

Understanding Hospice

A Life Choice Patient & Family Guide to Hospice Care



1-800-557-7570

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Dear Friends,

Thank you for letting Life Choice help you through this most difficult of times.

Our purpose is simply to provide the best, most professional care and comfort to individuals in the very late stages of life and their families. Our focus is on people. We take pride in caring for the whole person – mind, body and spirit – and supporting the relationships that mean so much. We treat everyone, and every family, as unique and special, with special needs and wishes. This is what makes Life Choice unique.

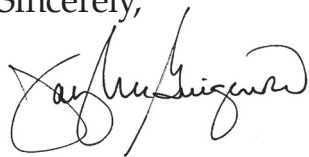
Hospice care is a Medicare benefit Americans have already paid for and, once qualified, are entitled to. We would like you and your loved ones to receive the best care from that benefit. We know you are going through a very difficult time and have had to make some difficult decisions. Life Choice is here to help you. We are committed to affirming and restoring dignity and control by listening, offering choices and caring day-by-day for you and your loved ones.

I take pride in our Life Choice team of nurses, social workers, chaplains, certified nursing assistants (CNAs) and volunteers. Each one is compassionate and dedicated to the challenging profession they have chosen. Each is highly trained and participates in an intensive Life Choice orientation program. Additionally, we provide them with the emotional and spiritual support they need to perform this special work to the highest standards.

I am always accessible to the people we serve, as are our team members. Please feel free to call me at 800-557-7570 (ext. 225) at any time if you have questions.

I wish you peace.

Sincerely,

A handwritten signature in black ink, appearing to read "Jay McGuigan". The signature is fluid and cursive, with a large initial "J" and "M".

Jay McGuigan, R. N.

FAQs

Frequently Asked Questions ...About Hospice

What is hospice?

Hospice is a concept of healthcare that provides holistic services for the physical, emotional and spiritual needs of the terminally ill and their families. Our care is designed to alleviate pain and control symptoms with expertise and compassion. In addition to physical care, hospice provides spiritual, social and emotional support. Hospice also provides bereavement counseling to the family for up to one year after the death of a loved one.

Who can receive hospice care?

Any person in the advanced stages of a terminal illness is eligible for hospice care if the following criteria are met:

- The physician thinks the patient is likely to live six months or less if the disease runs its predicted course
- Aggressive treatments are no longer working to provide relief for the patient
- The patient, family and physician agree and understand that the focus of hospice is comfort care and control of symptoms, rather than curative care

Who pays for hospice care?

Hospice is covered under Medicare Part A. Coverage provides comprehensive, comfort oriented medical care related to the terminal illness. It includes most medications, medical supplies and any equipment deemed necessary by the hospice team. It also covers payment for visits to the patient by the hospice team members.

Who are the hospice team members?

The team includes doctors, nurses, certified nursing assistants (CNAs), social workers, spiritual caregivers and volunteers. They are all involved in coordinating the care of the patient and meet regularly to ensure that the physical, emotional, social and spiritual needs of the patient and family are met.

Does hospice only take care of people with cancer?

No. Hospice serves those who are at the end stage of any disease, including diseases of the heart and lungs, AIDS, renal disease and neurologic disorders such as Parkinson's and Alzheimer's.

Is hospice affiliated with any religious organizations?

No. While some churches, synagogues and religious organizations have started hospices, sometimes in connection with local hospitals, hospices serve a broad community and do not require patients to adhere to any particular faith or set of beliefs. Life Choice Hospice is committed to understanding and respecting the beliefs, customs and rituals of all individuals.

How to Talk About End-of-Life Issues

It's all about talking. Talking with your loved ones about your healthcare preferences. Talking with your doctor about your options so that you can make informed decisions. Talking with the person you decide should have the power to make decisions for you so that your wishes are honored if you cannot make the decisions yourself.

