

## Chapter 27

# Hospice and Palliative Care: Options for Care at the End of Life

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"Hospice was great for my husband, but quite frankly, it saved my life." "I've never met such caring people — they made a tough time almost a pleasure." "Honestly, I think Mom lived longer with hospice care than she would have without it!" These are the kinds of comments we hear everyday from folks who have experienced hospice care. Ask around and you are likely to hear the same. After all, about half of all Coloradans who die receive hospice care. In a summary of survey results from 1,027 hospices across the country, compiled by the National Hospice & Palliative Care Organization in 2007, 98.4 percent of hospice patient family members said they would recommend hospice to others. That's amazing. Not even Geico has that kind of customer satisfaction!

Even so, many people and their families who could benefit from hospice care don't receive it — because they don't know about it or have inaccurate ideas about it; because they don't know it's fully covered by Medicare Part A, Medicaid, and most private insurance plans; because they wait too long and, in the crisis, don't have the information they need.

What exactly is "hospice," and how does it work? How is it paid for and how can you get it? And what is "palliative care," and how is it different from hospice? This chapter answers these questions and more.

## **27-1. What Is Hospice?**

"Hospice" is not a place, like a nursing home or hospital. It is a way of caring for persons with terminal, or "end-stage," illness and supporting their families, provided by a specially trained team of professionals. The team works together and with the patient and family to maximize comfort and quality of life. The hospice approach emphasizes care for the whole person: body, mind, feelings, spirit, and relationships. In hospice, you are not "the gallbladder in room 232," but a person with a history, complex and important feelings, goals and dreams, family, and friends — and, by the way, a serious illness.

Most hospice patients receive care in whatever setting they call home. This includes nursing homes and assisted living residences. The idea is to maintain independence, familiar surroundings, and meaningful relationships for as long as possible. Hospice is not focused on curing the disease, but easing its distressing effects: pain, fatigue, nausea, dry mouth and skin, breathing difficulty, anxiety, sleeplessness, depression, and so on.

Hospice care is just as "aggressive" as curative care. Vigorous attention and sophisticated treatments and medications are used to maintain quality of life and comfort. Many persons enrolling in hospice experience a kind of "hospice bounce." One recent study showed that persons enrolled in hospice actually lived longer — by weeks — on average than persons with the same diagnoses receiving curative treatment. And — like comic columnist Art Buchwald — about 16 percent of persons enrolled in hospice actually "graduate" and are discharged alive.

## 27-2. How Can I Get Hospice Care?

### Enrollment Criteria

In order to enroll in hospice, you must have a “terminal” illness and a life expectancy of six months or less, as certified by a physician. This means that a doctor — your attending or primary physician, any specialist involved in your care, or a hospice medical director — says that in his or her best professional judgment, your illness, if allowed to proceed without intervention, is likely to result in your death within six months. You must also agree to forego treatments that are intended for cure and not for comfort.

**Note:** The enrollment criteria and other information about duration of care and coverage of costs in this chapter are specific to the Medicare Hospice Benefit. If you are covered by private insurance, policies may differ. Be sure to check with the insurance agent or ask the hospice social worker to confirm your coverage.

Many hospices, however, have “open access” policies that offer a great deal of flexibility to allow and cover treatments that have traditionally been considered curative but can be “palliative” — that is, increase comfort or relieve pain. For instance, a hospice patient might receive “palliative radiation” to reduce the size of a tumor that is pressing on her spine in order to relieve pain or prevent paralysis.

Many hospices are now working to provide earlier access to hospice services by providing pre-hospice palliative care or transition programs. These programs allow patients and families to receive some of the services and symptom-management benefits of hospice care without formal hospice enrollment. Palliative care is covered in the second half of this chapter.

### Duration of Care

Once you are enrolled in hospice, your condition is closely monitored. If your condition is progressing as expected, you may stay enrolled in hospice as long as needed. Initial coverage extends for 90 days from enrollment; after that, your situation is assessed again after another 90 days and then after each 60 days. Your enrollment is “recertified” as long as the basic hospice criteria are met — even long past six months. Sadly, only about 13 percent of hospice patients receive a full six months of care or more; right now, half of all hospice patients are enrolled for fewer than 21 days before death, some only for hours. This is hardly long enough to obtain the full benefit of the program of care, and many, many families find themselves saying, “I wish we’d done this sooner!”

