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# Considering Hospice Care: A Discussion Guide for Families

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## What would you want?

If you were in control of your last months of life, what would you want? Most of us would want to be free from treatments that don't make us better and may make us worse. We would want to be comfortable, in the familiar surroundings of home and loved ones, with the best care available. We would want compassion and dignity. We would want our family to be relieved of stress so we could spend our time together reminiscing and sharing our thoughts.

Hospice makes this possible.

Although we can't control the time of our death, hospice, also referred to as palliative care, gives us control over how we are cared for near the end of life and where we choose to be. It's a powerful feeling to have options at the end of life, to be able to make our own decisions, to know that our personal wishes will be carried out. In addition, studies show that early hospice care can improve quality—and quantity—of life: In a study, patients who chose hospice care lived an average of 29 days longer than similar patients who did not choose hospice.<sup>1</sup>

VITAS Healthcare® provides this discussion guide to help you and your loved ones make well-informed decisions about care near the end of life. This guide is intended to help your family come to a consensus that benefits everyone and honors the wishes of those who want to live out their last months and weeks in comfort, peace and dignity.

If you want to do everything possible to make that choice easier for your loved ones, consider hospice.

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## What is hospice?

Hospice is not a place. Hospice is care that comforts and supports patients and their families when a life-limiting illness no longer responds to cure-oriented treatments. Hospice can be provided anywhere a person calls home. It is a medical discipline that treats symptoms, not causes, of terminal illness for people in their last months, weeks and days. The goal is not to cure, but to make the most of the time that remains.

Hospice care is provided by a remarkable team of professionals specially trained to care for the terminally ill. They control pain and discomfort. They help the whole family deal with the emotional, social and spiritual aspects of death and dying.

## Who pays for hospice?

All hospice organizations are reimbursed in the same way, so they do not compete on cost. It is the quality of service and spectrum of choices that differentiate one hospice from another. Hospice care can be paid for in a variety of ways. Below are the most common types of coverage.

**Medicare**—If a person is terminally ill and is a Medicare beneficiary with a Medicare-certified hospice provider, 100 percent of hospice services are covered. In 2010, 83.8 percent of hospice patients were covered by the Medicare Hospice Benefit.<sup>2</sup> Medicare regulations state that people cannot be refused hospice care based on their ability to pay. Hospice payments are separate from Medicare payments for other illnesses, diseases or care the patient may be receiving.

**Medicaid**—Nearly all states and the District of Columbia offer 100 percent hospice coverage under Medicaid (MediCal in California). In general, Medicaid hospice benefits parallel the Medicare benefit, although there may be some variations in certain states. The hospice you choose will know your state regulations.

**Private insurance**—Most insurance plans issued by employers and many managed care plans offer a hospice benefit. In most cases, the coverage is similar to the Medicare benefit, although there may be some variations. Review your coverage details or ask your insurance representative.

**TRICARE**—TRICARE is the health benefit program for military personnel and retirees. Hospice is a fully covered benefit under TRICARE. Only Medicare-certified hospices can provide for the TRICARE hospice benefit, so it is important for patients and their families to choose a qualified hospice agency.

**Private pay**—If insurance coverage is unavailable or insufficient, patients and their families can discuss private pay and payment plans. The hospice you choose will know your payment options.

**Charitable care**—Hospices have a financial specialist on staff to answer questions about financial assistance and any community resources that may be available. There is no need to defer hospice care due to financial concerns.

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## Your family's hospice conversation

Use this information, with input from legal, spiritual and medical hospice advisors, to help you and your loved ones begin and continue a conversation about end-of-life care and hospice.

Ideally, the conversation begins when everyone is healthy. The opening sentence begins, “What if...?” Ideally, family members fill out advanced directives\* and discuss what their healthcare wishes would be if they could not communicate themselves. Burial, funeral or memorial service plans\* are discussed. The conversations might be short and continue over time, but decisions would be put in writing (knowing they could change). Ideally, these discussions result in the whole family knowing that the most vital issues have been discussed and that everyone has the information needed to make informed decisions.

