Thinking About Hospice
A Discussion Guide for Families
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How do you want to live the last six months of your life?

Most likely, you would want to be free from treatments that don’t make you feel better and may make you feel worse. You would want to be comfortable, in the familiar surroundings of home and loved ones, with the best care available. You would want compassion and dignity. You would want your family to be relieved of stress so you could spend time together reminiscing and sharing your thoughts.

Although no one can control when death will come, hospice gives you control over how and where you are cared for near the end of life.

It’s a powerful feeling to have options at the end of life, to be able to make decisions and know that those wishes are being honored. Hospice is a type of palliative care, which means care that brings comfort, rather than trying to cure. Palliative is pronounced pah-lee-uh-tiv.

Studies show that early hospice care can improve quality—and quantity—of life. In one study, patients who chose hospice care lived an average of 29 days longer than similar patients who did not choose hospice.¹

You and your loved ones want to make well-informed choices about care near the end of life. That’s why VITAS® Healthcare provides this guide to help you all agree on plans that will work for you.

Hospice can be an important part of living the way you want to and getting the quality of life that matters.

What is hospice?

Hospice is a service, not a place. Hospice is care that comforts and supports patients and their families when an advanced illness can’t be cured. Hospice can be provided anywhere a person calls home. It treats the symptoms of advanced illness for people during their last months, weeks, and days of life. The goal of hospice is to make the most of the time that remains.

Hospice is provided by a team of professionals specially trained in end-of-life care. They manage a patient’s pain and discomfort and support the whole family around the emotional, social, and spiritual aspects of death and dying.
Who pays for hospice?

Most hospice patients don’t pay out of pocket for services related to the reason they are on hospice. Here are the most common ways hospice is paid for:

Medicare
Medicare Part A covers up to 100% of the cost of hospice care related to a hospice-eligible patient’s diagnosis (cause of illness), with no deductible or copayment. For patients with Medicare Advantage, hospice is covered by original Medicare. To choose hospice, a patient must have less than 6 months to live according to a doctor. The patient must also agree to focus their medical care on improving their quality of life.

Medicaid
Nearly all states and the District of Columbia offer 100% hospice coverage under Medicaid (Medi-Cal in California). In general, Medicaid hospice benefits match the Medicare benefit. The hospice you choose will know your state regulations.

Private insurance
Most private health plans follow Medicare in their requirements for hospice. 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 be TRICARE providers, so it is important for patients and their families to choose a qualified hospice agency.

Private pay
The hospice provider may offer options if the patient doesn’t have insurance, or if the insurance doesn’t cover the full cost. The options might include private pay and payment plans.

Care for the uninsured
You never have to avoid hospice because you are worried about money. Hospices have a financial specialist who can answer questions and help find resources to get the cost covered.

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Your family’s hospice conversation

Who should be involved in the decision-making process

This information will help you and your loved ones talk about end-of-life care and hospice. Some families will want to include their legal, spiritual, or medical advisor.

Ideally, the conversation begins when everyone is healthy, with “what if…?” questions. Patients and family members complete advance directives and discuss what their healthcare wishes would be if they could no longer speak for themselves. People often make plans for burial, funeral, or memorial services.

The conversations might be short, or they might continue over time. The best plan is to write down decisions, even when they could change. That way everybody understands that the most vital issues are covered. Writing your wishes down gives your loved ones the tools they need to make informed decisions. Telling your loved ones what you want also eases their minds. Caregivers often say that one of the most stressful things they deal with is trying to guess what their loved one would have wanted.

We should all write down our wishes for end-of-life care in an advance directive while we are healthy.

Most often, though, these conversations happen when the patient can’t take part because the illness is too far along. Medical choices are left to family members, caregivers, and surrogate decision-makers.

The people closest to the patient must agree on a plan by working together with the healthcare providers to make this plan.

This is hard work, and it can be stressful and upsetting. Everyone may not agree on what is best. In those times, step away from personal opinions and stick to your loved one’s best interests and values. That focus will bring peace of mind for all.

NOTE: In some states, a court-appointed guardian makes decisions in the absence of an advance directive. Check your state regulations.
How should you prepare for the hospice discussion?

