

Passare

Choosing Hospice Care at End-of-Life

eBook #16

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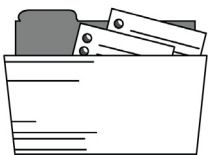
Everyone wants a comfortable, peaceful End-of-Life experience. Hospice is a care option devoted to exactly this purpose: improving the quality of a person's End-of-Life. Hospice helps ensure a graceful passage at End-of-Life by providing comfort, compassion and dignity.

As part of our eBook series, Passare™ shares resources and guidance to help you explore and understand issues surrounding hospice care at End-of-Life. Passare helps guide you through one of life's most important passages.



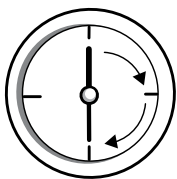
You Will Learn About:

1. What is Hospice Care?
2. What Services Does Hospice Offer?
3. Hospice Care Options
4. How-to Choose a Hospice Program
5. When and How to Engage Hospice Care
6. Financing Hospice Care
7. How-to Ensure Your Care Choices are Honored
8. Summary



The eBook includes:

- A. Frequently Asked Questions About Hospice
- B. Hospice Care Resource List



Estimated Time Required:

15 minutes

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What is Hospice Care?

Hospice is an End-of-Life care option that provides medical services, pain management, emotional support and spiritual resources for people who are in the final stages of a terminal illness. Hospice also helps family members manage the practical details and emotional challenges of caring for a loved one at End-of-Life, and includes spiritual support and bereavement services.

Hospice care honors each patient's unique needs and wishes. It focuses on *caring* rather than *curing*. The goal of hospice is to maintain or improve the quality of remaining life for someone whose illness or condition is unlikely to be cured.

Who Needs Hospice Care?

The term *hospice* comes from the word *hospitality*. It can be traced to medieval times when it described a place of shelter and rest for weary or ill travelers on a long journey.

Today, hospice provides medical or non-medical comfort and support to enable a peaceful End-of-Life journey. A person qualifies for hospice care when he or she has a life-threatening condition that cannot benefit from curative treatment. Most often, a physician has determined a life expectancy of six months or less. Hospice services are available to patients of any age, religion or race, and their families.

Seriously ill patients whose priority is to have the best quality of life possible are those best suited for hospice care. Hospice patients have conditions that make day-to-day living very uncomfortable—physically, emotionally and/or spiritually. Hospice specializes in easing pain, discomfort and distress on all levels.

Where is Hospice Care Provided?

In many cases, hospice care is provided in the patient's home yet may also be provided in hospice centers, hospitals, nursing homes and other long-term care facilities.

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Who Provides Hospice Care?

Hospice offers a team approach to End-of-Life care. The hospice team develops a care plan that meet a patient's needs for pain management and symptom control. The hospice team may include the following people:

- Patient or person receiving care
- Patient's family members, loved ones or caregivers
- Patient's personal physician
- Hospice physician or medical director
- Nurses
- Home health aides
- Social workers
- Clergy, counselors or other spiritual advisors
- Trained volunteers
- Speech, physical and occupational therapists

How Long Can Hospice Care Last?

Hospice patients are evaluated every 60-90 days to determine if hospice care is still appropriate. Although typically intended for a six-month period, hospice may last longer because many people live longer than the original six-month prognosis. A patient may be released from hospice care if their condition stabilizes, improves or their needs no longer require it. A hospice patient may choose to end hospice care at any time.

How Does Hospice Care Differ From Palliative Care?

Hospice and palliative care both focus on relieving suffering and improving quality of life by providing physical, emotional and spiritual support tailored to the unique needs of each patient.

Hospice care treats the person, rather than the illness or condition and focuses on the quality of remaining life. *Palliative care* is specialized medical care that provides patients with relief from the symptoms, pain and stress of any illness. Palliative care may be used in combination with medical care that is geared toward healing and curing a patient. Visit: <http://getpalliativecare.org/whatis/> for more information.

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What Services Does Hospice Offer?

