

Chapter 27

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

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SYNOPSIS

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Exhibit 27A. Hospitals and Hospice Agencies Offering Palliative Care

“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 every day from folks who have experienced hospice care. Ask around and you are likely to hear the same. After all, in 2017, approximately 50 percent of all Coloradans received hospice care before they died. According to the Hospice Compare tool (www.medicare.gov/hospicecompare), 90 percent of patients appreciated the emotional and spiritual support provided by hospice.

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; or 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, an advanced 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, on average, persons enrolled in hospice *actually lived longer* — some by weeks — than persons with the same diagnoses receiving curative treatment. And — like comic columnist Art Buchwald — about 17 percent of persons enrolled in hospice actually “graduate” and are discharged alive (per the Medicare Payment Advisory Commission’s Report to the Congress: Medicare Payment Policy), in many cases because their condition has so improved, they are no longer considered “terminal.”

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 two physicians. This means that your attending or primary physician or any specialist involved in your care and a hospice medical director say that in their 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, criteria may differ. Be sure to check with the insurance agent or ask the hospice social worker to confirm your coverage.

If you do not have a primary or attending physician or encounter resistance to a hospice referral, you can still request an evaluation directly from a hospice agency. The hospice medical director can, in some circumstances, certify your eligibility for hospice care. Also, many hospices 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 discussed in more depth 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, at the end of which your condition and eligibility are assessed. If you continue to be eligible for care, your situation is assessed again after another 90 days and then after each additional 60 days. Your enrollment is “recertified” as long as the basic hospice criteria are met — even long past six months. Sadly, less than 15 percent of hospice patients receive a full six months of care or more (13.6 percent, per NHPHO Facts and Figures 2017 Edition (revised April 2018)). Right now, half of all hospice patients are enrolled for just over three weeks before death, more than a quarter for less than a week, and some only for hours. This is not long enough to obtain the full benefit of the program of care, and many, many families find themselves saying, “I wish we’d gotten into hospice 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 disease has just outpaced available treatments. Most people these days do not die of classically "terminal" illnesses; rather, they suffer from long-standing 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. An important 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 patient, 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 or nurse 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 doctor 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, shortness of breath, 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 advanced 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 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 remain at home, the hospice can arrange a place in a care facility — typically a nursing home — 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. Nationally, 20 percent of hospices have their own inpatient residences (per National Hospice Locator, accessed November 1, 2018). In Colorado, only eight of the 60 hospices have inpatient residences: three in the Denver metro area and one each in Longmont, Fort Collins, Colorado Springs, Grand Junction, Greeley, and Pueblo.

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. Family members are offered free grief counseling and bereavement care for up to 13 months after the patient’s death. Many hospice agencies also offer grief education and support groups to the wider community.

Note: 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 of hospice.

Quality of Hospice Care

Hospice, as an industry, has grown tremendously since 2000. Between 2000 and 2016, the number of hospice agencies has increased by 94 percent, and the number of patients served has nearly tripled (Med PAC Report 2018).

In 2017, 1.4 million Medicare beneficiaries were cared for by 4,382 hospices (Med PAC Report 2018). In many ways, this growth is a good thing, signaling broader acceptance of the hospice model and increased access to services for more patients and families. However, growth has also created some concerns about quality and standards. For complicated historical reasons, hospice care has not been subject to the same level of supervision and consumer critique that other sectors of health care have experienced. However, with recent crackdowns on waste, fraud, and abuse in health care generally along with increasing emphasis on quality and outcomes, hospice is attracting much closer attention. The vast majority of hospices are providing excellent care with the best interests of patients, families, and communities at heart, but some cautions are worth noting.

Quality Indicators and Consumer Information. Agencies are now asked to collect and report to regulators a certain set of quality measures, which will be used to offer comparative information to the public. In order to help patients and family make informed decisions, the Centers for Medicare and Medicaid Services have launched Hospice Compare, a website that includes seven categories of data about nearly 4,000 hospices around the country. Categories include percentages of successful patient/family education and support around critical issues such as pain assessments and symptom management. However, data is self-reported by hospice facilities and currently limited in its information value; factors such as team caseload or inspection reports are not included. Also, each hospice has its own page, so there is no way to do a side-by-side comparison of several hospices. Additional information based on family member perceptions of hospice care was released in 2018 (www.medicare.gov/hospicecompare).