**Note:** Hospice enrollment is not a one-way street. If you don’t like hospice care, wish to resume curative treatments, or get better, you can check out of hospice care (or “revoke”) at any time. As long as criteria are met, you may re-enroll as well.

## Getting a Referral to Hospice

There are many paths to hospice care. Each person's circumstances are unique. In general, however, the starting point for hospice care is the recognition that your illness cannot be cured or effectively managed. This may be a new diagnosis, coming as a shock after a brief period of illness or mildly worrisome symptoms. Or it could be a further development of an illness that has been controlled but not getting any better for some months or years. Or it could be that the illness has just outpaced available treatments. Most people these days do not die of classically "terminal" illnesses; rather, they suffer from longstanding chronic illnesses, sometimes several at once, that just gradually get worse over an unpredictable period of time.

This can make it difficult to get a hospice referral at the right time. Doctors may resist stating clearly that an illness has reached this "terminal" phase, or "end stage." In today's health care world, it seems there is always something more to try in search of a cure, and doctors are rightly committed to their patients' survival. However, even when an illness is clearly terminal, doctors can be very reluctant to answer the question, "How long do you think Mom has?" Honestly, they just don't know. A recent research study showed that when asked to make predictions about their patients' likely survival time, doctors typically overestimated by a factor of 5; that means they thought, in all good faith, that their patients would live 5 times longer than they actually did. And the better the doctor knew the person, the more he or she overestimated.

**Tip:** If you have any question about whether hospice might be the right choice for you or your loved one, here's a good way to ask the question: "Would you be surprised if (Mom) were alive in a year?" If the answer is yes, a good follow-up question would be, "Would hospice be a good option for (Mom) now?" If the answer is yes, or even maybe, you now have a hospice referral.

If your illness has reached this stage, and if your own doctor is resisting the idea of hospice for whatever reason, you can ask for an evaluation by a hospice doctor as a first step. This evaluation can be done in the hospital, nursing home, or at home.

## 27-3. How Does Hospice Work?

During the evaluation or admissions interview, the physician or nurse can explain how hospice works. Here's an outline:

### The Hospice Care Team

Hospice care is provided by a team of professionals:

A *physician*, who supervises the care, meeting regularly with the other members of the team to discuss the care plan and how things are going. Visits from the physician are likely to be infrequent, but he or she is closely monitoring your care and available for consultation at any time.

**Note:** You don't have to give up your current doctor when you enter hospice. He or she can continue to supervise your care along with the hospice team. However, hospice doctors are specially trained in pain and symptom management and may have skills and "tools" other doctors lack.

A *registered nurse*, who visits you regularly, supervises the nurse's aide, and reports to the doctor and other team members. Just how often the nurse visits will depend on a lot of factors, but typically it's once or twice a week. The nurse, in consultation with the doctor, will work to relieve pain and other symptoms, including nausea, anxiety and depression, fatigue, skin irritations, problems with bowel and bladder function, and so on. Nurses keep a close eye on your mental and emotional health as well, and will alert other team members if difficulties arise.

A *certified nursing assistant*, who provides help with personal care, if needed. This includes bathing, dressing, hygiene, light food preparation (snacks), and so on.

A *social worker*, who can address social, emotional, practical, and financial challenges. For instance, social workers can help organize extra caregiving help; complete important financial or practical preparations for death; mediate family disputes; interpret insurance policies and obtain benefits; or provide support to your spouse or life partner, children, or other family members in distress.

A *chaplain*, who is specially trained to respond to the spiritual aspect of facing serious illness and the end of life. While chaplains may be ordained in or members of a particular religious tradition, they do not preach or promote any particular belief or faith. More than anything, they are expert listeners.

A *volunteer*, who can spend a few hours a week with you to give your family a break, do errands or laundry, prepare light meals, help with projects or tasks, or just visit.

Other specialists such as physical therapists or dieticians may be included, if needed. Some hospices even offer pet, aroma-, music, art, or massage therapy. All hospices have team members available 24 hours a day, 7 days a week, 52 weeks of the year. Help is only a phone call away at any time of the day or night.

**Note:** The nurse and certified nursing assistant (CNA) will probably be the most frequent visitors. In fact, the nurse is the only team member that you really must consent to see. The services of all the other team members are entirely optional and scheduled only as needed or desired. Everything is carefully tailored to individual needs and desires.