The hospice care team offers the following support services:

- Manages the patient's pain and symptoms with input from physicians and nursing staff
- Helps the patient cope with emotional, psychosocial and spiritual aspects of End-of-Life
- Provides necessary medications, medical supplies and equipment
- Offers dietary counseling and other personal care services
- Guides the family on how to care for the patient
- Offers short-term inpatient care when pain or symptoms become too much to manage at home, or when the caregiver or family needs respite
- Provides bereavement care and counseling to surviving family and friends
- Provides spiritual support to the patient and family through chaplain services

Hospice Care Options

There are four levels of care provided by US hospices:

- Routine Home Care (RHC) – patient remains at home with controlled symptoms
- Respite Care (RC) – patient is in a facility with controlled symptoms
- General Inpatient Hospice Care (GIHC) – patient is in a facility with uncontrolled symptoms
- Continuous In-Home Nursing Care (CC) – patient is at home with uncontrolled symptoms

Hospice Care Levels

A patient's unique needs determine their level of hospice care. A hospice patient can move from one level to another and back, depending on the services they need.

Routine Home Care (RHC)

RHC is the most common type of hospice care in the US. With RHC, the patient has physical symptoms that can be controlled by care that is administered at home or a long-term care facility. Depending on a patient's needs, they may receive up to twenty-four hours a day on-call services from registered nurses, social workers, religious or spiritual guides, home health aides, counselors, medications or equipment.

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Respite Care (RC)

Respite care (RC) is short-term inpatient care to relieve the patient's family or primary caregiver. Many hospice patients live at home. Family members provide most of their care, sometimes around the clock. Caring for a terminally ill loved one may be exhausting and stressful. Family members and/or caregivers need time to rest and care for themselves and it's important that they take that time. Respite care allows a patient to be temporarily placed in a facility with 24-hour care so the family can rest. If the patient is willing and the family requests it, hospice must provide the patient a place in a facility or a hospice home. RC is limited by Medicare regulations to five consecutive days.

General Inpatient Hospice Care (GIHC)

A hospice patient may require General Inpatient Hospice Care (GIHC) when his or her symptoms can no longer be managed by RHC. To control a patient's symptoms and ensure comfort, they may be temporarily placed in a hospice home or an acute care hospital. At this level of care, a continuous assessment of symptoms, needs and services occurs. The hospice team and the patient's physician will work together to ensure that the patient maintains a tolerable comfort level. Once this is achieved, the patient may return home and resume RHC.

Continuous In-Home Nursing Care (CC)

A patient receives Continuous In-Home Nursing Care (CC) if he or she has uncontrolled symptoms and chooses to remain at home. This is similar to inpatient care, except that the patient remains in his or her home instead of being placed in a facility. In most cases, a hospice nurse is required to provide CC if the patient's symptoms cannot be controlled while with RHC.



Take a few minutes to answer these questions.

1. What hospice care level(s) best fits your choices for End-of-Life care?
2. What hospice programs are available near where you live?
3. Where would you prefer to receive hospice care if you need it toward your End-of-Life?

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How-to Choose a Hospice Program

If you or a loved one and your physician(s) agree that hospice is the right care option, your physician may make referrals about hospice care providers in your area. You can also ask for recommendations from hospital discharge representatives or your loved one's assisted living community or nursing home.

Considerations when Choosing a Hospice Program

The relationship between a terminally ill patient and their hospice caregiver is based on sensitivity and trust. When choosing hospice providers, assess your first impressions after meeting the hospice representatives. Often, they are a good indicator of the relationship you or your loved one will develop with your hospice care providers.

Then consider the following questions and recommendations:

- Do others recommend this hospice?
Get references from friends, local hospitals, nursing homes or clinicians. Geriatric Care Managers may also be a helpful resource since they often make referrals based on what they learn about hospice care from families they serve
- Is this hospice Medicare or Medicaid-certified?
Medicare is the primary source of reimbursement for hospice care. Medicare certification is essential if the patient is a Medicare beneficiary or recipient.
- Can this hospice meet your loved one's care needs?
Discuss any specific care concerns you have and how they will be addressed.
- Are there limits to treatment?
Ask if there is any care that the patient is receiving now that this hospice cannot provide. For example, some services, like radiation or chemotherapy, are not required by Medicare, although may be offered by some, but not all hospices.
- What personal care services does this hospice provide?
Confirm whether help with bathing, dressing, eating or other personal care services are provided.