## Who should be involved?

In the ideal scenario above, each of us is involved in the decision-making process that determines how we want to be cared for near the end of life, and those decisions are written down in an advance directive. Reality, however, tells us that these conversations tend to take place when the patient is too sick or too sedated to participate, and decisions fall to family members, caregivers, surrogate decision makers, etc. Under those conditions, the hope is that a consensual decision can be reached by the people—spouse, significant other, adult children—who are closest to the patient, in cooperation with the medical team that has been providing curative care.

Decisions of such magnitude are emotionally stressful and are often a source of disagreement. Shifting the focus from personal opinions and beliefs to your loved one's best interests, in alliance with his or her life values, may help realign priorities and provide peace of mind for all.

It should be noted that in some states, a court-appointed guardian makes decisions in the absence of an advance directive. Check your state regulations.\*

## When and where should the discussion take place?

Assuming the discussion is not already ongoing in your family, hospice should be considered as soon as it appears that medical options may soon be exhausted and/or the loved one or family expresses a desire to stop seeking a cure. The sooner the key family members and decision makers can hold a meeting—whether in person, on the phone or via the Internet—the more effective hospice can be.

Optimally, the meeting will have some structure and everyone will have been educated about hospice—its purpose, benefits, etc.—beforehand. The meeting should be held in a place, and at a time, when distractions are at a minimum.

\*See suggested websites listed on page 17 for additional information on this topic.

## Things to consider

**Who will be involved in our family's hospice meeting?**

**Will we include outside advisors from hospice, legal, medical and/or faith organizations?**

**Have all participants received information ahead of time to help them understand hospice?**

**When and where will our meeting take place?**

## Seven key discussion topics

### 1. Assessing the need for hospice

#### **When is it time to consider hospice?**

One of the challenges for family members and caregivers of people who are near the end of life is knowing when it is time to consider hospice. In making this decision, consider these questions:

- Despite good medical care, have our loved one's condition and symptoms progressed to the point that they cannot be adequately controlled?
- Has our loved one endured multiple hospitalizations, emergency department visits or repeated use of other healthcare services?
- Has the attending physician or specialist said there is nothing more that can be done to slow or cure the condition?
- Has our loved one indicated that the side effects of medical treatments outweigh the benefits?

Your loved one's physician can play a key role in determining, from a medical standpoint, if the patient is clinically appropriate for hospice. Using a variety of medical criteria and guidelines—which vary according to specific illness—the physician can determine whether hospice is a viable choice.

Alternatively, you or your loved one can call a hospice provider for a free evaluation of hospice eligibility. If the patient is hospice appropriate, the hospice provider can help you have the conversation with your physician.

### Who can/should make the hospice decision?

Choosing hospice is considered a healthcare decision; the legal guidelines are those that apply to any healthcare or medical decision. If your loved one is lucid and mentally competent, he or she can make the decision to ask for hospice care—usually in consultation with physicians, counselors or spiritual advisors and family members.

If he or she is not mentally competent or is physically unable to communicate, the decision may be made by a healthcare proxy\* (also known as a healthcare surrogate or healthcare agent) who has been assigned in an advance

\*See suggested Web sites listed on page 17 for additional information on this topic.

directive called a durable power of attorney for healthcare\*. If an advance directive has been filled out, the family generally knows who has been designated the healthcare proxy.

In the absence of a healthcare proxy, caregivers and medical advisors should take guidance from a living will\* if one exists. In the absence of any advance directive, healthcare decisions are made by a court-appointed guardian or next of kin—usually spouse first, then adult children. Check your state regulations or with the patient's licensed clinical social worker or case manager.

## What happens when you call a hospice?

When a referral is made to a hospice, the hospice will call back to determine whether the patient is ready to set an appointment for an evaluation. VITAS makes this return call within 30 minutes, no matter the time of day or night.