## Hospice Care at Home and Other Options

As noted before, most hospice care is delivered to the person at home, including nursing homes and assisted living residences (ALRs). If or when a person cannot be at home, the hospice can arrange a place in a care facility — nursing home, ALR, or hospital — and continue to provide care there. For these patients and for long-time nursing home residents needing hospice care, the nursing home staff and the hospice team work together to

coordinate the best combination of skilled nursing and hospice care. Likewise, hospices offer brief “respite stays” in care facilities for patients to give family caregivers a break or if they must go out of town or become ill themselves. Some hospices have dedicated, stand-alone residences to provide this inpatient care.

## Hospice Care for the Family

Hospice considers the patient *and the family* to be under their care: all immediate family members, companions/life partners, and caregivers may ask for and receive attention and advice from members of the team. After the patient’s death, family members are offered grief counseling and bereavement care for up to 13 months. Many hospice agencies also offer grief education and support groups to the wider community.

**Tip:** While all hospices must offer some form of bereavement support, programs vary widely: some hospices call or send periodic letters or newsletters; others offer group support meetings or individual counseling. And some offer educational programs on various aspects of grief, bereavement, and coping. A few offer special programs for children and teenagers, including summer camps. If grief support will be important to you or your family, be sure to ask about these services when you are making your choice for hospice.

## Quality of Hospice Care

All hospices must be licensed by the state and adhere to state regulations for health care facilities. Hospices are not *required* to be certified by Medicare unless they want payment from Medicare for services provided to beneficiaries. As a practical matter, then, a hospice that hopes to be in business very long must be certified by Medicare. This requires a survey, conducted by either state Health Department officials or Medicare-approved accrediting organizations, to make sure that the hospice is operating according to the Medicare standards and state regulations. If you have concerns about quality, you may ask the hospice about their accreditation status or check for any survey deficiencies on the Colorado Department of Public Health and Environment website, [www.cdphe.state.co.us](http://www.cdphe.state.co.us), or by calling the Health Facilities division, (303) 692-2800.

**Note:** The National Hospice and Palliative Care Organization recently launched its “Quality Partners” initiative, intended to improve and ensure the quality of hospice care across the nation. Likewise, the Colorado Center for Hospice & Palliative Care (The Center) provides its members with assistance in maintaining quality. A “Quality Partners” or The Center membership is an indication of a hospice that has a special commitment to quality care.

## 27-4. How Is Hospice Care Paid For?

### Options for Coverage for Care

Hospice care is a fully covered Medicare Part A benefit for Medicare-enrolled persons, and most private insurance plans have a comparable hospice benefit. If you or your family member are not covered by Medicare or private insurance, Medicaid might be an option. Also, many hospices have a commitment to provide care regardless of a person's ability to pay, supported by community fundraising, donations, and grants.

### The Medicare Hospice Benefit

For persons receiving hospice care under Medicare, the Medicare Hospice Benefit covers all services of the team and all medications, equipment and supplies, and care related to the terminal illness. Items and services not related to the terminal illness remain your responsibility. For instance, if you are enrolled in hospice for a diagnosis of cancer and have a fall and break a hip, the costs of treating the broken hip will not be covered by the Hospice Benefit, but likely will be covered by other parts of Medicare or your private insurance plan.

In some cases, room and board — whether in a nursing home, hospice residence, or hospital — are covered by the Medicare Hospice Benefit or private insurance. In other cases, these costs must be paid by you. Just when room and board is covered depends on the level of care you are receiving and the reason for your stay in the facility. Even over the course of a single stay, some days might be covered and some not. Most rooms in standalone hospice residences are private; some hospices offer shared rooms to reduce costs. Rates vary depending on location and level of care, but they tend to range between \$170 and \$200 per day.

Prior to enrollment in hospice, it's a good idea to have a thorough conversation with the admissions nurse or social worker on financial matters. Ask questions and get clear answers from the individual hospice agency about what benefits apply, what they cover and don't, room and board rates and charges, and any other resources that might be available.

**Tip:** If you or a loved one are a veteran of the United States Armed Forces or National Guard, be sure to ask about Veterans Administration benefits and services. The Colorado Center for Hospice & Palliative Care Hospice–Veteran Partnership Workgroup has been working to inform hospices of veterans' issues and benefits, and the VA health care facilities of hospice services and benefits. There is good information on this topic on The Center's website at [www.cochpc.org](http://www.cochpc.org), or you can call (303) 756-1360 or (719) 594-9233 for more information.