The key is talking before a crisis, if possible. That way you and your loved ones will be prepared for any difficult decisions that may need to be made. This section will help you express your wishes and voice your decisions and end-of-life care plans to others. These conversations may be helpful as you prepare or revise advance directives, or "living will," and select your healthcare agent.

Advance Directives: Living Will and Healthcare Proxy

The term "advance directive" describes two types of legal documents that enable you to plan for and communicate your end-of-life wishes in the event you are unable to voice your decisions or choices:

- A living will allows you to document your wishes concerning medical treatments at the end-of-life.

- A healthcare proxy allows you to appoint a person you trust as your healthcare agent, or surrogate decision maker, who is authorized to make medical decisions on your behalf.

Your advance directive gives you a voice in decisions about your medical treatment, even if you are unresponsive or too ill to communicate. If you currently have an advance directive, or living will, be sure a family member knows where to find it so your wishes will be honored.

Life Choice Hospice supports the use of “The Five Wishes.” This document will take you through important issues to address, as well as the responsibilities of the person you choose to be your healthcare agent. A copy of “The Five Wishes” is provided along with this “Understanding Hospice” booklet and is available upon request from Life Choice Hospice.

Talking With Your Loved Ones

Talking about end-of-life issues can be difficult for anyone. Your family or loved ones are not likely to raise the issue for you. Chances are it's going to be up to you to take the initiative and express your wishes.

One way to approach the subject is to talk about why you have decided to discuss these matters. Ask yourself these questions, for example:

Did a particular event cause you to make the decision?

Did a story you read in the newspaper or something that happened to a family member make you think about it?

Is the decision to talk about it part of a broader effort on your part to prepare for the end-of-life? For instance, are you making your last will and testament for distribution of your property?

Have you received a new diagnosis that has you thinking about settling your affairs?

Sometimes sharing your views about what makes life worth living, your spiritual beliefs or personal concerns and values can be helpful. So can talking about specific treatments and circumstances. For example:

What aspects of your life give it the most meaning?

How do your religious or spiritual beliefs affect your attitude towards dying and death?

What are your particular concerns about dying? About death?

*How important is it to be to be physically independent and to stay in your own home? **(This is extremely important to some and is less so to others).***

How important would it be for you to be able to recognize people or interact with them?

Would you want the person who makes healthcare decisions for you, if you are not able to make them for yourself, to take into account the effect your illness may have on other people, especially your loved ones?

Should financial concerns enter into decisions about your treatment?

One final point: reassess your decisions over time. These are not simple questions and your answers may change as time passes. It's important to discuss your choices as your condition or circumstances change. All members of your Life Choice team are available to help you work through your decisions.

Talking With Your Healthcare Agent

Your healthcare agent – the person who will be responsible for making decisions about your care if you're not able to – needs to know about the quality-of-life that is important to you, and when and how aggressively you would want medical treatments provided. Talking to your agent means discussing values and quality-of-life issues, as well as treatments and medical situations. Because situations could occur that you might not anticipate, your agent may need to base a decision on what he or she knows about your values and your views of what makes

life worth living. These are not simple questions, and your views may change. For this reason, if at all possible, you need to talk to your agent in depth and over time.

The following questions may help you discuss these issues with your healthcare agent:

How do you want to be treated at the end of your life?

Are there treatments you particularly want to receive or refuse?

What are you afraid might happen if you can't make decisions for yourself?

Do you have any particular fears or concerns about the medical treatments that you might receive? Under what circumstances?

What makes those things frightening?

*What do phrases like "no heroic measures" or "dying with dignity" mean to you? **(People often use these expressions with different meanings).***

For example, if you had a massive stroke:

Would you want to receive aggressive treatments (such as mechanical ventilation, antibiotics or tube feeding) for a time, but have them stopped if there was not an improvement in your condition?

What kind of treatment would you want if you were in a state of prolonged unconsciousness and were not expected to recover?

Would you want life support, or would you rather receive palliative (comfort) care only? What are your views about artificial nutrition and hydration (tube feeding)?

Do you want to receive these types of treatment no matter what your medical condition? On a trial basis? Never?