A hospice team member meets with your family and your loved one to discuss clinical criteria, the hospice philosophy, services available and your expectations. In the conversation, he or she will cover pain and comfort levels, support systems, financial and insurance resources, medications and equipment needs. If your loved one is hospice eligible and you agree, the patient can be admitted to hospice care.

A member of the hospice team then communicates with your loved one's personal physician and the hospice physician to discuss medical history, current physical symptoms and life expectancy. The hospice team develops an individualized plan of care designed to meet the needs of your loved one and your family. The plan is reviewed regularly and revised based on your loved one's condition.

### Things to consider

**Has our loved one designated a healthcare proxy?**

**Who is it and what is the best way to reach him or her?**

**Is there a living will, and what does it indicate?**

**What is the legal progression of decision makers if there is no advance directive and our loved one is unable to express his or her wishes?**

## 2. Understanding what hospice can and should do

### Levels of care

Different hospices provide different types of service, but there are four levels of care recognized by Medicare/Medicaid as standard in the hospice industry. The hospice team, in consultation with the patient's personal physician, determines which level of clinical care best meets your loved one's needs. The patient may transition from one level of care to another as his or her condition changes.

\*See suggested Web sites listed on page 17 for additional information on this topic.

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In addition, you should know that even after your loved one goes “on” hospice, he or she can go “off” hospice if conditions improve. It is not an irreversible decision, and there is no limit to the number of times a patient can access hospice care.

**The four levels of care are:**

- **Routine home care**—available wherever your loved one considers home (private residence, nursing home, assisted living community). The hospice team members visit your loved one, usually singly and at varying intervals based on a routine that is determined by the plan of care. This could be daily, semiweekly, weekly, etc., depending on your loved one’s needs.
- **Intensive Comfort Care**®—provided in the home in continuous shifts of up to 24 hours by hospice nurses and aides during brief periods of crisis. This level of care would be appropriate if, for example, your loved one’s medical needs required constant monitoring in the home, nursing home or assisted living community.
- **Inpatient care**—provided in an inpatient hospice unit/bed in a designated healthcare facility for a short period when your loved one’s medical needs cannot be managed at home.
- **Respite care**—patients being cared for at home are offered a brief stay in an inpatient setting to give family members and other caregivers a rest or when they need to be away.

## Scope of care

What should you expect from hospice? Services and resources vary somewhat from one hospice to another, but in general you should expect the assistance of a interdisciplinary team of experts. In addition to managing pain, hospice professionals treat difficulties with swallowing, breathing, hydration, nutrition, skin care, agitation, recurrent infection, depression, anxiety, muscle stiffness, communication and more.

The team should help with medical, pain management and care issues as well as other challenges and emotions experienced near the end of life. Your hospice nurses should be able to educate caregivers and family members in providing appropriate care when hospice staff are not present.

You may not need or want the involvement of every team member—each patient and family decide, in collaboration with their hospice nurse, how much and what kind of support is wanted—but expect your hospice team to include, at minimum, the following professionals:

- **Hospice physician** specially trained in the care and comfort of terminally ill patients, who participates in the development of the plan of care, consults on comfort measures and works in cooperation with the patient’s personal physician

- **Registered nurse** who visits regularly to monitor the patient's condition, provides care and comfort, orders medications and medical equipment and reports to the hospice physician and personal physician
- **Social worker** who provides emotional support and helps the family access financial and community resources and end-of-life planning
- **Hospice aide** who can help with personal care and hygiene as well as light housekeeping, light laundry and occasional shopping
- **Chaplain** who offers spiritual and emotional support and can work with the patient's own clergy
- **Community volunteer** who offers companionship and respite relief
- **Bereavement specialist** who offers grief and loss support and holds memorial services and support groups for loved ones throughout the year

## Things to consider

**What do we imagine will be the care needs of our loved one over time?**

**What are our loved one's specific medical issues?**

**What other needs must be addressed?**

**What resources do we have among us to assist our loved one?**

**Which hospice professionals listed may play an important role in our loved one's end-of-life care, and why?**

**Does the hospice we are considering have specially trained staff who can meet our needs?**

## 3. Spiritual and cultural considerations

Spiritual care is not reserved for those who are “religious.” People from all belief systems—and no belief systems—benefit from loving, nonjudgmental spiritual care. As we reach the end of our lives, we ask what meaning our life had and question what lies beyond. It is common to want to complete any “unfinished business.”