## **27-5. How Can I Find Care and Choose a Hospice?**

### **Hospice in Colorado**

As of 2008 in Colorado, there are 53 hospice agencies providing care out of 67 locations to approximately 15,000 persons across the state. Ten hospice agencies now have dedicated inpatient residences. The majority of hospice programs in Colorado are independent not-for-profits, although the number of for-profit and national chain hospices is growing. A handful of hospices are run by the state or federal government.

About a third of Colorado's hospices are in urban areas, about a third in rural counties, and about a third in frontier regions. In urban areas, there may be a dozen or more hospices from which to choose, while rural and frontier areas are often served by one agency (22 of 64 total Colorado counties). Currently, only three counties in the state are not served by any hospice. Each hospice organization has its own "flavor," admissions policies, and range of offerings beyond the core, mandated services.

### **Locating and Evaluating a Hospice**

Just like any important decision in life, your choice of hospice should be made with care, based on up-to-date and reliable information, and after several deep breaths. Your doctor, hospital, or nursing home may recommend a particular hospice, but unless you live in an area served by only one agency, you do have a choice. Your top concerns should be quality and a good "fit" between you and the hospice staff and style.

To locate the hospices in your area, contact Colorado Center for Hospice & Palliative Care. On our website, [www.cochpc.org](http://www.cochpc.org), we have a searchable database of all the hospices in the state with contact information and some comparative criteria. Just click on "Find Care" and specify your city or county. If more than one agency is listed, you can select which ones you would like to compare and then click on the "Compare Selected Providers" button. You can select among eight different criteria, including the availability of inpatient care, for your comparison. Or you can e-mail us at [info@cochpc.org](mailto:info@cochpc.org) or call (719) 594-9233 or (303) 756-1360. We are happy to help in any way at any time for any information related to hospice and palliative care in Colorado.

**Tip:** Hospice programs are very sensitive to how ethnic, cultural, and religious factors can influence a person's approach to death, funeral preferences, and the family's style of coping. Some agencies have gained special certifications in caring for members of particular cultural or religious communities; some have Spanish-speaking patient and family assistance or care teams and other non-English language interpreters; some have particular affinities with or historical ties to religious traditions. If these factors are important to you, be sure to ask about them when you talk to the hospice representative.

As noted earlier, hospice enrollment has some requirements, but a meeting with a hospice representative to get acquainted and discuss their services can be arranged at any time. If the hospice has a standalone residence, you may tour the facility. When you contact a hospice to discuss their services, here are some key questions you should ask:

- ▶ Are you certified by Medicare and/or accredited? How long have you been operating as a state-licensed and certified or accredited hospice?
- ▶ Are you a member of The Center or the NHPKO Quality Partners?
- ▶ What services do you provide?
- ▶ What services are not covered by the Medicare Hospice Benefit? (If you will be covered by private insurance, ask if the hospice social worker can help you determine which services might not be covered by your policy. Likewise, if you do not have insurance, ask about Medicaid eligibility or the hospice's program for uninsured patients.)
- ▶ How can my or my loved one's current doctor(s) continue to be involved in my or my loved one's care?
- ▶ How often will the hospice team members visit?
- ▶ Will a volunteer be available to help?
- ▶ How do you respond to needs after hours and on weekends or holidays?
- ▶ What are our options if I or my loved one can't stay at home? Or what if my family needs a break?
- ▶ What are your room and board rates? When are these charges not covered by Medicare or my private insurance?
- ▶ If the patient now lives in a nursing home or assisted living residence, can you provide care there?
- ▶ What kind of support is available to the family/caregiver?
- ▶ In what ways do you provide bereavement care and grief counseling?
- ▶ Do you have special services for the members of my cultural/religious group? (If applicable.)

Hospice is a wonderful service to persons with end-stage illness and their families; but, it's not for everyone. Some people don't "qualify" for hospice care, and some just aren't ready or never get the opportunity to shift from curative treatment to hospice care. Fortunately, there is an alternative: palliative care.