*If your heart stopped, under what circumstances would you want doctors to use CPR to try to resuscitate you? **(A representative from Life Choice can help you understand the CPR process and answer any questions or concerns you have).***

Talking With Your Doctor

Do not wait until a crisis occurs before discussing concerns about end-of-life treatments with your doctor. Chances are that he or she is waiting for you to start the conversation.

When you discuss your concerns and choices:

- Let your doctor know that you are completing your advance directive.
- Ask your doctor to explain treatments and procedures that may seem confusing before you complete your directives.
- Talk about what to expect from pain and what may be your pain management options.
- Make sure your doctor knows the quality-of-life that is important to you. (**Make sure your doctor is willing to follow your advance directive. The law does not force physicians to follow directives if they disagree with your wishes for moral or ethical reasons.**)
- Give your doctor a copy of your completed advance directive. Make sure your doctor knows the name and telephone number of your appointed healthcare agent.
- Assure your doctor that your family and your appointed healthcare agent know your wishes.

You may want to ask your doctor specifically:

Will you talk openly and candidly with my family and me about my illness?

What decisions will my family and I have to make, and what kinds of recommendations will you give to help us make these decisions?

Will you go to bat for me with my insurance provider or health plan if you believe that their decisions are not in my best interest?

What will you do if I have a lot of pain or other uncomfortable symptoms?

If I reach a point where I am too sick to speak for myself, how will you make decisions about my care?

Will you still be available to me, even when I'm sick and close to the end of my life?

Remember, review and reassess your decisions over time. These are not simple questions and your views may change.

Talking With Your Faith Leader

It may also be helpful to speak with your faith leader about your wishes and care at the end-of-life from a spiritual perspective.

Here are some questions you might ask yourself in preparation for your discussion:

In what ways is your spirituality/religion meaningful for you?

How is your spirituality/religion important to you in daily life?

What specific practices do you carry out as part of your religious and spiritual life (e.g. prayer, meditation, service, etc.)?

When you are afraid or in pain, how do you find comfort?

From what sources do you draw strength in order to cope with illness?

For what in your life do you still feel gratitude, even though you may be ill?

How do your religious or spiritual beliefs affect your attitude towards dying and death?

Are there religious or spiritual practices or rituals that you would like to have available in the hospital, nursing home or at home?

Are there religious or spiritual practices that you wish to plan for at the time of death, or following death?

You may want to ask your faith leader specifically:

Will you understand and support my need for my spiritual self to be nourished and to grow, even as my physical being deteriorates?

If I have negative feelings like frustration, sadness, despair, anger at God or life, will you listen empathetically?

Will you help me if I have problems communicating with my family or friends?

Will you continue to visit me, even if I get very sick or it's difficult to talk with me?

Will you visit with my family and help them with their spiritual concerns about my illness?

Will you just sit and be with me, even if I don't want to talk?

Your Life Choice Pastoral Care Coordinator will work with you and your family in concert with your spiritual leader. Our Pastoral Care Coordinators are compassionate and understand the spiritual needs of the dying and their loved ones.

About the Hospice Care Team

At Life Choice our commitment is to provide the highest quality of hospice care. Our services include:

- Providing professional care and support for the patient and family
- Working with the primary caregiver to monitor and evaluate changes in patient care needs, making recommendations and adjusting the plan of care according to those needs
- Teaching the primary caregiver and other family members how to do hands-on care, administer medications and institute other necessary comfort measures
- Teaching the primary caregiver and others how to recognize signs of discomfort
- Having a hospice nurse available 24 hours a day, seven days a week to advise and assist you, and if necessary, make emergency visits
- When appropriate, helping the primary caregiver to coordinate assistance from other family members or community agencies on a private pay basis

Your Life Choice Interdisciplinary Team (IDT)

At Life Choice we have many kind, compassionate people to help and advise you and provide care and comfort.

The Medical Director, a doctor, collaborates with all members of the IDT to ensure that all symptoms are addressed.

