. Reviewing property titles is also an important part of planning. That way, you can be sure your family members are protected if the illness requires long-term care in a nursing home.

Strategies for financial gifts: Consulting a knowledgeable attorney is especially important before you transfer any property or make any gifts. The attorney can help you

review your financial situation to determine whether a gifting program or other financial strategy is appropriate. Making gifts can protect your family and help save your estate, but acting improperly can have severe legal consequences, and can even make you ineligible for government benefits. Thus it is crucial that you have sound advice in the event that long-term care is needed.

Long-term care strategies: In addition, you may want to consider the benefits programs that are available. For instance, Medicaid, a federally-funded program administered by the states, may pay some health care costs (assistance with bathing, light housekeeping, cooking and laundry and others), while an eligible patient remains at home. But there are strict rules about how you can qualify for this and what benefits may be available. With that in mind, let's review the basics of Medicaid and how to qualify.

The Basics of Medicaid

In order to understand Medicaid qualification, you first need to know how Medicaid treats your assets.

Basically, Medicaid breaks your assets down into two separate categories. The first are those assets which are exempt, and the second are those assets which are non-exempt, or countable.

Exempt assets are those which Medicaid will not take into account. At this time the following assets are exempt in Pennsylvania:

- **Home**, except for equity exceeding \$500,000. The home must be the principal place of residence and the resident may be required to show some intent to "return home" even if this never actually takes place.
- **Household and personal belongings** such as furniture, appliances, jewelry and clothing.
- **One vehicle** (a car or truck or van).
- **Pre-paid funeral plans and burial plots.**
- **Cash value of life insurance policies** - Up to \$1,500 in cash surrender values may be exempt, along with term life insurance, depending upon your situation.
- **Cash** (e.g. a small checking or savings account) – not to exceed \$2,400.

In certain instances, some other assets, such as IRAs, 401(k) plans, income-producing real estate, and so on, may be either countable or exempt, depending upon your particular situation.

The assets which are not exempt are then considered countable. This typically includes checking accounts, savings accounts, certificates of deposit, money market accounts, stocks, mutual funds, bonds, most IRAs, most pension plans, second cars, and so on.

While the Medicaid rules themselves are complicated and somewhat tricky, for a single person, it's safe to say that you will qualify for Medicaid so long as you have only exempt assets, plus a small amount of cash (less than \$2,400).

What is Division of Assets?

Division of assets is the name commonly used for the spousal impoverishment provision of the Medicare Catastrophic Act of 1988. It applies *only* to married couples. The intent of the law was to change the eligibility requirements for Medicaid in situations where one spouse needs nursing home care, while the other spouse remains in the community (i.e. at home or in an assisted living facility). Since then, changes in the law have now allowed spouses who are at home to sometimes qualify for Medicaid assistance for certain home and community-based services.

Basically, in a division of assets, a couple gathers all of their nonexempt (i.e. countable) assets together in a review. The exempt assets are the ones described earlier, such as the home, one vehicle, and so on. The non-exempt assets are then divided in two, with the community (or at home) spouse allowed to keep one-half of all of the countable assets, up to a maximum of \$101,640. The remainder of the assets must then be “spent down.”

In other words, there is a married couple who has \$100,000 in countable assets, then through a division of assets, the well spouse, or community spouse, will be able to keep one-half of those assets (i.e. \$50,000 in this example) and the ill spouse would be allowed to keep his or her \$2,400.

The laws are very tricky as to exactly how the spend-down is completed. Suffice it to say that someone who is pursuing Medicaid eligibility should consider the following types of spend-down items. These are listed in no particular order:

- **Purchase pre-paid funeral plans**
- **Purchase a new car**
- **Payment of healthcare costs (including nursing home if needed)**
- **Purchase of a new home**
- **Make home improvements**
- **Buy household goods or personal effects**
- **Repay debt**

These are not the *only* appropriate items for a spend-down. There are other expenses which would also qualify. The main rule to keep in mind is that whatever goods or services are purchased must be done at fair market value and must be for the benefit of the patient and/or for the spouse.

Some Frequently Asked Questions

As complicated as Medicaid is, there are certain questions which come up over and over again. While no book will be a substitute for the advice of an experienced attorney who counsels hospice patients, let's at least review some of the questions that seem to frequently come up.