Things to think about

• Who will be involved in your family’s hospice meeting?
• Will you include people from hospice, legal, medical, and/or faith organizations?
• Does everyone understand what hospice is? Have you shared information to help them know more?
• When and where will your meeting take place?

The hospice discussion starts when it’s time to focus on quality of life instead of trying to cure. The sooner the patient is on hospice, the more good hospice can do for the patient. Hospice can help a patient most over months or weeks, not just days or only hours.

Everyone who will help the patient make decisions will need to talk to each other. That can be in person, on the phone, or even online. The talk will go best when everyone understands what hospice is and there is a plan for what to cover in the talk. Plan to have this talk at a quiet time and place without distractions.
Arthur’s Patient Story

When is it time to consider hospice?

At 75-year-old Arthur’s check-up, his wife Dorothy and their family doctor discuss his chronic obstructive pulmonary disease (COPD). He becomes short of breath, has had pneumonia several times recently, and keeps losing weight.

The doctor suggests hospice care to support Arthur and Dorothy, although Dorothy doesn’t know what hospice involves. On their limited income, she is worried about costs.

Solution

Dorothy calls VITAS at 866.586.1909 (which you can call 24 hours a day, 7 days a week). She learns how hospice care supports patients with COPD.

She also finds out that Medicare Part A covers hospice services and learns about the 4 levels of hospice care:

• Routine home care

• Continuous home care*

• General inpatient care

• Respite care for caregivers

After a same-day evaluation with a hospice nurse, Arthur begins receiving hospice care at home.

* Shifts of continuous care for up to 24 hours a day when medically needed
Knowing when to think about hospice is one of the challenges for family members and caregivers of people with advanced illness. In making this decision, consider these questions:

- Has the patient gotten worse, to the point where their medical care isn’t managing the symptoms well enough?

- Has the patient been to the hospital, emergency department, or other healthcare services several times?

- Has the doctor said the patient can’t be cured and their disease can’t be slowed down?

- Has the patient said their treatments don’t make them feel well enough to be worth the side effects?

The doctor can talk with you about whether your loved one is able to receive hospice services. This is called being eligible.

Your loved one’s doctor and the hospice doctor must agree that your loved one has a life-limiting illness. They must agree that your loved one will likely live 6 months or less. Both doctors then sign a form saying your loved one may receive hospice care.

You can also call a hospice provider to ask about care. The provider will help you see if hospice services seem right for your loved one. This will not cost you anything. The provider will talk to the doctor if your loved one needs hospice.
Your loved one can make their own choice about hospice if they are able to make decisions; this is called being mentally competent. Usually patients get help with this choice from their family, medical providers, counselors, and spiritual advisors. Hospice team members can help, too.

If your loved one isn’t able to make decisions or communicate, there are other ways to get hospice care. Your loved one may have made an advance directive. In that document, they can name another person to make medical decisions. This person may be called a healthcare proxy, a healthcare surrogate, or a healthcare agent, depending on the state.

Your loved one may not have an advance directive. If not, then healthcare decisions are made by the next of kin: usually the spouse first, then adult children. Check your state regulations or contact your loved one’s licensed clinical social worker or case manager if you have questions.
You’ve called hospice. What’s next?

Things to think about

• Does your loved one have an advance directive?
• Does it include a healthcare power of attorney and a living will?

If yes:
• Has your loved one named a healthcare proxy in the healthcare power of attorney?
• Who is it, and what is the best way to reach the proxy?
• What does the living will say?

If no:
• What is the legal order of decision-makers if your loved one can’t express their wishes?

In-person check
The hospice provider will help you see if hospice care seems right for your loved one. To do this, they will need to schedule a check called an evaluation with your loved one. This should not cost you anything. You’ll need to decide if your loved one is ready right away or if the evaluation needs to be scheduled ahead.

Admission to hospice
You will meet with a hospice admission specialist for the evaluation. The specialist will talk to you and your loved one about what services you can get and what you can expect. This includes pain and comfort levels, where to get support, and answers to questions about medicines, equipment, finances, and insurance. The specialist will also tell you more about clinical guidelines and the hospice philosophy.