## **27-6. What Is Palliative Care?**

Palliative (PAH-lee-uh-tiv) care is a relatively new kid on the block of American health care. It began growing rapidly in the mid-1990s and was granted official "sub-specialty" status by the American Board of Medical Specialties in 2006. Like hospice care, palliative care focuses on comfort rather than cure; aggressive treatment of distressing symptoms; and emotional, social, and spiritual support for patients and families. It involves a team of pro-

professionals addressing the needs and concerns of the whole person and family members. Unlike hospice, palliative care does not require a doctor's certification of life expectancy; it can be offered along with curative treatment; and it is not limited to "end stage" or "terminal" illness.

Other big differences between hospice and palliative care are that, right now, there is very limited insurance coverage for palliative care services and very few accepted standards and regulations governing them. Both of these issues are discussed more below.

### **27-7. How Can I Get Palliative Care?**

Palliative care can begin at any point in the course of a serious illness and be provided side-by-side with treatment oriented toward cure. Right now, it is most commonly used when a person's illness has become very advanced but is not yet at the terminal stage. Many chronic conditions are well suited to this approach: COPD, congestive heart failure, Alzheimer's disease, multiple sclerosis, kidney or liver disease, Parkinson's, AIDS, cancer, ALS (Lou Gehrig's disease), diabetes, and others.

If you think you might benefit from palliative care, you should talk first to your primary physician, the hospitalist (the doctor overseeing your care in a hospital), or the specialist treating your illness to discuss what services might be helpful and available. You can also consult the Colorado Center for Hospice & Palliative Care (The Center) website, [www.cochpc.org](http://www.cochpc.org), or call (719) 594-9233 or (303) 756-1360.

### **27-8. How Does Palliative Care Work?**

Palliative care is a rapidly growing field; consistent models of care, standards, or even criteria defining in detail what it is and is not and what it does and does not provide have not yet gained wide acceptance. As a result, there can be big variations in palliative care services and quality. Several national organizations are working on these issues now. In 2008, the Colorado Center for Hospice & Palliative Care developed criteria and evaluations for hospital- and hospice-based palliative care programs and contacted every program across the state. The services that met the palliative care criteria are included in the database on The Center's website at [www.cochpc.org](http://www.cochpc.org). To search this database, from the home page click on "Find Care," select the desired location(s), and then select "Palliative Care Provider" in the Facility section. You may also call (719) 594-9233 or (303) 756-1360 for more information.

When you contact a provider for palliative care, be sure to get a clear and thorough explanation of just what is being offered. At its most basic, a palliative care program provides consultation with a specially trained doctor or nurse to develop a plan of care to provide comfort rather than cure. More fully fledged programs involve consultation with a full palliative care team and perhaps some limited follow up with or ongoing care of the person at home or in a health care facility.

In general, palliative care programs come in three styles from three different provider types: hospitals, hospice agencies, and nursing homes.

## **Hospital-Based Palliative Care**

About 20 hospitals around the state offer palliative care consultation services, including University of Colorado Hospital, Aurora; the Veterans Administration; selected facilities in the Kaiser, Exempla, Health One, and Centura systems; Memorial Hospital, Colorado Springs; Poudre Valley Hospital, Fort Collins; and The Children's Hospital, Aurora. The typical situation involves someone with a serious, advanced illness for which he or she is receiving continued curative treatment but is "wiped out" by the side effects, or the treatment is not working as well, fewer options are available, and a shift in goals of care should be considered. A palliative care consultation with a specially trained doctor or nurse — and, ideally, a social worker and chaplain — can identify symptoms that can be eased by palliative treatment. Beyond this, the consultation can help clarify goals and plans for the future management of the disease. In most hospital-based programs, however, there is no ongoing follow-up.

## **"Pre-Hospice" Palliative Care**

Another type of palliative care program, often called "pre-hospice" or "transition," is offered by hospice agencies. In these programs, you can receive a palliative care consultation and a limited amount of follow-up from the hospice team without enrolling in hospice. This provides a real option for persons who are not quite ready for hospice from the standpoint of their personal goals or the progress of their illness. The Center's website, [www.cochpc.org](http://www.cochpc.org), will help you identify which hospices offer this kind of program. From the home page, select "Find Care," then location, then "Hospice Care Providers." When the results are returned, check the agencies you would like to compare and select the "Palliative Care Provider" criterion. You may also call The Center at (719) 594-9233 or (303) 756-1360.