There are also cultural traditions to consider. People of different backgrounds, nationalities and faiths may have special preferences and practices with regard to how loved ones are cared for before and after death and what mourning practices are important.

Finally, there are ethical questions at the end of life faced by families, patients, physicians—in fact, all of society. Decisions related to the use of artificial nutrition, IV hydration, informed consent, Do Not Resuscitate (DNR) orders—all must be decided by each patient and family in the context of their individual circumstances. Families who talk about what they would wish near the end of life—and then document it in an advance directive—are better able to make difficult decisions if necessary.

All hospices have chaplains to help patients and their families with all of these issues at the end of life. At VITAS, every team has a chaplain assigned to provide this special kind of care.

If your loved one has a priest, minister, rabbi, imam or other close spiritual advisor, the hospice's chaplain will work in cooperation with him or her, serving as a liaison between your loved one, family and hospice staff. As you select a hospice and make plans for the care of your loved one, it is important to take these issues into consideration and make sure the hospice you select can meet your unique needs.

## Things to consider

**Do we know what our loved one wants and needs in the way of spiritual guidance and support, if any?**

**What patient and family traditions, customs and beliefs may play a part?**

**What ethical dilemmas may we face?**

**Have we discussed the possible scenarios and how we might approach them?**

## 4. Hospice settings

Most people prefer to receive hospice care at home—whether “home” is a private residence, an assisted living community or a nursing home. But clarify your options when you speak to a hospice representative; all hospices should provide the full spectrum of care settings. Below are the most common and the services you can expect in each.

### Private residences

Even though hospice providers offer home hospice services, it is important to know that, in most home-based situations, a family member or friend is designated the primary caregiver and provides care when hospice staff are not on site. Typically, one primary caregiver is designated, but this role can be filled by several people working as a team; they can be educated by hospice nurses to provide hands-on care and be prepared for anything unexpected.

Often, through their own creative scheduling and good teamwork, families are able to ensure that someone is always with their loved one. In addition, your hospice provider should offer clinical backup support 24 hours a day.

If the patient lives alone and independently, without additional help, ask if this is a barrier to hospice care for the providers you are considering. VITAS is committed to caring for all appropriate patients, even when there is no full-time caregiver in the home.

### Assisted living communities and nursing homes

Many nursing homes and assisted living communities provide hospice services. They may have specially trained nursing staff to care for residents who are receiving hospice care, or they may have a partnership with a hospice such as VITAS to bring hospice care to terminally ill residents. If your loved one is a nursing home resident, inquire about available hospice services. If your loved one can no longer live independently, consider a nursing home that offers excellent hospice services.

**Dedicated space in a hospice house/facility/hospital**

Some hospice providers have freestanding “hospice houses” where a terminally ill loved one lives instead of living at home. Some hospitals have hospice programs that allow appropriate patients to transition to hospice without leaving the facility. Some hospice providers have a designated hospice area in a long term care facility, nursing home or hospital where they provide in-patient care when symptoms cannot be managed at home.

Such arrangements ensure that your loved one has immediate access to support services and healthcare professionals. Typically, these are homelike facilities designed to make patients and their families feel as comfortable as possible, with soothing surroundings and round-the-clock staffing.

**Things to consider**

**Where is the best place for our loved one to receive care at the end of life?**

**Where does he or she want to be?**

**If we opt for home-based hospice, who will be the primary caregiver?**

**Can we ensure that someone is with our loved one around the clock, if necessary?**

**What “care team” can we put together?**

**5. Physical and medical considerations****Pain assessment and management**

Pain control is one of the central goals of hospice care. Federal and state laws mandate that hospice providers make every reasonable effort to control patients’ pain. If your loved one is experiencing pain or discomfort, your hospice provider should have the skills and expertise to assess and relieve or manage the pain effectively.