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- What are the respite care options?
Family members often become exhausted and stressed caring for a terminally ill loved one. Ask under what conditions the hospice provides CC care and for how long.
- Is this hospice affiliated with a hospital or facility that provides inpatient care?
Caring for a terminally ill loved one may be unpredictable. Having a plan to manage emergencies and knowing where the GIHC facility is located is essential.
- What emotional and spiritual support is offered to the patient and family members?
If you or family members or close friends may benefit from counseling or bereavement services, ask from whom, when and where they are offered.
- What is the family's role in caregiving?
Be sure expectations match what your family is able to do. Ask if this hospice can train family members or friends to help provide patient care if needed or desired.
- How are patient or family concerns handled?
Confirm that there is a clear process for sharing concerns in a timely manner.



Important Note: Be sure that your hospice program is Medicare-certified. Medicare is the primary source of reimbursement for hospice care. In addition, confirm whether the hospice is accredited, and if required, state-licensed. For example, if the hospice is Joint Commission Certified, this means that it has met a higher care standard set by the Joint Commission on the Accreditation of Healthcare Organizations (JCAHO).



Take a few minutes to answer these questions.

1. What hospice programs do your physicians, friends, loved ones or caregivers recommend?
2. What part of your End-of-Life care will your loved ones provide?
3. How will your loved ones feel about receiving the emotional, spiritual or bereavement counseling that hospice care provides?

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When and How-to Engage Hospice

If you or a loved one and your physician(s) agree that hospice is the right care option, your physician may make referrals to hospice care providers in your area. You can also ask for recommendations from hospital discharge representatives or your loved one's assisted living community or nursing home.

When to Engage Hospice

A person qualifies for hospice when a physician diagnoses them with a terminal illness with a prognosis of six months or less of remaining life expected. Yet it is appropriate at any time during a life-threatening condition to discuss your health care options, including hospice care, with your healthcare provider or loved ones.

Many people are understandably uncomfortable with shifting the focus from curative measures to conquer their illness to improving the quality of their remaining life. Healthcare and hospice providers understand these concerns and are prepared to discuss them.

Hospice is most helpful if it is engaged as soon as possible after a physician's prognosis, or when there is adequate time to care for the physical and emotional needs of the patient and their loved ones. This process requires trust, sensitivity and time. Many clients engage hospice when treatment is no longer an option yet symptoms have not yet fully developed. This allows them to benefit most from hospice care, and most importantly, to improve the quality of their remaining life.

How-to Engage Hospice

Once a hospice agency or program is chosen, you will need to formally enroll in it. You'll begin by calling to set-up an initial assessment of the patient's needs. The patient, if they are able, or a physician or family member may place the initial call. A hospice staff member will request initial information during the call and then schedule a visit with the patient to assess their eligibility, condition and needs, and pain and symptom management options.

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During the assessment, the hospice staff will counsel the patient and family members on End-of-Life issues and care options. They may also discuss End-of-Life planning, including the need for End-of-Life documents like an Advance Healthcare Directive (AHD). Hospice staff members will help you manage their program's necessary paperwork and will answer any questions you or family members have. If your loved one isn't physically or mentally able to give consent or information, their Healthcare Proxy or Medical Power of Attorney (MPOA) will need to enroll them in the hospice program. If no Healthcare Proxy or MPOA is appointed, a family member or physician may enroll the patient. For more information on appointing a Healthcare Proxy, MPOA or completing an AHD, please read "[How-to Ensure Your Care Choices Are Honored](#)" later in this eBook.

Does Hospice Care Always Mean End-of-Life?

Hospice does not always mean End-of-Life is imminent. It's important to remember that due to the nature of the services and support provided by hospice, people often live longer than expected. A physician may suggest hospice care simply as a comfort care option. Hospice care may lengthen the prognosis by increasing the quality of the time remaining. It is important that you and your healthcare provider talk about goals for maintaining quality of life.



Take a few minutes to answer these questions.

1. Whom will you choose to make End-of-Life hospice care choices for you if you are unable to do so?
2. When will you request that hospice care be engaged if you become terminally ill?

Financing Hospice Care

Hospice care often costs less than other types of End-of-Life care because it typically involves less equipment and fewer medical procedures. Also, the patient is most often cared for at home by family members, friends or volunteers instead of in a hospital.

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Hospice Care Coverage via Medicare, Medicaid and Private Sources

Medicare, Medicaid and most private health insurance providers cover nearly all hospice care costs with little or no out-of-pocket expense to the person or their family. If a person does not have Medicare or Medicaid coverage, or private insurance, many hospice programs offer care free of charge or based on a person's ability to pay. Hospice will work with the patient and their family to ensure that needed services are provided. Under Medicare law, no person may be refused hospice care due to inability to pay.

