

**A Consumer's Guide
to
Hospice Care**



A H R E N S D E A N G E L I
L A W G R O U P

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% 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 the 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 the 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. In addition to Medicare, for military patients as well as those covered by CHAMPUS (the health benefits program for retired military personnel and dependents) will frequently cover 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 **health care 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. Although Idaho's Medical Consent Act gives priority to the spouse, it is always preferable to have a health care power of attorney in place to clarify the order of priority of persons you want to speak for you if you cannot make health care decisions for yourself.

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 your loved one can no longer communicate his or her 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 and/or conservator.

From my experience as a board certified 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. Not all financial powers of attorneys are created equal. There are many powers that I build in to the financial powers of attorney for my clients that allow their agents to engage in crucial planning to address legal and financial issues that have arisen because of the need for long-term care or because death is imminent that form financial powers of attorney simply do not have. In this regard you truly to "get what you pay for."

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 a certified elder law 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. Such planning can also help avoid the probate process which of course avoids additional time and expense.

Strategies for financial gifts: Consulting a knowledgeable elder law 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 or transfers into an irrevocable trust 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/Public Benefits advice: In addition, you should 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. Please see our Consumer's Guide to Medicaid Planning, available on our website (www.IdahoElderLaw.com) or by calling our office at 208-387-0729.

A Veterans Administration special monthly non-service connected pension is also an incredibly powerful benefit that is available to seniors veterans AND their surviving spouses. To learn more about this program and how it can actually increase your monthly income to help you pay for the care you need and protect your life savings, see our Nuts and Bolts Guide To Veteran's Benefits available on our website (www.IdahoElderLaw.com) or by calling our office at 208-387-0729.

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 five 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.

Leave property titled solely in your name (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 probate. This means that a court will order your property to be divided among your surviving relatives according to the probate laws of your state. Basically, the courts, via 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. It usually takes about nine months or longer before all of your assets are distributed if they have to go through this type of probate process. 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. With the supervision of the court, your representative will then distribute your property as you have outlined in your will. A will can sometimes be advantageous since a court will become involved in the distribution of your assets. 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 the guardian of your children. However, in order for a will to be administered, it must be through the probate process. Having a will does not avoid probate.

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.

In cases of married couples in Idaho, the law now allows a special title on deeds to real property so that the property passes to the surviving spouse without a probate. This is referred to as a community property with right of survivorship deed.

Add beneficiary designations to your property – Adding a beneficiary designation (pay-on-death [POD] or transfer-on-death [TOD]) to your 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.

Establish a revocable living trust – A revocable living trust is an estate planning document which allows an individual to direct another person (the trustee) to distribute property upon their death, according to their specific wishes. Unlike a will, however, a revocable living trust is not probated. In addition to avoiding the time and expense of a court proceeding, the benefits of a revocable living trust are numerous: they insure your financial affairs remain private (as court records are open to the public); they allow an individual to retain control over their property; trusts can incorporate planning for you if you become incapacitated; and sometimes trusts can result in estate tax savings.

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, my experience as a board certified elder law attorney who helps families with this type of planning is that the opposite occurs. I find that my 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. I have personally reviewed dozens of books, plus the literature commonly given to families who have someone on Hospice, and I've given and attended the public workshops and lectures. And I've found that these leave out most of the **critical financial and legal information** you need to know.

That's why I wrote this brief handbook entitled *A Consumer's Guide to Hospice Care*. And that's why I'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 Idaho families successfully deal with these issues, then call Ahrens DeAngeli Law Group LLP at (208) 387-0729.

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.

My best wishes to you.

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Brought to you as a service of

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