Many state and national hospice organizations offer hospice provider directories so consumers can locate agencies, but most do not provide much information beyond hospice name, location, service area, and maybe areas of specialty. However, the National Hospice Locator, hosted by Hospice Analytics (www.hospiceanalytics.com), is a database of every known hospice in the country, including abundant comparative criteria about services and some quality measures.

Certification and Accreditation. All hospices must be licensed by the state and adhere to state regulations for health care facilities. Licensure, in Colorado, requires an application and “attestation” that the hospice meets the state regulations for operation. Hospices must be certified by Medicare or accredited by a Medicare-approved organization in order to receive payment from Medicare for services to Medicare beneficiaries. Certification or accreditation requires a survey, conducted either by the state health department or the accrediting organization, to ensure that the hospice is operating according to the Medicare standards and state regulations. Certification ensures that the agency is meeting minimum standards; accreditation often requires a higher standard of performance.

Hospices without a license cannot legally serve any patients. An operating hospice that is licensed but not certified or accredited, however, requires closer scrutiny. It is possible that the hospice is very new. In order to be certified or accredited, the hospice must be serving at least a few patients in order to demonstrate their level of care to the surveyors. Care from a brand-new hospice may be excellent, even superior, or it may be deficient. Before enrolling in an uncertified hospice, ask a lot of questions and make sure you are satisfied with the answers (see “Locating and Evaluating a Hospice” in section 27-5). Volunteer or government-owned hospices (such as prison hospices or those operated by states, cities, or counties) might not be certified because they do not receive payment from Medicare. Again, caution is advised.

Surveys and Deficiencies. Hospices, like all health care facilities, are subject to periodic surveys in order to retain their certification or in response to a complaint. Until recently, surveys of hospices were required to be conducted only on an average of once every eight years, and some hospices had gone more than a decade without a survey. In 2014, federal legislation was passed to increase the frequency of routine hospice surveys to an average of once every three years. Surveys in response to a complaint look only at the circumstances of the complaint.

When hospices are surveyed, any problem or failure to meet regulations is termed a “deficiency.” Deficiencies can be very minor or have no impact on patient care (e.g., unclear documentation or lightbulbs of the wrong wattage) or very serious indeed (e.g., medication errors or failure to respond to a pain crisis). A perfect survey is very rare; almost every survey turns up a few deficiencies. The raw number of deficiencies incurred by a hospice does not, by itself, tell much about the hospice’s quality of patient care. What matters is the seriousness of the deficiencies and how well they have been corrected. Survey results, deficiencies, and plans of correction are typically available online from the state health department.

Fraud and Abuse in Hospice. It’s a terrible thing and many hospice professionals are uncomfortable admitting it, but hospice is not exempt from fraud and abuse. Fraudulent practices include admitting patients who are not eligible (for instance, their condition is not terminal) or who do not understand they are signing up for comfort care only; keeping patients on service when they no longer meet strict criteria; bumping patients up to a more intensive level of care (for which the hospice is paid a higher amount); “cherry picking” patients according to diagnosis in order to minimize expense or maximize profitability; or providing extra services or equipment to nursing facilities in order to gain preference in referrals. Patient abuse can result from promising services the agency can’t deliver; maintaining patients on a routine level of care when they require more intensive interventions; not providing adequate after-hours or weekend/holiday coverage; providing inadequate screening, training, or supervision to clinical personnel resulting in harm to patients; or misusing potent medications.

While occurrences of these kinds have been reported, fortunately they are extremely rare. *A very small percentage of hospices are identifiably practicing outside the norms* in a way that signals possible fraud. Cases of patient harm are harder to quantify, but they are by no means common, despite occasional distressing stories in the media. Still, any occurrence is one too many, and numerous organizations in the industry are working closely with regulators to eliminate them.

Note: Much of the growth in hospice care since 2000 has been in for-profit hospice, and concerns have been raised by journalists and watchdog groups that the pressure to increase profits is at the root of problems in hospice care. Data does show that for-profit hospices, as a group, spend less on patient care, provide less of the more intensive levels of care, have a higher rate of discharge of live patients, and frequently keep patients on service much longer than typical. However, the for-profit/nonprofit status of a given agency is not, by itself, an indicator of quality. In Colorado, the only three hospices closed for reasons of fraud and abuse were nonprofit agencies, and numerous for-profits across the state provide excellent care. Each hospice should be evaluated on its own merits, not its corporate tax status.

