

# HOSPICE in Long-Term Care Facilities



**Information for Individuals in Long-Term Care  
Facilities and Their Families**

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in  
Long-Term Care Facilities*

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To request additional copies, please  
contact:  
Maine Long-Term Care Ombudsman  
Program at (800) 499-0229 or (207) 621-1079

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# *Hospice in Long-Term Care Facilities*

## **Table of Contents**

- 3 What is Hospice?
- 4 What can Hospice do for me in a Long-Term Care Facility?
- 5 What can Hospice do for My Family and Caregivers in a Long-Term Care Facility?
- 5 Who is Eligible?
- 6 How is Hospice Paid for in a Long-Term Care Facility?
- 6 How is Room and Board paid for in a Long-Term Care Facility?
- 7 How to Enroll in Hospice
- 8 What Happens to My Medicare Part A Coverage
- 9 Hospice Discharge (Voluntary or Involuntary)
- 10 Ombudsman Assistance with Questions or Complaints
- 12 Transition from a Hospital to Long-Term Care Facility with Hospice
- 13 Resources

## *What is Hospice?*

**Hospice is care focused on maintaining dignity and quality of life for individuals with life-limiting illness.\***

Hospice care is based on the philosophy that at the end of your life, you deserve to have relief from pain and the distress of other physical symptoms. Your medical, social, and spiritual needs are met through the use of an interdisciplinary hospice team plus the staff at the long-term care facility.

### **Your team consists of these hospice caregivers:**

- Your doctor
- Hospice medical director
- Nurses
- Home health aide
- Social worker
- Chaplain
- Volunteer

**Hospice is about living.** Hospice care does not hasten nor prolong death. Hospice strengthens your role in making informed decisions about your care, or allows your designated legal representative to make those decisions.

\*Life-limiting illnesses included but are not limited to: heart disease, cancers, Alzheimer's, and related dementias.

## *What Can Hospice do for me in a Long-Term Care Facility?*

- Working as a team with your doctor and the long-term care staff, the goal will be to ensure that pain and other symptoms will be managed to maintain your comfort.
- There will be a reduced need for emergency room visits and hospitalizations.
- Trained volunteers will be able to provide help with reading, letter writing, companionship, and errands.
- The hospice chaplain, along with your own religious leader, will be available for additional spiritual care to decrease fears and concerns about the dying process while supporting your beliefs.
- The hospice staff is comfortable discussing end of life care; supporting your decisions and beliefs.
- The hospice program will provide additional staff to assist the long-term care staff in taking care of your medical, physical, emotional, and spiritual needs.

## *What Can Hospice do for My Family or Caregivers in a Long-Term Care Facility?*

- The hospice chaplain is available for spiritual support to address fears and concerns.
- The hospice social worker is available to listen and support family members as they deal with end-of-life concerns, and anticipate life without their loved one.
- Bereavement services are offered to your family and other caregivers for one year after your death.

## *Who is Eligible?*

Hospice services are for individuals and families with cancer, Alzheimer's disease/dementia, heart disease, and other life-limiting illnesses. Your doctor is required to certify that your life expectancy is six (6) months or less should your illness "run its normal course".

There are times that a person is on the hospice benefit longer than six months, if certain requirements are met.

## *How is Hospice Care Paid for in a Long-Term Care Facility?*

- Hospice is a benefit under Medicare.
- You do have to choose hospice care to receive the care.
- You also need to sign a statement agreeing to the terms of hospice care.
- The hospice benefit pays for the services of the hospice team members, medications related to your terminal illness, and any special equipment you might need (oxygen, special hospital bed).
- MaineCare and many private insurance policies have a hospice benefit.

## *How Is Room and Board paid for in a Long-Term Care Facility?*

Room and board is paid for by:

- MaineCare
- private funds
- long-term care insurance policy, if applicable.

## *How do I Enroll in Hospice?*

**Anyone can refer you to hospice.**

- You or your family can speak to your doctor, or you can have the staff contact your doctor. Your doctor will write an order for a hospice evaluation.
- If there is more than one hospice program in the area, the long-term care staff will give you a choice.
- Once you have selected a hospice program, a hospice nurse will visit you and your family to talk about their program.
- After the visit, the nurse will discuss your case with the hospice medical director and other members of their hospice team.
- When the decision is made that they can meet your needs, the nurse will return to have you fill out the paperwork.
- You and your family or caregivers will be invited to participate in a team meeting. During this meeting, a plan will be developed to address your needs.