Question: Is a married couple always required to spend down one half of their assets before qualifying for Medicaid?

Answer: Not always. In fact, oftentimes, couples have over \$100,000 and qualify for Medicaid benefits without spending down. Although there are income and asset criteria a couple must meet before one of them qualifies for benefits, federal and state laws were written to protect individuals from becoming impoverished if their spouse needs care. Medicaid planning is like tax planning in that the laws provide certain "safe harbors" that, with expert advice from a knowledgeable professional, can save Medicaid applicants and their families thousands of dollars. An experienced elder law attorney can help you determine if there are ways to protect additional assets in your particular situation.

Question: Will I lose my home?

Answer: Many people who apply for Medicaid ask this question. For many people, the home constitutes much or most of their life savings. Often, it's the only asset that a person has to pass on to his or her children.

Under the Medicaid regulations, the home is generally an unavailable asset. That means it is not taken into account when calculating eligibility for Medicaid.

In 1993, Congress passed a law which requires the states to try to recover the value of Medicaid payments made to recipients. This process is called estate recovery.

Estate recovery does not take place until the recipient of the benefits dies. In the case of a married couple, it occurs after the death of both spouses under the current laws. At that point, the law requires states to attempt to recover the benefits paid from the recipient's (or spouse's) estate. In recent years, as state budgets have gotten tighter, many states have become more aggressive about their estate recovery programs. You will need assistance from someone knowledgeable about the rules and regulations to determine whether or not there will be estate recovery, and whether it can be avoided in any particular situation.

Question: Is it true that under current Medicaid laws, a parent cannot make gifts to their children once they are contemplating Medicaid or have even entered a nursing home?

Answer: No. In fact, a proper gifting program can be a great Medicaid planning technique. At the time an applicant applies for Medicaid, the state will "look back" five years to see if any gifts have been made. Any financial gifts or transfers for less than fair

market value during the five year look back may cause a delay in an applicant's eligibility. Also, just because the state may ask about gifts made during the prior five years, does not mean that all of those gifts will be considered. You do need to be aware of a new law which became effective February 8th, 2006. Under the terms of that new law, the gifting rules have become far more complicated. There may be some special opportunities for asset transfers for hospice patients. An elder law attorney can help determine if hospice planning could be a benefit in your situation.

Question: I've heard that \$10,000 is the most an individual can give away if they are going to apply for Medicaid.

Answer: No, the \$10,000 figure (which recently went up to \$12,000 per year) is a gift tax figure, and not relevant with respect to Medicaid's specific asset transfer rules. The maximum monetary figure Medicaid applicants need to concern themselves with is the "penalty divisor" for their state. The penalty divisor is the state-assessed average cost for nursing home care by which the state assesses Medicaid penalties. The penalty divisor for Pennsylvania is currently \$222.17 per day. Therefore, a gift will cause a penalty of one day for each \$222.17 given away.

Question: A Medicaid applicant's house is considered "exempt" under current Medicaid laws. Can an applicant give away the house without incurring penalties?

Answer: No. Any assets which are given away are considered transfers for less than fair market value. If an applicant gives the house away, the state will assess a penalty based on the fair market value of the house at the time the property was transferred.

Suffice it to say that the Medicaid laws are complicated. There are a number of steps which smart families can take to preserve their assets and to qualify for benefits. These can range from gifting strategies to personal care contracts to annuities to increasing the amount of money which the at home spouse is allowed to protect. It's important to keep in mind that these laws are constantly changing, and that the advice which was given to a friend or neighbor last year may no longer be relevant, or even appropriate. It's also important to understand, however, that with expert advice you may be able to protect yourself and your loved ones while qualifying for all the benefits the law allows.

What Is Probate And Can You Avoid It?

One of the primary concerns that someone on hospice faces is how to be sure that their property will pass to their loved ones in the event of their death.

There are basically four ways an individual can transfer property to their loved ones upon their death. Depending upon the age of the persons who will be receiving property or the dynamics among family members who are receiving the property, it is important to choose your method of transfer very carefully.