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 beneficiaries, 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 also has a hospice benefit in Colorado and many other states. 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. There may be a modest copay for some drugs. Items and services not related to the terminal illness remain your responsibility. For instance, if you are enrolled in hospice due to cancer and have a fall and break your 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 stand-alone 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 \$200 and \$700 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.

Note: 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. There is good information on the VA website about their palliative care services and death and burial benefits. Go to www.va.gov/geriatrics.

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

Hospice in Colorado

As of 2017, in Colorado, there were 64 hospice agencies providing care out of 88 locations and more than 20,000 Coloradans received hospice care. Nine hospice agencies now have dedicated inpatient residences. Since 2015, the number of for-profit hospices exceeded the number of nonprofit hospices in Colorado. A handful of hospices are run by the state or federal government.

About two-thirds of Colorado's hospices are in urban areas and about a third are in frontier regions. In urban areas, there may be a number of hospices from which to choose, while some rural and frontier areas are served by one agency (5 of 64 total Colorado counties). In 2017, only one Colorado county (San Juan) had no hospice patients receiving care under the Medicare Hospice Benefit. 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 carefully, 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.

A good first step in locating a hospice is to ask around. Chances are good you will know friends, colleagues, neighbors, and others who have had a family member in hospice. Even with a glowing recommendation, though, it is good to look closer.

There are two comprehensive resources for locating hospices in your area: Hospice Analytics' National Hospice Locator (www.hospiceanalytics.com) and the Colorado Department of Public Health and Environment (CDPHE; www.colorado.gov/pacific/cdphe/find-and-compare-facilities). The National Hospice Locator allows you to search by state or zip code. You can compare agencies on several criteria: ownership type (nonprofit, for-profit), agency type (free-standing, in a nursing facility, affiliated with a hospital), size (based on number of patients served daily), innovative or special services, inpatient residence, state and national organization memberships, accreditation, certification, and a set of utilization measures that can be used as indications of quality. The results provide contact information and direct links to agency websites. The CDPHE online directory lists all the hospices in the state, but does not provide any comparative criteria. Be aware that hospices tend to serve several counties, so if you do not find a hospice with an office in your city or town, there may be one nearby that serves your area.

Note: 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 stand-alone 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?**

See “Quality of Hospice Care” in section 27-3 for comments regarding certification and accreditation. If the hospice is not certified or accredited, determine why and consider carefully whether this hospice is right for you.

► **How long have you been operating? Are you for-profit or nonprofit?**

Older hospices are likely to be better established and better resourced, with more history of patient experience and survey results. Newer hospices can still be very good but might require extra evaluation.

Medical Aid in Dying

The Colorado End-of-Life Options Act, passed in November 2016, has been in effect for two years. The eligibility requirements to become qualified to use the law are basically the same as in the other seven jurisdictions that have already instituted Medical Aid in Dying (MAID) laws (Oregon, Washington, Montana, Vermont, Washington state, Hawai'i, and Washington, D.C.). A resident adult with mental capacity must be certified as terminally ill by two physicians. The person then must make two oral requests at least 15 days apart and must also submit one written, witnessed request. Comprehensive measures are taken to educate the person about other alternative or additional treatment opportunities, such as palliative care and hospice. The person must understand clearly what his or her prognosis is and must understand both the risks and results of taking the medication. He or she must also be able to self-administer the medication.

The “developmental” issues in Colorado continue to be similar to those in other states: Although physicians are immune from prosecution or professional disciplinary action, many are reluctant to engage in a practice as controversial as this. Although it is *per se* illegal to forbid a physician to prescribe the medication, many still fear conflict or retribution within their organizations or with their employers. Patient abandonment is a significant concern for medical providers — am I abandoning my patient if I help them to end their lives, or am I abandoning my patient if I refuse to support their desire to use MAID? At this time, locating an attending physician or the second (consulting) physician who will assist their process has fallen primarily to patients, families, and advocates. No registry has been or will be developed to locate physicians.