Ideally, your loved one will be able to communicate his or her pain. But when patients are unable to verbalize, your hospice team should have specialized training and experience to assess pain through nonverbal cues, including grimacing, writhing, moaning and groaning, restlessness, agitation and sensitivity to touch.

A pain management plan will be established by your hospice physician, who should be trained and experienced in the specialty of palliative medicine. The physician will order all medication and treatment called for in the plan. The caregiver and hospice staff, including nurses, will administer treatment and monitor your loved one closely. Everyone on the hospice team is focused on the same goal: to keep your loved one comfortable.

Pain therapy may interfere with your loved one’s ability to remain lucid and interact meaningfully with others. When that point is approaching, your hospice team will discuss it with you and work out a plan that meets your needs.

## Medications

Depending on the stage of your loved one's condition, your physician may start by treating pain with over-the-counter medications such as acetaminophen (Tylenol), ibuprofen (Motrin), aspirin or others. But pain levels could increase to the point where these medications are no longer effective. Stronger, narcotic medications—used in combination with other medications or alone—are commonly used to relieve pain in the terminally ill.

It is important that your loved one receive not only adequate levels of pain medication but also the appropriate medication or therapy for his or her condition. If there is bone pain, one type of medication is useful, while abdominal pain from spasms may respond better to something else. Alternative therapies, such as radiation therapy, may be prescribed in conjunction with medication. Every patient and every situation is different. Your hospice physician should be experienced with all aspects of pain management.

## Nutrition

Managing your loved one's nutrition is vital to his or her comfort and quality of life. Your hospice team should assess your loved one's nutritional needs and suggest meals that minimize constipation and other symptoms. Don't be surprised if you are encouraged to prepare your loved one's favorite meals—from Mom's homemade chicken soup to Uncle Joe's famous cookies—because nothing improves appetites better than familiar favorites and comfort foods.

Your hospice team can also provide the education and information you need to make difficult end-of-life decisions prompted by hydration and nutrition issues such as the inability to chew or swallow. The team can help put your mind at ease by explaining natural processes such as a gradual decrease in thirst and hunger at the end of life.

## Things to consider

**What are our loved one's pain and comfort needs?**

**Is he or she able to verbally communicate?**

**Do we know our loved one's wishes with regard to pain medication and the ability to remain lucid?**

**Are we comfortable using stronger pain medications like morphine if they will control our loved one's pain?**

**Do our family caregivers understand and accept that our loved one may eventually stop eating?**

## 6. Practical and logistical considerations

Choosing hospice care can be emotional and may require a shift in the way your family thinks about your loved one's future. But it is also a logistical transition. If your loved one is receiving care at home, you may ask: What if there is an accident? Can we call our primary physician with questions? Is our home a safe environment? As our loved one becomes weaker and more disabled, how will we care for him/her?

Your hospice provider should be able to discuss every practical detail of hospice care. You may want to be ready with a list of questions, including:

- Can we keep our loved one's primary physician if our loved one goes onto hospice?
- If we need special medical supplies or equipment, does hospice cover those? What about medications?
- What if we do not have a family member who is physically capable of caring for our loved one? What if we can't provide 24-hour care available if he/she needs it?
- What if our loved one needs to be lifted, moved and bathed?
- If our loved one is still mobile, is it safe for him or her to be at home?
- Is our loved one alert enough to manage things like cooking, grocery shopping and self care?
- Is it safe to transport our loved one in the car?
- What if there is an emergency in the middle of the night?
- Who should we call if we notice a change?

## Things to consider

**What are some of the logistical challenges we might face in caring for our loved one?**

## 7. The emotional side of hospice

Everyone handles the foreseeable decline and death of a loved one in a different way. Caregivers typically try to anticipate the dying person's every need, believing that if they do everything right, their loved one will be more comfortable and may live longer. Sometimes caregivers become overwhelmed and exhausted.