More than 90% of US hospices are Medicare-certified. Each hospice agency has a financial specialist on staff to answer questions about financial assistance. Funds may be available from donations, gifts, grants or other community sources to help cover the costs of care.

The Medicare Hospice Benefit, initiated in 1983, is covered under Medicare Part A, or hospital insurance. Medicare beneficiaries who choose hospice care receive full medical and support services for their life-threatening condition. Medicare also covers hospice support services for the patient's family and loved ones.

Hospice Care Coverage via TRICARE

TRICARE is the health benefits program for US Military Servicemembers and Veterans. Hospice is a fully covered benefit under TRICARE. Only Medicare-certified hospices may accept TRICARE. It is important that patients and family members check with their Healthcare Benefit Advisor or Health Care Finder to help them locate a qualified hospice agency that supports TRICARE coverage

For more information on finding Medicare-certified hospices please visit:
www.HospiceDirectory.org.

How-to Ensure Your Care Choices are Honored

It's important to decide the type of care you want in the event of an emergency or when facing End-of-Life. Make your wishes clear in advance to remove the decision-making burden from loved ones and to ensure that your wishes are honored. Consider completing the following legal documents and tasks:

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- **Advanced Healthcare Directive (AHD) or Medical Power of Attorney (MPOA)**
Prepare a living will and/or AHD or MPOA. These legal documents provide directions for what kind of treatment you want if you become unable to make your own decisions. Include your choices for hospice and/or palliative care and other pain management options.
- **Healthcare Proxy**
Consider appointing a Healthcare Proxy or Healthcare Agent. A Healthcare Agent or Proxy gives legal power to a person you appoint make your healthcare decisions if you are unable.
- **Do Not Resuscitate (DNR) Order**
This document prevents medical personnel from doing cardiopulmonary resuscitation (CPR) to save or prolong your life.
- **Physicians Order for Life-Sustaining Treatment (POLST)**
A POLST or a Medical Order for Life Sustaining Treatment (MOLST) is a physician-signed order that becomes part of your official medical record and explains your wishes for End-of-Life care.

Copy and Store Your Important Documents

Once you have documented your End-of-Life care choices, we suggest you:

- **Copy documents**
Give copies of important documents to your loved ones, healthcare provider and other trusted advisors involved in your End-of-Life care.
- **Securely store documents**
Store documents in a secure, accessible place. Keep important documents in a home safe, a safe deposit box or with a trusted advisor

Talk with Your Care Providers and Loved Ones

Your End-of-Life care choices are useful only if others know about them. Discuss your thoughts, concerns and choices with your family and friends. Talk to your healthcare provider, family and doctor about your choices. Let your loved ones know you have a plan and where your important documents are stored.

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Frequently Asked Questions (FAQ)

1. What is Hospice?

Hospice is an End-of-Life care option that provides medical services, pain management, and emotional and spiritual support for people who are in the final stages of a terminal illness. Hospice helps family members manage the practical details and emotional challenges of caring for a loved one at End-of-Life.

2. Who provides Hospice care?

Hospice offers a team approach to End-of-Life care. The hospice team may include the patient, the patient's physician, family members, loved ones and caregivers, a hospice physician or medical director, nurses, home health aides, social workers, clergy, other spiritual advisors, volunteers, and speech, physical and occupational therapists.

3. When does hospice care begin?

Hospice care may begin once a physician makes a referral. A person qualifies for hospice when a physician estimates a prognosis of six months or less of remaining life.

4. Do only certain patients receive hospice care?

Hospice care is appropriate for anyone at any age suffering from a life-threatening condition with a prognosis of six months or less.

5. Is all hospice care the same?

Medicare requires certified hospices to provide a basic level of care, yet the quantity and quality of services may vary among hospice providers. To find a hospice program for your needs, ask your doctor, healthcare providers, or friends who have experience with hospice care.

6. Is hospice care only for people facing End-of-Life?

Hospice care focuses on the grieving family as well as the patient nearing End-of-Life. Many hospices provide grief services to the community.

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7. Does using hospice mean giving up hope?

Hospice does not always mean End-of-Life is imminent. Hospice care may lengthen the prognosis by increasing the quality of life. If a patient's condition stabilizes or improves, they may be discharged from hospice and choose to return to therapy or their typical daily life.