Your Physician maintains a relationship with the patient and family and works with the Hospice Medical Director and other IDT members to ensure the best care possible.

A Registered Nurse (R.N.) coordinates the patient's care, communicates with the physicians and other team members, assesses the patient's and family's needs, and supervises care in the patient's home and other settings.

A Social Worker helps patients and families access community resources and provide counseling for death related issues, including communication problems, anticipatory grief, bereavement issues, and follow-up grief and bereavement.

A Pastoral Care Coordinator - Chaplain - addresses spiritual and religious issues, coordinates and/or provides spiritual interventions, and offers spiritual support for the patient and family members.

Certified Nurse Assistants (CNA) perform personal care, assists with activities of daily living, offers comfort measures and reports changes in the patient's and family's condition.

Volunteers provide respite care for family members, reading to the patient or just being quietly present and may do various tasks such as grocery shopping for home patients' families.

Your team members will schedule time with you depending on your needs. We make every effort to coordinate our schedule with yours, but occasionally there may be an emergency that requires your team member to be with another patient.

The amount of time spent with each person will be determined by his/her need. Each plan of care is designed to address the physical, emotional and spiritual needs of the patient and will change as the patient's needs change.

Our Life Choice nurses are on-call 24 hours a day, seven days a week at **800-557-7570**.

The Role of the Primary Caregiver

The primary caregiver:

- Agrees to be responsible 24 hours a day, seven days a week for the ongoing care and safety of the patient
- Is willing and able to adjust his/her level of involvement to meet the changing needs of the patient as his/her illness progresses
- Will follow recommendations, treatments and suggestions made by the hospice team to the best of his/her ability
- Will initiate and coordinate any alternative care arrangements that may be required, such as nursing home placement or private duty assistance
- Will act as primary spokesperson, working with the hospice team to help evaluate and coordinate the needs of the patient
- Will inform the hospice primary nurse or social worker of concerns or inability to follow the prescribed plan of care
- Will inform Life Choice Hospice immediately if there is a change in the condition or location of the patient
- The role of the primary caregiver is assumed by the nursing staff if the patient resides in a long-term care facility, and is a shared responsibility if the patient resides in assisted living facility.

Your Rights as a Patient

Basic Rights

As a patient, you have rights related to your care. These rights also pertain to the patient's legal guardian, if the patient is legally incompetent or a minor.

You have the right to:

- Be fully informed of these rights and of all rules and regulations involving patient conduct. Your written acknowledgment of such rights is required prior to or at the time of admission.
- Be fully informed of services available, the care you are to receive, changes in the care plan and the frequency of visits proposed, prior to or at the time of admission.
- Be assured that the staff members who provide care are able, through education and experience, to carry out the services for which they are responsible. You have the right to know their names.
- Be informed by your physician of your medical condition. You will only participate in research investigation, experimental studies or clinical trials if you choose to and provide the agency with documented, voluntary informed consent.
- Participate in the planning of your care and any proposed changes to this care or services.
- Receive information about your condition in order for you to make decisions regarding your care. You, or someone you select to represent you, may accept or refuse all or part of your treatment to the extent permitted by law, and have the right to be informed of the medical consequence of such actions.
- Make an advance directive and be informed about the agency's policies regarding advance directives.
- Participate in decisions involving ethical issues related to your care, as well as involvement in decisions to withhold resuscitation and to forego or withdraw life-sustaining care. When appropriate, staff and your physician will participate with you, or your designated representative, in the consideration and resolution of these issues.