Hospice provides a variety of services to ease the caregiving experience:

- The hospice team will educate family and caregivers about the best way to care for their loved one. Replacing guesswork with knowledge provides confidence and relief.
- Hospice provides aides to help with bathing, grooming and light housekeeping.
- Hospice trains volunteers from the community who can provide companionship and support to your loved one. The volunteers can read, reminisce, play games or just "be there." Volunteers also provide respite relief for caregivers.

- The hospice team offers emotional support to help the family deal with the pending decline and death, with feelings of abandonment, anger, sadness and other emotions that may accompany loss.
- As described earlier, hospice offers spiritual support. Your family may find comfort in talking with a spiritual counselor about the issues of life, death and loss.
- Hospice can help you find information and make arrangements for advance directives, financial issues like paying for burial or a memorial service, handling probate, etc.
- Hospice will support your family during the grieving process. VITAS provides information, education and resources throughout the year, including:
  - Quarterly bereavement support letters, newsletters and educational materials
  - Bereavement support groups led by professional VITAS staff
  - Memorial services
  - Bereavement support telephone calls and visits by professional staff and volunteers
  - Community resource referrals: grief therapists, support groups, legal services, etc.

## What hospice is—and what it isn't

Nearly half the U.S. population will be touched this year by the death of a friend, family member or colleague. Every culture has its own set of beliefs about terminal illness and the dying process. Let's consider some of the most common myths about hospice care.

### Myth #1: Hospice is a place.

Reality: Hospice isn't a place. It's the treatment of physical and emotional pain and symptoms at the end of life. A Gallup poll reveals that 90 percent of adults, if given the choice, would prefer to die at home, free of pain, surrounded by family and loved ones.<sup>3</sup> Hospice is designed to respect that wish.

### Myth #2: Hospice is “giving up.”

Reality: Hospice is not about giving up. When medical treatments cannot cure a disease, an interdisciplinary team of hospice professionals can do a great deal to control pain, reduce anxiety and provide medical, spiritual and emotional comfort to patients and their families. The goal is to improve the quality of life for patients and their loved ones while easing the discomfort, the fears and the financial burden that can accompany incurable illness.

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### Myth #3: Hospice is for cancer patients.

Reality: Hospice provides care for adult and pediatric patients with a wide range of life-limiting illnesses, including but not limited to cancer, heart disease, stroke, lung disease, liver disease, kidney disease, multiple sclerosis, ALS, Alzheimer's, Parkinson's and AIDS.

### Myth #4: Hospice is basically hand-holding at the bedside of the terminally ill.

Reality: Hospice is much, much more. Hospice is palliative, not curative. Studies show hospice may extend life as long as one month, because aggressive pain and symptom management may reduce discomfort and stress and improve quality of life.

### Myth #5: Hospice care is expensive.

Reality: Compared to multiple hospital readmissions and complex and intensive hospital care at the end of life, hospice care saves healthcare dollars.<sup>4</sup> The Medicare Hospice Benefit is all-inclusive—covering 100 percent of the cost of hospice care, including medication and medical equipment related to the terminal diagnosis. There are no deductibles; there are no out-of-pocket expenses to patients or their loved ones. Families don't have to spend themselves into poverty to qualify for hospice coverage. In most states, Medicaid/MediCal provides hospice coverage. Most private insurance plans also include a hospice benefit.

## More hospice realities

- Hospice cares for more than 1.58 million Americans, and their families, every year—a number that continues to grow.<sup>2</sup>
- For 2010, the National Hospice and Palliative Care Organization (NHPCO) estimated that of approximately 2,452,000 U.S. deaths, 1,029,000 deaths, or 41.9 percent, were under the care of a hospice program.<sup>2,5</sup>
- The best hospice care takes time. Hospice is most beneficial to those whose life expectancy is approximately six months. A patient in the final phase of life may receive hospice care for as long as necessary when a physician certifies that the patient continues to meet eligibility requirements.
- Transitioning to hospice is a simple process. The patient or a loved one asks the patient's physician for a referral or contacts a local hospice program for a hospice evaluation. If the patient is clinically appropriate, admission can be accomplished in less than 24 hours.
- NHPCO research shows that 94 percent of families who had a loved one cared for by hospice rated the care as very good to excellent. VITAS' patient satisfaction score for 2011 was 96 percent.<sup>6</sup>