8. Is hospice available 24 hours a day, seven days a week?

Hospice care is available on call seven days a week, 24 hours a day. Most hospices have nurses who respond within minutes. Some hospice programs also have chaplains and social workers on call 24/7.

9. What is the goal of hospice?

The goal of hospice is to keep the patient as pain free and alert as possible. Hospices meet this goal successfully through continual patient consultation.

10. What if I don't have Medicare or health insurance?

Many hospice programs offer care free of charge or charge based on a person's ability to pay. Hospice works with the patient and their family to provide services regardless of funds or health insurance coverage.

11. How can I ensure that my hospice program provides quality care?

To ensure that hospices provide quality care, the National Hospice and Palliative Care Organization (NHPCO) has developed recommended standards called, Standards of Practice for Hospice Programs. NHPCO also offers a self-evaluation to compare to the NHPCO Standards. Ask your hospice program when they last completed a NHPCO self-assessment.

12. Are there other ways hospice programs are evaluated?

Hospice programs must meet state license requirements to provide care. Hospices must also comply with federal regulations to be approved for Medicare reimbursement.

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Hospice Care Resource List

Passare suggests that you consider these resources to learn about:

- Legal forms to document End-of-Life care choices
- Hospice and palliative care resources for families
- Medicare coverage and reimbursement for hospice care
- Hospice benefits for US Military Servicemembers and Veterans

Legal Forms to Document End-of-Life Care Choices

American Bar Association: 1-800-285-2221 or: www.americanbar.org

National POLST Office: 503-494-3965 or: www.polst.org

US Department of Health and Human Services
<http://nihseniorhealth.gov/endoflife/planningforcare/01.html>

National Institutes of Health/Senior Health
<http://nihseniorhealth.gov/endoflife/faq/faq18.html>

Hospice and Palliative Care Resources

Caring Connections: 1-800-658-8898 or: www.caringinfo.org

Center to Advance Palliative Care: 1-212-201-2670 or: www.caringinfo.org

Children's Project on Palliative / Hospice Services (ChiPPS): 1-703-837-1500
or: www.pediatrics@nhpco.org or: www.nhpco.org

Eldercare Locator: 1-800-677-1116 or: www.eldercare.gov

HospiceDirectory.org: 1-800-854-3402 or: www.HospiceDirectory.org

Hospice and Palliative Nurses Association: 1-412-787-9301 or: www.hpna.org

Hospice Association of America: 1-202-546-4759 or: www.nahc.org/HAA/

Hospice Foundation of America: 1-800-854-3402 or:
www.hospicefoundation.org/advancecare or www.hospicedirectory.org

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Hospice Net: www.hospicenet.org

National Association for Professional Geriatric Care Managers: www.caremanager.org

National Hospice and Palliative Care Organization:
1-703-837-1500 or: 1-800-658-8898 or: www.nhpco.org

Medicare Coverage for Hospice Care

Centers for Medicare and Medicaid Services: 1-800-633-4227 or:
www.medicare.gov

To find Medicare-certified hospices please visit: www.HospiceDirectory.org.

Hospice Benefits for US Military Veterans and Servicemembers

National Hospice and Palliative Care Organization:
1-703-837-1500 or: 1-800-658-8898

US Department of Veterans Affairs: 1-800-827-1000 or:
http://www.va.gov/geriatrics/guide/longtermcare/Hospice_and_Palliative_Care.asp

www.nhpco.org/billing-and-reimbursement/departments-veterans-affairs-va or:
<http://www.wehonorveterans.org/get-practical-resources/resources-topic/family-evaluation-hospice-care-veterans-survey>

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Summary

Everyone deserves a comfortable, peaceful End-of-Life experience. Hospice is an enriching and meaningful care option because it offers a broad range of services to benefit those who are nearing End-of-Life. It also helps loved ones during hospice care and after their loved one passes away. Whatever your final care choices are, this eBook is intended to provide guidance to help you explore and understand the benefits of hospice care at End-of-Life.

Please visit: www.passare.com/resources/experts for expert resources on many End-of-Life Management topics.



From birth to death, life is a series of passages. Only Passare allows you to connect and collaborate with your family any time, anywhere to easily explore and plan for End-of-Life.

With Passare, you can engage with trusted End-of-Life experts and relevant resources that guide you through one of life's most important passages and ensure that the specific needs and wishes of you and your family are honored. Please visit www.passare.com for more information on how we can help simplify End-of Life Management.

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