If you, your loved one, and the specialist agree, then the next step is to involve the doctors. Your loved one’s doctor and the hospice doctor must agree that your loved one has an advanced illness. They must also agree that your loved one will likely live 6 months or less because of the illness. Both doctors then sign a form saying your loved one can get hospice care. At that point, your loved one will be admitted to hospice.

Plan of care
A team will come together to plan your loved one’s care with you. The team will include your loved one’s doctor, a hospice doctor, and other hospice team members. They will talk about your loved one’s medical history, current symptoms, and how long they expect your loved one to live. The hospice team will make a plan of care just for your loved one and you. As things change, the plan will change to match.
Mei was diagnosed with Parkinson’s disease 15 years ago. Her adult children have always promised to care for her at home. Recently, her children have worried about how much help she needs to eat and take care of herself. They share their worries with Mei’s doctor.

When Mei’s doctor suggests hospice care, they are afraid it means she has to go to a nursing home or hospice facility.

**Solution**

The family agrees to an in-home hospice evaluation. Mei’s son Jin is relieved to learn that his mother can get care at home, where she prefers to stay. She will have regular visits from different experts on her hospice team.

Mei has options if her symptoms and pain get worse and can’t be managed at home. She can get 24-hour bedside nursing care, and even go inpatient, if the doctor thinks she needs to.
Medicare/Medicaid recognizes 4 levels of hospice care. The hospice team works with the patient’s doctor to choose the right level of clinical care for the patient. The patient can move among the 4 levels as their health changes.

A patient “on” hospice can go “off” hospice if their health improves or to try a treatment that may cure. There is no limit to the number of times a patient can get hospice care.

The 4 levels of care include:

**Routine home care**
Available wherever the patient considers home (private residence, nursing home, assisted living community, etc.). Members of the hospice team will visit the patient. They usually visit one at a time. The visits are based on the plan of care. Visits may be every day, a few times a week, once a week, or whenever the patient needs.

**Intensive Comfort Care® (ICC)**
ICC by VITAS is also called continuous home care. ICC keeps patients at home and out of the hospital. The care happens in the patient’s home during brief periods of crisis, as medically needed. One example would be if the patient needs constant checks by a nurse. Hospice nurses and aides will come to the home in shifts of up to 24 hours a day.

**Inpatient care**
Hospice care can be given to a patient for a short time in a healthcare facility, like a hospital or nursing home. This inpatient care usually happens when the patient’s symptoms and pain can’t be managed at home.

**Respite care**
Sometimes family caregivers need a break so that they can keep giving the best care to their loved one. Patients getting hospice care at home can also get care for up to 5 days and nights at a healthcare facility. This is called respite care.
Darius, 82, is the primary caretaker for Alicia, his 81-year-old wife. Alicia was told she has Alzheimer’s disease 5 years ago, and now she has been referred to hospice care. Alicia is often confused, unable to talk, and has been to the hospital twice for concussions after falling. Darius is overwhelmed. He can’t cook for Alicia, lift her, or carry her. He asks Alicia’s hospice team for help.

Solution
Alicia’s hospice nurse teaches Darius how to move Alicia safely. The hospice medical equipment team installs a Hoyer lift at home to move her in and out of bed.

With Alicia safely settled in her new bed, the hospice social worker arranges for Meals on Wheels to help Darius care for Alicia and himself.
What to expect from the hospice team

Your hospice team will have many different experts. They can help with:

- Managing pain
- Trouble swallowing and breathing
- Getting enough fluid (hydration)
- Eating enough food (nutrition)
- Skin care
- Infection that keeps coming back
- Feeling anxious and restless (agitation)
- Depression and anxiety (mental health)
- Muscle stiffness
- Talking and communication

Some hospice providers also have extra complementary services, therapies, and resources.

The hospice team can help with medical issues for the patient, including pain. They can also help with emotional and spiritual care for both the patient and the family. You can learn to help care for your loved one. The hospice nurse will train you to give medicines and help with activities of daily living when hospice staff are not there.

Your hospice team can include all the people listed below. You may not need or want the help of all these people. Each patient and family can choose how much help they want and what kind of help.