- The National Hospice Foundation found that the four top priorities U.S. residents would want for a loved one who has fewer than six months to live are:
  - That the loved one's wishes be honored
  - That there be a choice about types of service the loved one can receive
  - That pain control be tailored to the loved one's wishes
  - That emotional support be provided to the patient and the family

## Test your hospice knowledge

### True or false?

1. Hospice helps people with terminal illness die more quickly.
2. Hospice is a place.
3. Hospice is a last resort when nothing else can be done.
4. Hospice improves quality of life at the end of life.
5. Hospice is a mode of therapy.
6. Hospice prefers a "natural" death process, meaning no medications or treatments are allowed.
7. You keep your own doctor when you enter hospice.
8. Once a person starts hospice, loved ones no longer participate in his or her care.
9. You don't need hospice until a few days before you die.
10. Hospice is for cancer patients.
11. You need to be religious to use hospice.
12. Families should be shielded from a dying patient.
13. Hospice care is expensive.
14. Hospice provides an interdisciplinary team to address the clinical, spiritual and psychosocial needs of a terminally ill person and his or her family.

## Answers:

1. Hospice helps people with terminal illness die more quickly. **False.** In reality, just the opposite occurs. Research published in the *Journal of Pain and Symptom Management* found that Medicare beneficiaries who opted for hospice care lived an average of 29 days longer than similar patients who did not take advantage of hospice (J Pain Symptom Manage. 2007;33(3):238-246).

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2. Hospice is a place. **False.** This is one of the commonly held myths about hospice. Hospice care generally takes place in the person's home, whether a private residence, nursing home or assisted living community. Some hospitals have hospice beds. There are freestanding hospices in some communities. However, the vast majority of people prefer to spend their final days at home.
  3. Hospice is a last resort when nothing else can be done. **False.** When medical treatments can no longer cure a disease, hospice professionals can do many things to control pain, reduce anxiety, offer spiritual and emotional support, and improve quality of life for terminally ill people and their families.
  4. Hospice improves quality of life at the end of life. **True.** While the goal of hospice is not to add days to someone's life, hospice does add quality of life to someone's final months, weeks and days.
  5. Hospice is a mode of therapy. **True.** Hospice is a mode of medical therapy that may be more appropriate than curative procedures for people with terminal illness. Hospice focuses on symptom management, controlling pain and addressing spiritual, emotional and psychological comfort.
  6. Hospice prefers a "natural" death process, meaning no medications or treatments are allowed. **False.** Hospice takes advantage of state-of-the-art medications to relieve pain and symptoms and keep patients comfortable.
  7. You keep your own doctor when you enter hospice. **True.** Your doctor can choose to be part of your care team. Your hospice physician will work closely with your doctor to determine your plan of care.
  8. Once a person starts hospice, loved ones no longer participate in his or her care. **False.** Hospice professionals design a care plan that family and friends help carry out at home to the extent that they are willing and able.
  9. You don't need hospice until a few days before you die. **False.** Ideally, families choose hospice when their loved one has six months to live. This gives him or her more time in comfort and without pain, allowing the enjoyment of family and friends, time to get final affairs in order, etc.
  10. Hospice is for cancer patients. **False.** Hospice is for people with any terminal illness. Many hospice patients have cancer, but they may have heart disease, stroke, lung disease, liver or kidney disease, ALS, Alzheimer's disease, multiple sclerosis, AIDS or any other life-limiting illness.
  11. You need to be religious to use hospice. **False.** Hospice has no religious affiliation. Hospice provides chaplains from all faiths and other spiritual counselors. They respect all cultures and points of view. Many people have a fear of dying, and discussing their feelings often brings profound relief.
  12. Families should be shielded from a dying patient. **False.** Hospice professionals believe that when family members—including children—experience the dying process in a caring environment, it helps counteract the fear of their own mortality and the loss of their loved one.

