

# Discussion Guide for Families Considering Hospice

What would we choose if we had control over how we live close to the end of life? We would want comfort, compassion, and dignity. We would not want to feel like we are a burden to those around us. We would want to feel supported and that our loved ones have the support they need, too. We would want to enjoy each other's company. We would want to feel at peace. Through hospice care, this is possible.

Although we can't control the time of our death, we do have control over how we are cared for and where we choose to be near the end of life. It is important to understand our options, to be able to make our own decisions, and to rest assured that our wishes will be respected. Hospice is not giving up. In fact, 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.

Hospice of Frederick County 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.



## What is hospice?

Hospice is a patient-centered, family-oriented approach to care for people with life-limiting illness. **Hospice is not a place.** Hospice can be provided anywhere a person calls home. Using a combination of medical, emotional, and spiritual support, hospice care neither hastens death nor prolongs life, but allows the illness to run its natural course. The goal is not to cure but to provide symptom management, control pain and discomfort, and provide quality of life for the time that remains. It is a shift in focus from aggressively trying to cure the illness that is no longer responding to treatment to focusing on your loved one’s needs and aggressively managing their symptoms. Our interdisciplinary team of professionals also provides the whole family with emotional, social, and spiritual support.

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.

## How much do the services cost?

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 patient qualifies for hospice, the Medicare Hospice Benefit covers 100 percent of the cost of hospice care, including medication and medical equipment related to the terminal diagnosis. There are no deductibles, and there are no out-of-pocket expenses to patients or their loved ones. 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.

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**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, ask your insurance provider, or call Hospice of Frederick County and we can help you understand your coverage.

**TRICARE**

TRICARE is the health benefit program for military personnel and retirees. Hospice is a fully covered benefit under TRICARE. Hospice of Frederick County is also a proud member of the “We Honor Veterans” Program.

**PRIVATE PAY**

If insurance coverage is unavailable or insufficient, **Hospice of Frederick County will provide care to anybody eligible for hospice services regardless of their ability to pay.** Through generous donations from the community, we are able to continue the mission of caring for all who need us, regardless of their ability to pay.

**How to start a conversation about end of life choices**

The best time to start the conversation is when everyone is healthy. The opening sentence begins, “What if...?” Family members can fill out advanced directives and discuss what their healthcare wishes would be if they could not communicate themselves. Discuss plans for burial, funerals, and memorial services with your loved ones. It is ok if the conversation is ongoing and takes place on multiple occasions, but decisions should be put in writing, even if they change over time. This way, there will always be a document that contains your wishes for end of life care. The goal is for the entire family to know and understand your wishes and decisions you’d make for end of life care.

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## What if the conversation doesn't take place until the family member is sick?

Ideally, 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. However, most often 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.

If these conversations have not been had, 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.

## Point to discuss during the conversation

### *EVALUATING 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?

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## What happens when you call hospice?

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 quickly and efficiently.

After you or your doctor make the call, 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.

## What to expect from your hospice care provider

There are four levels of care recognized by Medicare/Medicaid/private insurance 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.

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 one at a time 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.

**Continuous 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.

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**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.

**Kline House** A home-like environment where compassionate care is provided. If it is not possible for the patient to remain in a private residence or nursing home/facility, the hospice house is available for short term room and board on a sliding scale fee

## Who is in your care team?

Your care team consists of interdisciplinary experts who, in addition to managing pain, treat difficulties with swallowing, breathing, hydration, nutrition, skin care, agitation, recurrent infection, depression, anxiety, muscle stiffness, communication, and more. Additionally, your hospice nurses will be able to educate caregivers and family members in providing appropriate care when hospice staff is 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** is specially trained in the care and comfort of terminally ill patients. He or she 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** 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** provides emotional support and helps the family access financial and Community resources and end-of-life planning.

**Home health aide** can help with personal care and hygiene as well as light housekeeping, light laundry, and occasional shopping.

**Chaplain** offers spiritual and emotional support and can work with the patient’s own clergy.

**Community volunteer** offers companionship and respite relief.

**Bereavement specialist** offers grief and loss support and counseling at no charge for up to 13 months following the death of a loved one.

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## Cultural beliefs and spiritual needs

Spiritual care is not reserved for those who are “religious.” People from all belief systems and/or no belief systems can benefit from loving, nonjudgmental spiritual care. As we reach the end of our lives, we ask what meaning our life has 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, and all of society. Decisions related to the use of artificial nutrition, IV hydration, informed consent, and Do Not Resuscitate (DNR) orders—all must be decided by each patient and family in the context of their individual circumstances. Families that talk about what they would wish for near the end of life—and document it in an advance directive—are better able to make difficult decisions if necessary.

## Where does hospice provide care?

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. 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.

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**ASSISTED LIVING COMMUNITIES AND NURSING HOMES**

Many nursing homes and assisted living communities have a partnership with a hospice such as Hospice of Frederick County to bring hospice care to terminally ill residents. The same levels of care are provided to the residents of these communities and nursing homes, just like they would receive in a private residence.

**KLINE HOSPICE HOUSE**

Provides a residential hospice care for patients in their last weeks of life in a home-like environment.

**Physical and medical considerations**

Pain assessment and management 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 keeping 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.

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### *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. When pain levels increase to the point where these medications are no longer effective, stronger, narcotic medications in combination or alone with other medications 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 their favorite 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.

### **Other questions to ask**

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?

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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?

### A note on hope

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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## How we support family members

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.**
- 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 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. We provide information, education and resources throughout the year, including:

- Quarterly bereavement support phone calls, cards, newsletters, and educational materials
- Bereavement support groups and workshops led by our professional staff
- Remembrance services
- Bereavement support telephone calls and visits by professional staff and volunteers
- Community resource referrals: grief therapists, support groups, legal services, etc.

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## We Honor Veterans Program

At Hospice of Frederick County, we are grateful to our United States veterans and their service to our country. That is why we have become a national partner of We Honor Veterans, a pioneering campaign developed by the National Hospice and Palliative Care Organization in collaboration with the Department of Veteran Affairs with the focus helping us provide care and support that reflects the contributions made by our men and women in uniform. Dedicated services we provide to our veterans include:

- A customized plan of care to reflect the needs of each of our veterans, not only physically, but psychologically, emotionally, and spiritually
- Specialized and ongoing training for our staff on issues of care particular to our veteran population to better understand and address their needs
- A veteran liaison who will help to guide you in taking advantage of some military services you are entitled to, but may have not yet utilized. Among these benefits are:
  - *Obtaining discharge documents*
  - *VA pensions, including aid and attendance*
  - *Burial benefits in veteran cemeteries*
  - *Survivor benefits for spouses and dependents*
  - *Medals and awards*
  - *Death pensions*
  - *Monuments and final military honors*
- Pairing between a veteran and a volunteer who is serving or has served in the military, whenever possible

Tri-Care covers 100% of costs with no out of pocket expenses to the veteran or family. Medicare, Medicaid and VA also cover hospice at 100%. Even if you have not utilized your benefits, or are uninsured or underinsured, we will provide care to the patient and family regardless of ability to pay.

To learn more about this program, please visit [wehonorveterans.org](http://wehonorveterans.org)

## For more information

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

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 [hospiceoffrederick.org](http://hospiceoffrederick.org) or [NHPCO.org](http://NHPCO.org).

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