## **Palliative Care in Long-Term Care**

For better or for worse, many of us will likely spend some part of our final days in nursing facilities. Most elders who enter nursing homes for full-time residence die within two years of admission. Nursing homes have worked closely with hospices for many years to provide high-quality end-of-life care, but many are also now developing their own programs of palliative care.

More so than in the hospice or hospital setting, long-term care palliative care programs are subject to wide variation. In some cases, palliative or "comfort" care here simply means pain and symptom management performed under the guidance of a doctor who may or may not be well trained in palliative or end-of-life care. In other cases, it is very high-quality and full-spectrum end-of-life care up to and including the hospice phase. If you or a loved one reside in a nursing home and are a good candidate for palliative care, be sure you get a thorough explanation of just what this means at that facility and be sure your needs will be appropriately addressed.

**Note:** The Colorado Center for Hospice & Palliative Care in collaboration with the Colorado Health Care Association has developed a set of “Best Practice” guidelines for palliative care in the long-term care setting. If your nursing home is not yet following these guidelines, they are available from both CHCA ([www.cohca.org](http://www.cohca.org); (303) 861-8228) and The Center ([www.cochpc.org](http://www.cochpc.org); (719) 594-9233 or (303) 756-1360).

## **27-9. How Is Palliative Care Paid For?**

The other big difference between hospice and palliative care is that there is no Medicare Palliative Care Benefit. At this writing, Medicare will cover one visit from a hospice or hospital-based palliative care doctor. Some private insurers and managed care organizations are adding palliative care benefits. Hospice agencies offering palliative care programs often do so at their own loss or out of charitable monies. The Veterans Health Administration offers palliative care services at no extra charge to qualified persons. Palliative care can also be obtained through a few private practice doctors and advanced practice nurses and nurse practitioners on a fee-for-service basis.

## **27-10. How Can I Find Palliative Care?**

First, ask your physician. You can also ask your hospital or hospice agency of choice about their palliative care programs. For comprehensive information on palliative care around the state, contact Colorado Center for Hospice & Palliative Care ([www.cochpc.org](http://www.cochpc.org); (719) 594-9233 or (303) 756-1360).

## **27-11. Conclusion**

Hospice and palliative care are relative newcomers to medical care, but really they are new and improved forms of what medicine and health care has been about for thousands of years: caring for the sick, comforting the hurt, and supporting those who love them. Their shared goal is to help all persons live well at the end of life and never suffer needlessly. The Colorado Center for Hospice & Palliative Care is committed to helping all Coloradoans obtain the care they need when they need it.

## **27-12. Glossary**

**Accreditation.** A process undertaken by private organizations by which a hospice is determined to be following all the rules and regulations governing hospice care. (Compare with *Medicare Certification*.)

**Attending Physician.** The doctor who at a given time is most responsible for your care.

**Bereavement Care.** A service provided as part of the hospice care program at no charge to family members for 13 months after the patient has died. This can involve grief support groups, occasional phone or mail contact, education classes, or individual counseling.

**Chronic Illness.** An illness that cannot be completely cured and persists over time, likely getting gradually worse, but is not considered “terminal” or “end stage.”

**Comfort Care.** Care focused on comfort and relief of suffering rather than cure. It is often used to mean hospice care or palliative care but may indicate pain relief only, without emotional, practical, and spiritual support.

**Curative Care.** Medical care that is focused on curing disease.

**End-Stage Illness.** An illness that has progressed to the point that curative treatment is not effective and death is likely within months or weeks.

**Grief Counseling.** A special kind of emotional/psychological counseling that helps persons cope with the effects of normal or, in some cases, abnormal grief.

**Hospice Agency.** A health care organization or company that provides hospice care to patients and families.

**Hospice Care.** An approach to care for persons with terminal illness and their families, involving a team of professionals — doctor, nurse, nurse’s aide, social worker, chaplain — that focuses on quality of life and relief of pain and suffering.

**Hospice Enrollment.** The process of signing up to receive hospice care.

**Hospice Evaluation.** A physical examination by a hospice doctor to determine if you are eligible for hospice; that is, that your illness is “terminal” and that your life expectancy is six months or less, and that you are willing to forego curative treatment.

**Hospice Medical Director.** A doctor specially trained in hospice or palliative care who supervises the care of patients for a hospice agency.

**Hospice Residence.** A specially designed or adapted facility for hospice patients only. Most hospice residences are designed to feel more like home than a health care facility.