**Hospice Physician** who is specially trained in the care and comfort of advanced illness patients, helps develop the plan of care, gives advice on comfort care, and works with the patient’s personal doctor

**Registered Nurse** who visits regularly to check the patient, provides care and comfort, orders medicines and medical equipment, organizes activities of the hospice team, and reports to the doctors

**Social Worker** who gives emotional support and helps the family get financial, community, and end-of-life planning information

**Hospice Aide** who can help with personal care and keeping clean (hygiene)

**Chaplain** who offers spiritual and emotional support and can work as a partner with the patient’s own clergy

**Community Volunteer** who is trained to offer companionship when it’s needed

**Bereavement Specialist** who offers grief and loss support and holds memorial services and support groups for loved ones throughout the year
Bettina was admitted to hospice care for metastatic breast cancer. She often can’t eat and complains of pain throughout her body. Olivia, her daughter, is worried that prescribed pain medicine no longer eases Bettina’s pain. She also worries about giving Bettina more medicine.

**Solution**

Bettina’s hospice nurse explains pain medicine and side effects as the end of life gets closer. The nurse encourages Olivia to offer her mother only small sips of water or bites of food.

The nurse works with the hospice doctors to get the right medicines. She suggests other things that can help Bettina too. Olivia can help relieve her mother’s pain with things like gentle massage, loving touch, music, poetry, pet visits, and quiet conversations.

The hospice nurse works with the social worker and chaplain to start talking about what Bettina cares about most. They will help Bettina make her wishes for the end of her life clear.
Spiritual care

Things to think about

• Do you know what your loved one wants and needs for spiritual guidance and support, if any?

• What traditions, customs, and beliefs matter to them?

• What ethical dilemmas arise?

• Have you talked about things that might happen and what to do?

Spiritual care is not just for those who are “religious.” People from all belief systems—and no belief system—benefit from loving, nonjudgmental spiritual care. As people reach the end of their lives, questions often come up about the meaning of life and what lies beyond.

People of different backgrounds and faiths may have specific wishes for how they are treated before and after death. Different cultures have their own ways to mourn loss.

Ethical questions come up at the end of life for families, patients, doctors—in fact, all of society. Each patient and family has to make their own choices about things like:

• Getting food and liquid from tubes (artificial nutrition and hydration)

• Having the right information to know what medical choices you want to make (informed consent)

• Having a doctor’s written note telling health providers not to revive you if your heart or breathing stops (do-not-resuscitate, or DNR, order)

Families who talk about what they want near the end of life—and then document those wishes in an advance directive—have the tools to make tough choices. They feel better knowing they are doing what their loved one wants.

All hospices have psychosocial experts to help patients and their families at the end of life. The hospice chaplain or social worker works with a patient’s priest, minister, rabbi, imam, or other close spiritual advisor. They can also connect the patient, the family, and the hospice staff to each other.
Alejandro and Sofia’s elderly father, Luis, has advanced kidney disease. They’re worried that dialysis is getting more painful and no longer helping. Currently in a hospital, Luis asks to return home. They arrange for hospice care.

**Solution**

The hospice team supports Luis moving home, schedules regular visits, and provides equipment and supplies to take care of Luis.

The hospice nurse also teaches Alejandro and Sofia about end-of-life care for a patient with end-stage kidney disease.

They learn that their father can get care in an inpatient hospice unit if his symptoms and pain can’t be managed at home.
Most people prefer to get hospice care at home—whether “home” is a private residence, an assisted living community, or a nursing home. Make sure you talk to a hospice team member who can help you understand your options. All hospices can provide care in many settings.

These are the most common settings and the services you can expect in each one.

### Private residences

One person will be named as the primary caregiver at the start of hospice care. That person is often a family member or close friend. The caregiver provides most of the daily care most of the time while the patient is at home.

Other people can be part of the caregiving team too. Hospice nurses train all the caregivers how to give hands-on care and be prepared for the unexpected.

If the patient lives alone without extra help, ask the hospice provider if living alone is a barrier to care.
Dedicated space in facilities or hospitals

Hospice can happen in many settings when patients need more care than they can get at home:

- Inpatient hospice in its own building
- Inpatient hospice unit inside a hospital
- Dedicated hospice beds inside a long-term care facility, nursing home, or hospital

All these choices have plenty of staff to take care of patients, and they give 24/7 support in a warm and comforting environment. That means your loved one has easy, quick access to support services and healthcare professionals.