There are several health systems in Colorado, including UC Health, Kaiser Permanente, Denver Health, and Boulder Community Health, that are currently in full compliance with the law and provide complete supportive services to their patients, from sophisticated education to help navigating the process, obtaining the medication, and supporting the patient and family during ingestion and afterward. Several other systems are in process; see the Compassion and Choices Find Care tool (<https://compassionandchoices.org/find-care>) for updates. Colorado hospices have developed policies ranging in the extreme from refusal to engage in dialogue with patients at all to providing full support, with many hospices “in the middle” providing education and family support, including voluntary staff presence in the house at the time of ingestion.

A controversial issue in Colorado is the sparsity of reporting requirements. Physicians must only report to the Colorado Department of Public Health and Environment when they have written a prescription and a health care provider must report when they have dispensed the medication.

At the time of this writing, the Colorado Department of Public Health and Environment reported that in 2017, 69 patients received prescriptions for aid-in-dying medications; 50 of those actually filled the prescriptions. The vast majority of those patients had forms of cancer, followed by Amyotrophic Lateral Sclerosis (ALS), heart disease, and chronic lower respiratory diseases (including COPD). Visit www.colorado.gov/pacific/cdphe/medical-aid-dying for more information.

As noted, for-profit or nonprofit status does not, by itself, say anything about the quality of care the hospice provides, but it is an important feature to be aware of.

► **What services do you provide?**

Services should match the description of hospice care provided in this chapter. Make sure social work, chaplain, and volunteer services are mentioned; they are important aspects of the hospice model even if you don't think you will need them. If it is important to you, ask if your doctor can stay involved in your care.

If you or your family member might benefit from specialty services — such as those designed for children/teens, veterans, or particular ethnic or cultural groups — be sure to ask specifically about these programs.

► **What are our options if I or my loved one can't stay at home or our family needs a break?**

Any hospice should have an option to care for patients in a facility (nursing home or stand-alone residence) if home care is not possible. Likewise, respite care should be available to give families a break.

If you or your loved one already reside in a nursing home, ensure the hospice can provide care in that facility. Also ask how a hospice enrollment will change your financial arrangements with the facility.

In rare cases, hospice patients may need “continuous” care in the home, for instance if symptoms get out of control or when they are very near death. This level of care may not be needed, but should be available.

► **Do you have your own hospice residence for inpatient care? Under what circumstances are patients admitted to the residence? What are your room and board rates? When are these charges not covered by Medicare or my private insurance?**

Most inpatient hospice residence rooms are reserved for patients with intensive care needs — out-of-control symptoms, pain crisis, or “active dying.” However, some residences admit routine level of care patients who do not have caregivers at home or nearby. Make sure you understand how the hospice operates its facility, what it charges, and when.

► **Is everything covered by Medicare/my insurance? What services are not?**

Items not covered might include some drug copays; non-medical caregiving/housekeeping; one-on-one grief counseling; and care for conditions or events not related to the terminal illness (*e.g.*, broken bones or infectious illness).

► **How can we pay for care if I or my family member is not on Medicare?**

The hospice social worker can review your private insurance and determine what your benefits cover.

If you lack insurance, payment assistance might be available from Medicaid, veterans benefits, or other programs for uninsured patients. The hospice should provide every assistance to address your financial questions.

► **How do you respond to needs after hours or on weekends or holidays?**

Be sure the hospice has adequate coverage from its own staff for care in these situations. At a minimum, an after-hours phone number should be available and, if needed, a visit from a nurse.

► **What is your average length of stay for patients and rate of live discharge?**

Significant deviations from national averages (currently 70 days mean/25 days median for length of stay and 9.9 percent live discharge) might be cause for concern. *All other factors being equal*, a hospice that operates closer to the norm may be a better choice.

► **Have you had any recent complaints or patient care deficiencies?**

This information is publicly available from the state health department website. It's worthwhile to scan the information on the website first and then ask about particular instances that concern you. The hospice may not be able to discuss specifics due to patient privacy limitations, but they should confidently communicate that they take all complaints and deficiencies seriously and ensure that any problems are addressed and corrected. Defensiveness, evasion, denial, or referral to legal representatives should be red flags.

► **What kind of support is available to the family/caregiver?**

At a minimum, this should include education and emotional/spiritual support throughout the hospice patient's stay; assistance with practical, financial, and logistical challenges; visits from a volunteer; and bereavement counseling.