- Be treated with consideration, respect, dignity and full recognition of individuality, in treatment and personal needs. You have the right to optimal comfort and to be free from verbal, physical and psychological abuse and to have your values and beliefs respected.
- Request an explanation of any charges you must pay and those to be paid by Medicare and other insurance companies.
- Be assured that all medical records will be treated with confidentiality and require your consent for their release to any individual or outside agency, except as required by law or third party payment contract.
- Receive service without discrimination on the basis of age, sex, mental and/or physical handicap, race, color, religion, ancestry, national origin, sexual preference or source of payment. Complaints of discrimination can be filed with the Pennsylvania Human Relations Commission, Harrisburg Regional Office at (717) 787-9784.
- Have the staff communicate in a language or form that you can reasonably be expected to understand. Whenever possible, we will provide or assist in obtaining special devices, interpreters or other aids to ease communication.
- Have your privacy and security maintained and property treated with respect. Staff may not accept any gifts, including food or money, and may not borrow or buy anything from you. Staff cannot work extra hours or on a private contract basis. Additionally, staff are prohibited from privately visiting you during your home care stay.
- Be taught about your illness so that you and your family can participate in your plan of care.
- Recommend changes in policy, services or staff, or voice a complaint or concern to management without concern of discrimination, reprisal, or unreasonable interruption of services. You also have the right to have your complaint heard, reviewed and, if possible, resolved.

- Be informed by staff that you may file a complaint, if not resolved, including concerns regarding the implementation of advance directives, to the State Department of Health Services, Division of Primary Care and Home Health, 132 Kline Plaza Suite-A, Harrisburg, PA, 17104, in writing or by calling a toll-free home health hotline 1-800-222-0989, Monday through Friday, 8:30 a.m. to 4:30 p.m.

Complaints or concerns may be reported to:

Administrator or any nursing manager by calling: **800-557-7570**

Confidentiality of Records/Access to Records

Life Choice Hospice policy requires that all clinical records are confidential and available only to authorized personnel, clients and those authorized by law.

Your Responsibilities as a Patient

As a patient, you have certain basic responsibilities. These responsibilities pertain to the legal guardian, if the patient is legally incompetent or a minor. You have the responsibility to:

- Remain under a licensed physician's care while receiving services.
- Give accurate and complete information about past illnesses, hospital stays, allergies, use of medicines, insurance coverage and other issues pertaining to your receipt of services. You must also report any changes about the above to the staff.
- Contact our office if you are hospitalized, cannot keep an appointment or have changes in address or phone number.
- Report to the staff any changes in medical treatments or medications made by your physician or specialist.
- Provide a copy of an advance directive, or a living will, and the name of your healthcare agent for healthcare, if available, to the agency and your physician. An advance directive does not substitute for talking with your doctor. Only your doctor can write an order for your wishes to be carried out. We encourage you to discuss advance directives with your doctor and family.

- Provide requested insurance and financial information, the name of your power of attorney and sign required consents and releases. Changes in insurance coverage should be brought to the attention of the office staff to facilitate proper billing procedures. If you fail to notify office staff, you may be financially responsible for services performed and/or supplies.
- Assume financial responsibility for all services rendered either through third-party payers or personal responsibility for services not covered by insurance including, but not limited to, co-payments and deductibles.
- Accept the responsibility for any refusal of treatment.
- Abide by agency policies which restrict duties our staff may perform. Staff may not transport patients in any vehicle, work for patients privately on their time off or accept gifts, loans or money, or borrow or buy anything from you.
- Cooperate with your physician and our staff by following instructions and by asking questions about directions and/or treatments you do not understand. If you believe that you cannot follow through with any aspect of your treatment, you need to discuss that with the staff and your physician.
- If at home, provide a safe home environment in which your care can be given. Cooperate in making adequate physical arrangements in your home to help allow for safe care. It is expected that you will not take drugs which have not been prescribed by your attending physician and that you will not complicate or endanger the healing process by consuming toxic substances during your admission.
- Treat agency staff with respect and consideration.
- Voice complaints or concerns regarding staff, services or policies. Notify the agency of missing or damaged property, money or valuables by contacting:

Jay McGuigan, Administrator
800-557-7570

Financial Concerns

Medicare Hospice Benefits

Who is eligible for Medicare hospice benefits?