## *What Happens to My Medicare Part A Coverage?*

- Medicare Part A may be used if you need it for a medical problem unrelated to your terminal illness (for example, if you had a cataract that you wanted removed to improve your eyesight).
- If you have been using Medicare Part A for the skilled nursing benefit (SNF), then you will need to give up this benefit under most circumstances.

## *What Happens to My Medicare Part D Coverage?*

- You can still use Medicare Part D to cover medications that are unrelated to your terminal illness.

## *Will I Have to Change My Doctor?*

- **No**, you and your doctor have a relationship and it's important for this relationship to continue.
- If you want to change doctors, you have that right. The staff along with your family and hospice team can help you with that process.

## *What Happens if I Decide I Don't Want Hospice Care any Longer?*

- You can tell the hospice nurse that you would like to discontinue your hospice benefit.
- Once that happens, the hospice staff will stop providing services.
- Your medications that hospice paid for will be covered by Medicare Part D. You may have to return any special equipment.
- If you want to re-enroll into the hospice benefit, the long-term care staff will contact your doctor and the hospice nurse. The hospice nurse will review the program with you and your family again.
- You will need to sign a new set of forms.

## *Can I be Discharged from the Hospice Program?*

**Medicare has certain requirements that the hospice team has to follow.**

- If the person's medical condition has stabilized to the point where there has been no physical decline from one certification period to another, then a decision has to be made about discharge.
- The decision to discharge is a tough one, so everyone is involved in the decision-making process.

*- continued on the next page*

- Discharge is a good thing because it means that you are now expected to live longer than the anticipated six (6) months.
- If your condition changes and your doctor feels your health is declining once again, you can go back onto the hospice program.

### *Can My Family be Involved in My Care?*

- **Yes**, the hospice program is based on family and caregiver participation. Everyone, including you, will be participating in developing the plan for your care.
- Hospice does not take the place of family. Hospice staff assists the family members with care.

### *What Happens if I Have a Complaint about My Care?*

- First, contact the hospice provider and/or the long-term care facility administrator to try to resolve the complaint.
- If you are uncomfortable talking with them about your complaint, or do not feel the complaint has been satisfactorily resolved, you can contact the **Maine Long-Term Care Ombudsman Program at (800) 499-0229 or (207) 621-1079** for assistance.

## *What Happens if I Have Trouble Accessing Hospice Care?*

You can contact the **Maine Long-Term Care Ombudsman Program** at **(800) 499-0229** or **(207) 621-1079** and request that they help you access hospice care.

### *What is an Ombudsman?*

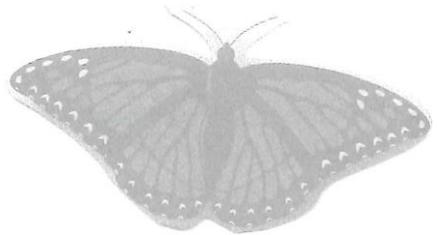
A Swedish word, Ombudsman (pronounced om-budz-man) is a specially-trained advocate who is given authority under federal and Maine law to investigate and resolve complaints made by, or on behalf, of people receiving long-term care or home care.

An Ombudsman:

- investigates and resolves complaints, and advocates for consumers with staff and hospice providers;
- educates consumers, families, and providers about consumer rights under the Medicare and MaineCare Hospice Benefit;
- guides consumers through the complex requirements of the Medicare and MaineCare Hospice Benefit;
- refers to the Maine Insurance Bureau if a private insurance policy is in question.

## *Can I Make a Decision about Hospice if I'm Waiting to Be Transferred from the Hospital to a Long-Term Care Facility?*

- If you are waiting in the hospital for a long-term care placement, your family, caregivers or you can discuss your wishes with your doctor, social worker or case manager. They can invite the hospice nurse to visit with you in the hospital, to answer questions.
- When you are ready for transfer, hospice services can start immediately.
- Remember, you have choice in selecting your hospice provider. In most circumstances, if you decide to use your hospice benefit, you will not be able to use your Medicare skilled-nursing benefit (SNF).
- You and your family need to make a decision about which program under Medicare Part A will work best for you. The hospital social worker or case manager can help you with this decision.
- If you have questions about the Medicare Hospice Benefit, or need assistance in finding hospice services, contact the Maine Hospice Council at (800) 438-5963 or Maine Long-Term Care Ombudsman Program at (800) 499-0229 or (207) 621-1079.



For further information or answers to questions, please contact the following:

- Maine Long-Term Care Ombudsman Program: (800) 499-0229 or (207) 621-1079.
- Office of Aging and Disability Services: (800) 262-2232.

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