13. Hospice care is expensive. **False.** Hospice care is usually less expensive than conventional care during the last six months of life. Hospice is an all-inclusive benefit covered by Medicare, Medicaid and most private insurance companies. Under Medicare and Medicaid, there are no co-pays for physician visits, nursing care, medications, hospice equipment or medical supplies related to a patient's primary illness.

14. Hospice provides an interdisciplinary team to address the clinical, spiritual and psychosocial needs of the ill person and his or her family. **True.** An interdisciplinary team consisting of a physician, nurse, aides, a social worker, a chaplain, a volunteer and other specialists work together to address the patient's pain and other symptoms related to the terminal illness and provide care for the emotional and spiritual needs of the ill person and his or her family.

## Discussion checklist

We at VITAS hope that this information has helped you better understand hospice and make decisions as a family that will benefit your loved one as he or she nears the end of life. Here is a list of items that should be covered before you take the next step:

- Our loved one has talked to us or written his/her wishes about care near the end of life.
- If there is a living will/advanced directive, we have examined its contents.
- We know who in our family will call the hospice of our choice or ask our physician for a referral.
- We know who is designated to make decisions if our loved one is unable to communicate verbally.
- We understand the levels of hospice care and have an idea of what resources hospice will provide.
- We have considered the spiritual needs of our loved one and our family.
- Our loved one has decided in what setting he/she will receive hospice care.
- If he or she is remaining at home, we know who will serve as the caregiver(s).
- We have discussed with our loved one or have written instructions to guide hospice staff on our loved one's wishes regarding pain management.
- We have prepared a list of practical and logistical questions for our hospice team.
- We have acknowledged that this will be a difficult time for our family but understand that emotional support is available.
- We have done our research and know how hospice will be paid for.

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## For more information

If you think hospice care may be the right choice for you or your loved one, talk with your physician. VITAS can provide a free, no-obligation evaluation and review options for care during a life-limiting illness. Call 800.723.3233.

If now isn't the time to consider hospice, you have the information you need to make an informed decision when the time comes. Meanwhile, if you would like more information on hospice, please visit [VITAS.com](http://VITAS.com) or [NHPCO.org](http://NHPCO.org).

Additionally, there is a wealth of information and state-specific legal forms available on the Internet to facilitate family discussions. Try:

[caringinfo.org](http://caringinfo.org)  
[agingwithdignity.org](http://agingwithdignity.org)  
[familydoctor.org](http://familydoctor.org)  
[mayoclinic.com](http://mayoclinic.com)  
[putitinwriting.org](http://putitinwriting.org)

## References

<sup>1</sup>Connor SR, Pyenson B, Fitch K, Spence C, Iwasaki K. "Comparing hospice and nonhospice patient survival among patients who die within a three-year window." *J Pain Symptom Manage*. 2007 Mar;33(3):238-46.

<sup>2</sup>2010, NHPCO National Data Set and/or NHPCO Member Database.

<sup>3</sup>National Hospice Organization—commissioned Gallup poll, 1992.

<sup>4</sup>Stanton MW. "The High Concentration of U.S. Health Care Expenditures" *Research in Action*, Issue 19. AHRQ Publication No. 06-0060, June 2006. Agency for Healthcare Research and Quality, Rockville, MD. Web. <http://www.ahrq.gov/research/ria19/expendria.htm>. Accessed August 18, 2011.

<sup>5</sup>Provisional monthly and 12-month ending number of live births, deaths, and infant deaths and rates: United States, January 2009—Provisional data from the National Vital Statistics System, National Center for Health Statistics, CDC, available online at: [http://www.cdc.gov/nchs/data/dvs/provisional\\_tables/Provisional\\_Table01\\_2010Dec.pdf](http://www.cdc.gov/nchs/data/dvs/provisional_tables/Provisional_Table01_2010Dec.pdf).

<sup>6</sup>Data on file at VITAS.