Nursing homes and assisted living communities

Many nursing homes and assisted living communities provide hospice services. They may have specially trained nurses to care for residents who are getting hospice, or they may have a hospice partner bring hospice care to residents with advanced illness. If your loved one is in a nursing home, ask about hospice services.
Pain management is one of the core goals of hospice care. Federal and state laws say that hospice providers must make every reasonable effort to control a patient’s pain. Your hospice provider should be a skilled expert at managing your loved one’s pain.

Hospice will talk to your loved one about the pain they are feeling. If your loved one can’t talk, the hospice team can use their special training and experience to measure pain through nonverbal cues.

Your hospice doctor will make a pain management plan and order all the medicines and treatments in the plan. The doctor will be an expert in care that makes the patient comfortable, called palliative care. The caregiver and hospice staff, including nurses, will give the treatment and watch the patient closely. Everyone on the hospice team is focused on the same goal: Keep the patient comfortable.

Getting treated for pain may mean that your loved one won’t be awake, aware, or able to interact with you very well. Your hospice team will talk with you when that point comes so you can agree on a plan that’s best for everyone.
The way you feed your loved one is a big part of their comfort and quality of life. Your hospice team will help by suggesting meals that won’t make problems like constipation worse. The best way to encourage your loved one to eat is to offer foods they like. Your hospice team may suggest you make some family favorites, from Mom’s homemade chicken soup to Uncle Joe’s famous cookies. Nothing increases appetites more than familiar favorites and comfort foods.

Your loved one may not be able to chew or swallow at some point. If that happens, your hospice team can help you understand what’s going on and help you decide what to do next. They will explain what is normal at the end of life, like how people stop feeling hungry or thirsty. They can also give you ideas for other ways to show love and care.

Medicines

Treating pain may start with over-the-counter medicines like acetaminophen (Tylenol), ibuprofen (Motrin or Advil), or aspirin. Those medicines may stop working for your loved one at some point. If that happens, the doctor can prescribe stronger medicines. These medicines are normal for patients with advanced illness.

Other therapies may be tried along with medicines: palliative radiation for cancer pain, for example. Every patient and every situation is different. Hospice doctors work together with the patient’s doctor to make decisions about medicine.

Food
Everyone handles the death of a loved one differently. Many caregivers wear themselves out trying to make everything perfect. They may feel that if they do everything right, their loved one will be more comfortable and may live longer. This effort can leave the caregiver overwhelmed and exhausted.

Hospice provides many services to make caregiving easier.

Hospice can help you find out about and make an advance directive. It can also help with financial issues like paying for a burial or memorial, handling probate, and more.

Hospice will support families as they grieve. VITAS supports families throughout the year with features like:

- Bereavement support letters, newsletters, and educational materials 4 times a year
- Grief support groups led by professional VITAS staff
- Community memorial services
- Bereavement support telephone calls and visits by professional staff and volunteers
- Referrals to help in your community, like grief therapists, support groups, legal services, and more
- Memory Bears made by VITAS volunteers, from a loved one’s favorite clothing or fabric donated by family members
Hospice supports people in body, mind, and spirit

Khalil, 37, is overwhelmed by the physical, mental, emotional, and financial stresses of caregiving. He is alone in caring for his mother, Adela, at home after a severe stroke. Then hospice comes to help.

Solution
Adela’s hospice nurse teaches Khalil about caring for stroke patients. A hospice aide visits each day and helps Adela with getting clean and neat, taking care of her teeth and mouth, and any light housekeeping.

Other hospice team members help take the pressure off Khalil. A social worker connects him with a caregiver support group. A chaplain visits each week to talk and pray together. Khalil gets some time for himself and to run errands while a hospice volunteer spends a few hours a week with Adela.
Practical things to think about

Many details have to be organized when your loved one is near the end of life. Hospice can help you understand what needs to be done and how to do it.

When you talk to hospice providers, it helps to have a list of questions to ask. You may want to know:

• Can our loved one keep the same primary care doctor if we agree to hospice?