**Hospitalist.** A doctor who is employed by a hospital and supervises the care of patients while they are in the hospital.

**Life Expectancy.** The period of time a person is expected to live.

**Medicare Certification.** A process by which state Health Department or Medicare officials determine that a hospice is following all the rules and regulations governing hospice care.

**Medicare Hospice Benefit.** A Medicare Part A benefit available to all Medicare enrollees, which covers all the costs of hospice care — the services of the care team, medications, equipment, supplies, etc. — related to the terminal illness.

**Palliative Care.** Care focused on comfort and relief of suffering rather than cure. Differs from hospice care in that it can be offered along with curative care and is not limited to terminal illnesses.

**Pre-Hospice Program.** A program offered by a hospice agency that offers palliative care to patients without requiring a hospice enrollment.

**Terminal Illness.** An illness that cannot be cured and will result in the person's death within a foreseeable period of time.

**Recertification.** After two 90-day periods following enrollment, and then after each subsequent 60-day period, the process by which a hospice patient is evaluated and considered to qualify for continued hospice care.

**Respite Stay.** A brief stay in a nursing home or hospice residence by a hospice patient in order to give family caregivers a break or if the caregiver leaves town or becomes ill.

**Revoke.** To disenroll from hospice care.

**Room and Board.** Costs charged by a nursing facility, assisted living residence, or hospice residence for the room and meals provided to a patient resident.

## **27-13. Resources**

### **Colorado Center for Hospice & Palliative Care**

*Offers "one-stop" shopping for all your hospice and palliative care information needs, providing information on hospice, palliative care programs, advance care planning, veterans resources, public and professional education on end-of-life concerns, and caregiving.*

(719) 594-9233 or (303) 756-1360

info@cochpc.org

www.cochpc.org

### **Life Quality Institute**

*Offers community education around the needs of caregivers, in particular the Share The Care program for creating communities of care from neighbors, friends, and families.*

(303) 398-6326

www.lifequalityinstitute.org

### **Colorado Health Care Association**

*The statewide association supporting nursing homes and assisted living residences. Can provide information on hospice and palliative care in the long-term care setting or specific information on skilled nursing facilities and assisted living residences.*

(303) 861-8228

www.cohca.org

### **Center for Medicare & Medicaid Services**

*Offers a free booklet, "Medicare Hospice Benefits," which explains in detail the coverage Medicare and Medicaid provide for the costs of hospice care.*

1-800-MEDICARE

www.medicare.gov

### **Colorado State Department of Public Health and Environment**

*Offers listings for all nursing and assisted living facilities and hospices in the state. To view detailed profiles, including survey results, go to [www.cdphe.state.co.us/hf/index.html](http://www.cdphe.state.co.us/hf/index.html); select the facility type; click on "Get detailed profiles." Once you have located the facility you are interested in, click on its name and the survey results and other information will come up. You may also call (303) 692-2800.*

### **National Hospice & Palliative Care Organization**

*Primarily geared toward professionals, but offers a toll-free help line, (800) 658-8898; a Spanish language help line, (877) 658-8896; and a searchable database of hospice agencies nationwide, [www.nhpco.org](http://www.nhpco.org).*

### **Caring Connections**

*A national consumer-focused information source on all things end-of-life: state-by-state advance medical directives (living wills, etc.), caregiver resources, grief and bereavement support, information for businesses supporting employees involved in caregiving or grieving, and more.*

(800) 658-8898 (toll-free help line)

(877) 658-8896 (Spanish language help line)

[caringinfo@nhpco.org](mailto:caringinfo@nhpco.org)

[www.caringinfo.org](http://www.caringinfo.org)

### **GetPalliativeCare.org**

*An all-Web resource for the public on palliative care nationwide, including a quick quiz to determine if palliative care is right for you and easily printed informational handouts. Information on Colorado-based providers is limited to hospitals and only contact addresses and phone numbers provided — no details on the services offered and information may be inaccurate. Confirm any information on Colorado providers with the provider or with Colorado Center for Hospice & Palliative Care (see above).*

[www.getpalliativecare.org](http://www.getpalliativecare.org)

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\*Excerpted and adapted with permission from *How Hospice Can Save Your Life: A Guide to End-of-Life Care Options in Colorado*, by Jennifer Ballentine, Colorado Center for Hospice & Palliative Care, forthcoming. © Jennifer Ballentine, 2008 and 2009.