Hospice care is covered under Medicare Part A (hospital insurance). You are eligible for Medicare hospice benefits when you meet all of the following conditions:

- You are eligible for Medicare Part A (hospital insurance), and
- Your doctor and the hospice medical director certify that you are terminally ill and probably have less than six months to live, and
- You sign a statement choosing hospice care instead of routine Medicare covered benefits for your terminal illness, and
- You receive care from a Medicare-approved hospice program

Please note: “traditional” Medicare will still pay for covered benefits for any health problems that are not related to your terminal illness. As this can be a difficult issue to sort through, for further explanation, please speak with your nurse.

What hospice services does the Medicare hospice benefit cover?

Medicare covers these hospice services and pays nearly all of their costs:

- Visits to and services provided by your doctor
- Nursing care
- Medical equipment (such as wheelchairs or walkers)
- Medical supplies (such as bandages and catheters)
- Drugs for symptom control and pain relief
- Short-term inpatient and respite care
- Home health aide and homemaker services
- Physical and other therapies when related to the primary diagnosis
- Social work services

What Services Are Not Covered?

When you choose hospice care, Medicare will not pay for any of the following:

- **Treatment to Cure Your Terminal Illness**

As a hospice patient, you receive comfort care to help you cope with your illness, not to cure it. Comfort care includes drugs for symptom control and pain relief, physical care, counseling and other hospice services. Hospice uses medicine, equipment and supplies to make you as comfortable and pain-free as possible. Under the hospice benefit, Medicare will not pay for treatment to cure your illness. You should talk with your doctor if you are thinking about possible ways to treat and cure your illness. As a hospice patient, you always have the right to stop hospice care and receive the “traditional” Medicare coverage you had before choosing hospice.

- **Care From Another Hospice**

Once you choose a hospice program and sign the enrollment forms, you must receive hospice services from that hospice program. You cannot receive hospice care from another hospice care provider, unless you officially change your hospice program. The only time another hospice can care for you is if you are traveling, and your hospice program arranges for another hospice to provide short-term care during your trip.

- **Care From Another Health Care Provider That the Hospice is Supposed to Give You**

All care that you receive for your terminal illness must be given by your hospice team. You cannot receive the same type of care from a different provider unless you change providers.

- **The Cost of Room and Board in a Nursing Facility or Hospice Residential Facility**

Room and board in a nursing home/facility or hospice residential home/facility are not covered by the Medicare hospice benefit. The cost of residential long-term care is typically paid by the individual, or through long-term care insurance, or Medicaid if the person is financially eligible.

In addition to homecare, the Medicare and Medicaid hospice benefits do cover short-term stays in a hospital, hospice facility and nursing facility. These short stays include respite care of up to five days, and general inpatient care when a person is admitted for pain or symptom management and is discharged when the pain and/or symptoms are under control.

This section was adapted from U.S. Department of Health and Human Services, Centers for Medicare & Medicaid Services, 7500 Security Boulevard, Baltimore, Maryland 21244-1850. Publication No. CMS 02154. Revised July 2003, Rights in Your Area. A copy of this Medicare booklet is provided along with this "Understanding Hospice" booklet and is available from Life Choice Hospice upon request. It is also directly available from Medicare.

Medicaid Hospice Benefits

Medicaid is health insurance that helps people who cannot afford to pay some or all of their medical bills. Medicaid is available to those individuals that meet the financial eligibility requirements set by their state law. Under Medicaid, like Medicare, there is a Hospice Benefit. The Medicaid Hospice Benefit is an optional benefit that individual states may choose to make available to people in the Medicaid program. Currently, 47 states, including Pennsylvania, have the Medicaid Hospice Benefit.

Generally the Medicaid Hospice Benefit covers the same services that the Medicare Hospice Benefit covers. However, there may be some differences, so it will be important for you to ask your hospice provider about the services provided under your state's Medicaid Hospice Benefit.

Private Insurance

Most private health insurance policies have a hospice benefit that includes some or all of the services provided under the Medicare and Medicaid Hospice Benefits.



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