► **What kind of bereavement/grief support or counseling do you offer?**

At a minimum, this should include regular contact from the hospice following the death of the patient for 13 months by phone or mail. More robust services might include support groups, grief education sessions, one-on-one counseling, retreats for adults or camps for children and teens, regular memorial services, and so on.

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 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 terminal disease or

life expectancy. It can be offered along with curative treatment, and it is not limited to “end-stage” or “terminal” illness. Conditions that can benefit greatly from palliative care include Alzheimer’s disease and other dementias; heart, lung, kidney, and liver diseases; chronic cancer; multiple sclerosis; cystic fibrosis; Parkinson’s and Huntington’s diseases; traumatic brain injury; frailty of old age; and other chronic conditions.

Other big differences between hospice and palliative care are that, right now, there is very limited insurance coverage for palliative care services and only very general 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 advanced, not curable, and difficult to manage, but is not yet at the terminal stage, such as those listed above.

If you think you might benefit from palliative care, you should first talk to your primary physician, the hospitalist (the doctor overseeing your care in a hospital), the nursing home medical director, or the specialist treating your illness to discuss what services might be helpful and available. A list of Colorado hospices and hospitals offering palliative care is included as Exhibit 27A to this chapter.

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 been consistently adopted. As a result, there can be big variations in palliative care services and quality. In 2011, the Colorado Center for Hospice and Palliative Care, along with the Center to Improve Value in Health Care and Life Quality Institute, developed a set of guidelines to assist state surveyors in evaluating whether so-called “palliative care” services really offer what they should in the way that they should.

In January 2014, Colorado became the first state in the nation to adopt a regulatory definition and standards for palliative care. The definition and standards (see box, below), approved by the Colorado Board of Health, went into effect in March 2014, and are applicable to any health care facility or setting offering “palliative care,” “comfort care,” “supportive care,” or other substantially similar services.

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 service provides consultation with a specially trained doctor or nurse to develop a plan of care to enhance comfort and quality of life rather than cure and to address any areas of distress. 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. If you have any concerns, refer the provider to Sections 2.2.12 and 3.3 of the Colorado Code of Regulations for health care facilities, “Chapter II General Licensure Standards.”

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 23 hospitals around the state offer palliative care services of some kind, though the scope of service may vary. A list of Colorado hospitals reporting palliative care services can be found in Exhibit 27A. Typically, palliative care in the hospital setting is offered to patients with serious, advanced illness for which they are receiving continued curative treatment but are “wiped out” by the side effects, or the treatments are not working as well, fewer options are available, and a shift in goals of care might be warranted. A consultation team comprises a specially trained doctor or nurse — and, ideally, a social worker and chaplain — who identify physical and psychosocial-spiritual suffering that can be eased by palliative treatment. Beyond this, they help clarify the patient’s goals for care and work with the patient’s other doctors to develop a plan that matches or meets those goals. In most hospital-based programs, however, there is no ongoing follow-up after the patient is discharged.

Palliative Care Definition and Standards Approved by the Colorado Board of Health for Inclusion in the Colorado Health Care Facilities Regulations as of March 2014

Definition:

“Palliative care” means specialized medical care for people with serious illnesses. This type of care is focused on providing patients with relief from the symptoms, pain and stress of serious illness, whatever the diagnosis. The goal is to improve quality of life for both the patient and the family. Palliative care is provided by a team of physicians, nurses and other specialists who work with a patient’s other health care providers to provide an extra layer of support. Palliative care is appropriate at any age and at any stage in a serious illness and can be provided together with curative treatment. Unless otherwise indicated, the term “palliative care” is synonymous with the terms “comfort care,” “supportive care,” and similar designations.

Standards:

If palliative care is provided within a licensed health care entity, the licensee shall have written policies and procedures for the comprehensive delivery of these services. For each patient receiving palliative care, there shall be documentation in the plan of care regarding evaluation of the patient and what services will be provided. The licensee’s policies and procedures shall address the following elements of palliative care and how they will be provided and documented:

- (1) Assessment and management of the patient’s pain and other distressing symptoms; and
- (2) Goals of care and advance care planning; and
- (3) Provision of, or access to, services to meet the psychosocial and spiritual needs of the patient and family; and
- (4) Provision of, or access to, a support system to help the family cope during the patient’s illnesses; and
- (5) As indicated, the need for bereavement support for families by providing resources or referral.