• Our loved one can still move around alone. Is it safe for them to be at home?

• No one in our family has the body strength to take care of our loved one. We can’t do all the lifting, moving, and bathing they need. Who can help?

• Who should we call if we see a change in our loved one?

• What should we do if our loved one needs care around the clock and none of us can help?

• What do we do if there is an accident or emergency in the middle of the night?

Choosing hospice care can be emotional. You may have to change how you think about your loved one’s future. Asking questions can help you get the practical answers you need.
1. **Hospice is for people with advanced illnesses.** It includes heart disease, cancer, stroke, lung disease, liver disease, kidney disease, ALS/Lou Gehrig’s disease, Alzheimer’s disease, HIV/AIDS, sepsis, multiple sclerosis, and other neurological diseases. Hospice helps cope with serious illness in patients of any age, culture, beliefs, or cause of illness.

2. **Hospice can happen anywhere.** Hospice is a service that comes to the patient. Patients at home feel better, surrounded by the faces and things they know and love.

3. **Hospice is a choice.** Patients can leave, or “revoke their hospice status,” at any time for any reason. Patients can also come back to hospice at any time, as long as they meet eligibility guidelines.

4. **Patients can keep taking medicines and treatments while on hospice.** Hospice patients get treatment that brings comfort and improves quality of life.

5. **Hospice gives medicines as needed to help with symptoms.** Hospice doctors try to give the smallest amount of medicine that will bring relief and comfort. That means they give just enough medicine to help the patient feel better, from anti-inflammatory pain relievers to opioids.

6. **Family or friends provide care with support from the hospice team.** Family or friends take on the role of primary caregivers, supported and trained by an expert team that makes regular, scheduled visits. Patients in assisted living communities or nursing homes are already getting care from staff. The hospice team provides extra care that works together with the facility staff.
7. **There is no limit to the time a patient can be on hospice.** Hospice is for patients who have 6 months or less to live according to a doctor. Hospice care can be extended if the doctor agrees that the patient still has less than 6 months to live and the plan focuses on quality of life. In surveys, family members often say “we wish we had known about hospice sooner.”

8. **Hospice provides home medical equipment and supplies related to the cause of the illness.** This includes shower chairs, hospital beds, toileting supplies, and more. Having these tools handy is convenient and can improve quality of life for the patient and caregivers.

9. **Hospice supports the family.** Hospice addresses emotional and spiritual pain suffered by loved ones. In fact, bereavement support for the family continues for more than a year after the death.

10. **Ninety-nine percent (99%) of hospice patients do not have any out-of-pocket expenses.** Medicare Part A covers up to 100% of the cost of hospice care related to a hospice-eligible patient’s illness, with no deductible or copayment. For patients with Medicare Advantage, hospice is covered by original Medicare. Patients with a private or employer-provided health plan should check with their insurance provider for details about hospice eligibility, coverage, and out-of-pocket expenses. Medicaid provides hospice coverage, but it varies by state.
Now that you know more about hospice, you can start to get ready. You can gather as a family to talk about taking these steps:

- Your loved one has talked to you or written down their wishes about care near the end of life.

- Your loved one has made an advance directive or a living will. You have read it and know where it is.

- One person is chosen to call hospice or to ask your loved one’s doctor for a referral.

- One person is chosen to make decisions if your loved one can’t talk.

- You understand the 4 levels of hospice care. You know how hospice can help you care for your loved one.

- You have talked about the spiritual needs of your loved one and your family.

- Your loved one has chosen where they want to get hospice care.

- One person is chosen as the main caregiver while your loved one is at home.

- You have talked with your loved one about handling pain. You can guide the hospice team members on your loved one’s wishes.
You have a list of practical questions for your hospice team about how to get organized.

You understand that this will be a difficult time for your family, and you know emotional support is available.

You have done your research and know how hospice will be paid for.

For more information

Your doctor and VITAS can help you see if hospice care seems right for your loved one. This will not cost you anything. You can call VITAS at 866.586.1909, 24 hours a day, 7 days a week.

If you would like more information on hospice, please visit VITAS.com or NHPCO.org.