Die without a Will (i.e. do nothing to plan for your property at your death) – if you do absolutely nothing to plan for the transfer of your assets, and if the property is titled only in your name at the time of your death, then your property will go through a process known as intestacy. This means that your property will be divided among your surviving relatives according to the probate laws of your state. Basically, state statutes provide who will receive your property if you have done no planning. In essence, the state has written a will for you. It typically says that, at your death, if you have taken no steps, then a certain amount will pass to your spouse, if you have one, and a certain amount to your children. If there is no spouse or children, then more distant relatives will receive your assets. Obviously, most people want to have a greater say in where things go. That’s why they take other estate planning measures, such as those described below.

Establish a Last Will and Testament – Establishing a last will and testament allows you to provide written instructions on how your property is to be divided upon your death. In your will, you designate an “executor” or “personal representative” of your estate who opens the probate estate. Your representative will then distribute your property as you have outlined in your will. That way you’ll be assured things go where you want them to, and that family dynamics will not affect your wishes. Also, if you have one or more minor children, then it is critical to have a last will and testament in place so that you can designate who you would like to be their guardian.

Add a joint owner with rights of survivorship to your property – Adding a joint owner with a right of survivorship to your property (a joint tenant) will pass 100% of that property to the joint owner upon your death. There is no probate necessary. This is often the way spouses choose to title their property. Joint tenancy can, however, be a problem. For instance, if a child is added to an account, and that child is later sued (e.g. divorce, car accident, etc.), 100% of that account may be subject to the lawsuit, and the parent may be left with no recourse. Joint tenancy “overrides” any last will and testament you may have executed.

Add beneficiary designations to your property – Adding a beneficiary designation (pay-on-death [POD] or transfer-on-death [TOD]) to your real or personal property is another way to avoid probate. Again, 100% of your property passes to the person(s) you have designated as the beneficiary. Unlike a joint owner, however, the beneficiary has no access to your property until you have passed away, thus avoiding any problems with attachment of your assets by the beneficiary’s creditors. Like joint tenancy, however, the beneficiary designations “override” any last will and testament you have executed.

Proper planning for a hospice patient regarding legal issues is a must. For instance, if the patient has young children, then it is crucial for him or her to have a will (and where appropriate, a trust) in place. That’s because minor children cannot take title to property in their own names. What’s more, it will be important to arrange for the care of the children after the death of the parent. And it’s critical to be sure that, where possible, the person who will be caring for the children will have access to the funds to properly care for the children. In addition, some people are not emotionally equipped to

handle sums of money they receive outright, and it's common to see individuals who have received an inheritance to quickly spend that inheritance in the matter of a few short weeks or months. But proper thoughtful planning can avoid this and insure that everyone is protected and your life's savings, no matter how large or small, are not squandered.

What Steps Should You Take Now?

As you can tell from reading these materials, planning for someone who has a life-threatening illness can be complicated. You may be torn by the emotional component...thinking that if you put your wishes down in the form of a last will and testament or a trust, you are somehow surrendering your fight and giving in to the disease.

Actually, our experience as attorneys who help families with this type of planning is that the opposite occurs. We find that our clients experience a great peace of mind once they have done their planning so that they can concentrate on the other issues they are facing.

When a life-threatening illness strikes, it's the responsibility of the spouse or family leader to become fully informed – to get smart – about these things. We have personally reviewed dozens of books, plus the literature commonly given to families who have someone on hospice, and we've given and attended the public workshops and lectures. And we've found that these leave out most of the **critical financial and legal information** you need to know.

That is why we wrote this book entitled **The Consumer's Guide to Hospice Care**, and that's why we've been on a legal crusade of sorts, to make sure that families who have a loved one facing a terminal illness become smart about these things.

The time to act is now. With proper planning, you will insure that things are handled according to your wishes and that you've taken the best steps possible to protect your loved ones and to protect your family's financial security.

If you would like the guidance of a law firm which has helped hundreds of families successfully deal with these issues, then call: Levandowski & Darpino, LLC, 17 Mifflin Avenue, Suite 202, Havertown, PA 19083. 610-446-9626 Phone; www.levandowskidarpino.com

Imagine the peace of mind you'll have when you stop reacting to your situation and start putting into place a positive action plan which will allow you to protect yourself and your loved ones.

Our best wishes to you.

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This guide is brought to you as a service of

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