“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 without enrolling in hospice. Some of these programs are led by nurse practitioners, some by social workers. The programs focus on pain and symptom management and clarifying goals of care. They provide 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.

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 — for rehabilitation, skilled nursing, or long-term residence. Most elders who enter nursing homes for long-term residence die within two to three years of admission, and they suffer from an average of five concurrent chronic illnesses. 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.

Note: The Center for Improving Value in Health Care (CIVHC), in collaboration with other organizations, 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 CIVHC (www.civhc.org; (720) 583-2095).

Even more than in the hospice or hospital setting, palliative care programs in long-term care facilities 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 specifically 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. As of March 2014, any nursing facility offering palliative or “comfort care” must meet the new standards. 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.

Caution: Some nursing homes will offer what they call a “comfort care benefit.” **There is no specific benefit offered by Medicare or Medicaid for “comfort care”!** If the nursing facility offers “comfort care” for you or your loved one, instead of arranging a hospice or palliative care consultation, you should ask very probing questions about exactly how their “comfort care” will be different from their standard care, who will be supervising it, what the plan of care will entail, whether it will meet the new standards, and why hospice or palliative care is not the best course. If comfort care is recommended, it is best to ensure involvement from a hospice or specifically trained palliative care provider.

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, nurse practitioner (NP), and sometimes a licensed clinical social worker for palliative care consultation. Additional visits may be billable by physicians and NPs under some circumstances, but visits by social workers are rarely covered, and no visits by chaplains are reimbursed. Some private insurers and managed care organizations (notably, Kaiser Permanente) are adding palliative care benefits. Hospice agencies offering palliative care programs often do so at their own loss, out of charitable monies, or through private pay arrangements. 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, advanced practice nurses, and nurse practitioners on a fee-for-service basis. When you are offered or evaluating palliative care services, be sure to ask about payment.

27-10. How Can I Find Palliative Care?

First, ask your physician. You can also ask your hospital or local hospice agencies about their palliative care programs. For a list of Colorado hospitals and hospices offering palliative care services, see Exhibit 27A. For services and programs outside Colorado, you can visit the National Hospice Locator (www.hospiceanalytics.com), the National Hospice and Palliative Care Organization (www.nhpco.org), or the American Academy of Hospice and Palliative Medicine (www.aahpm.org). Phone numbers for these organizations may be found in the resources section of this chapter.

27-11. How Can I Learn More?

If you would like to know more about hospice or palliative care, most hospice agencies are happy to answer your questions. The Center to Advance Palliative Care offers consumer-oriented information and resources on its website, www.getpalliativecare.org.

27-12. Conclusion

Hospice and palliative care are relative newcomers to the health care system, 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.

27-13. Resources

National Hospice Locator

Offers a comprehensive directory of hospice agencies by state; also offers several comparative criteria, with contact information and direct links to agency websites.

www.hospiceanalytics.com

The Iris Project

Offers community and professional education as well as private consultation on end-of-life care options, advance care planning, advance directives, caregiving, health care ethics, and more.

(303) 521-4111

www.irisproject.net

Practically Dying

Offers community and professional education as well as private consultation on end-of-life care options, advance care planning, advance directives, grief and loss support, and more.

(720) 434-5942

www.practically-dying.com

GetPalliativeCare.org

An online 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 are provided — no details on the services offered. Confirm any information with the facility itself.

www.getpalliativecare.org

The Colorado Advance Directives Consortium

Offers information on advance care planning and advance directives, including the Medical Orders for Scope of Treatment (MOST) program in Colorado. Template forms for medical durable power of attorney appointments, living wills, CPR directives, and MOST forms are available, along with clear explanations of each tool and how to use it. Links to other resources and education are also provided.

www.coloroadvancedirectives.com

Hospice & Palliative Care Association of the Rockies

Provides information on hospice in Colorado and education for hospice staff.

(303) 848-2522

info@hpcar.org

www.hpcar.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 coverage provided by Medicare and Medicaid for the costs of hospice care.

1-800-MEDICARE

www.medicare.gov

Colorado 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.colorado.gov/pacific/cdphe/categories/services-and-information/health/health-facilities.

(303) 692-2836

www.colorado.gov/cdphe

National Hospice & Palliative Care Organization

Primarily geared toward professionals, but offers a toll-free help line, a Spanish language help line, and a searchable database of hospice agencies nationwide (organization members only).

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

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

www.nhpco.org/learn-about-end-life-care

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)

caringinfo@nhpco.org

www.caringinfo.org

*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, forthcoming. Copyright © Jennifer Ballentine, 2008–2017.

Exhibit 27A.

Hospitals and Hospice Agencies Offering Palliative Care

Hospitals and Hospice Agencies Offering Palliative Care (as distinct from hospice services)*		
	Hospitals Offering Palliative Care	Hospices Offering Palliative Care
Boulder-Broomfield-Longmont-Loveland	Boulder Community Health Palliative Care Program (303) 449-7740	Halcyon Hospice & Palliative Care (Mead) (303) 329-6870
	Longmont United Hospital Palliative Care Program (303) 485-4380	TRU Community Palliative Care Program (303) 449-7740
Colorado Springs	Centura Health—Penrose-St. Francis Health Services Palliative Care Program (719) 776-5646	Optum (formerly Evercare) Hospice & Palliative Care Program (719) 265-1100
	Memorial Hospital Central & North Palliative Care Program (719) 365-2567	Pikes Peak Palliative Care Program (719) 633-3400
	St. Francis Medical Center (SFMHC) Palliative Care Program (719) 571-5010	
Denver Metro	Centura Health—St. Anthony Central Hospital Palliative Care Program (720) 321-1590	Exempla Lutheran Hospice at Collier Hospice Center (303) 403-7281
	Centura Health at Home—Butterfly Program (303) 561-5270	Mountain Journey Palliative Care (Evergreen) (303) 674-6400
	Children's Hospital Palliative Care Program (Aurora) (720) 777-6787	Namaste Hospice (303) 860-9915
	Exempla Good Samaritan Medical Center Palliative Care Program (Lafayette) (303) 689-5253	Optio Health Services (The Denver Hospice) (303) 321-2929
	Exempla Lutheran Medical Center Palliative Care Program (Wheat Ridge) (303) 403-7281	Peoplefirst (303) 639-9243
	Exempla Saint Joseph Hospital (303) 746-9197; (303) 548-1697	
	Medical Center of Aurora Palliative Care Program (303) 873-5795	
	National Jewish Health Palliative Care Program (303) 388-4461	
	North Suburban Medical Center Palliative Care Program (Thornton) (303) 450-3551	
	Presbyterian/St. Luke's Medical Center Palliative Care Program (303) 839-6458	
	University of Colorado Hospital Anschutz Inpatient Palliative Care Program (Aurora) (720) 848-6799	
	VA Hospital Aurora VA Palliative Care Program (303) 399-8020	
Durango	Centura Health--Mercy Regional Medical Center Palliative Care Program (970) 382-2000	Hospice of Mercy (970) 382-2000
Grand Junction	St. Mary's Hospital and Medical Center Palliative Care Program (970) 241-2212	HopeWest (970) 241-2212
Greeley / Fort Collins	Northern Colorado Palliative Care Program (Greeley) (970) 810-4543	Hospice of Northern Colorado (Greeley) (970) 352-8487
		Pathways Hospice (Fort Collins) (970) 292-0882
Pueblo / South-Central Colorado	St. Mary Corwin Palliative Care Program (719) 557-5654	Arkansas Valley Hospice & Palliative Care (La Junta) (719) 384-8827
		Fremont Regional Hospice/Palliative Care (Canon City) (719) 275-4315
		Hospice and Palliative Care of the Gunnison Valley (Gunnison) (970) 641-4254
		Hospice Del Valle (Alamosa) (719) 589-9019
		Sangre De Cristo Palliative Care Program (Pueblo, Canon City, Walsenberg, Trinidad) (719) 296-6201
*Adapted with permission from Appendix B: 2013 Colorado Hospital Palliative Care Providers and Appendix C: 2013 <i>Colorado Hospice Palliative Care Providers in Palliative Care in Colorado: Trends, Gaps, and Opportunities to Improve Care in Colorado</i> , May 2015, Center to Improve Value in Health Care (www.civhc.org), based on research provided by Hospice Analytics (www.hospiceanalytics.com).		