



COMPASSIONATE CARE

OVERVIEW OF HOSPICE AND PALLIATIVE CARE

We hope this brochure can serve as a helpful, quick guide for you and your loved ones. For additional end-of-life planning information, please visit parmenterfoundation.org.



Hospice Care

Hospice is comprehensive, compassionate care for a seriously ill person, which includes physical, emotional, spiritual and bereavement care and support for the ill person's whole family. Hospice care helps patients living with a variety of medical conditions, such as cancer, heart disease, lung disease, dementia, stroke, and many others.

The purpose of this care is to help the patient and family live as well as possible, while managing pain and other symptoms of the illness. Care is **palliative**, that is, focused on **comfort** and not on seeking a cure, however a patient may stop hospice care and re-enter active curative treatment at any time. The priority of hospice care is **quality of life** for the ill person and family unit. The care is uniquely patient-centered and considers the needs of the entire family.

What is the difference?

Both hospice and palliative care are focused on **comfort** and the needs of the whole family. Both palliative and hospice care help patients living with a variety of medical conditions, such as cancer, heart disease, dementia, stroke, and many others. The main difference between hospice care and palliative care is that hospice is for patients with a limited lifespan. **Hospice is a type of palliative care** that addresses the unique needs of people with serious illnesses who are nearing or at the end of life. To put it simply, **all hospice care is palliative care, but not all palliative care is hospice**.

Palliative Care

Palliative care is for people at any stage of a serious illness, and their condition does not have to be incurable. Palliative care focuses on relieving pain and other symptoms, relieving emotional distress and improving the quality of life for both the patient and family. While receiving palliative care, a patient may also pursue curative or life-prolonging treatment.

A team of palliative care specialists, including doctors, nurses, social workers and chaplains, partners with a patient's primary physician/team and works as an added layer of support to develop a plan to address the goals of the patient and family. Some of the symptoms addressed include pain, shortness of breath, constipation, nausea, fatigue, depression, anxiety, and others. Palliative care may be provided in the hospital, in care facilities and at home. Care is covered by Medicare, Medicaid and most private health insurance.



When the focus of treatment shifts from curing illness to managing symptoms and seeking comfort and support, it is time to consider hospice care.

How Hospice Care Works

A team of hospice specialists including physicians, nurses, social workers, chaplains, hospice aides and volunteers work with a patient's primary physician to manage the patient's complex physical symptoms, improve his/her comfort, address the patient's and family's emotional and spiritual needs, educate the family about end of life and provide bereavement support to the family. Hospice care addresses physical symptoms including pain, shortness of breath, constipation, nausea, fatigue, anxiety, depression and others. Care is provided where the patient is: at home, in a nursing facility, in the hospital, or in a hospice facility. Hospice care is covered by Medicare, Medicaid (MassHealth) and most private health insurance.

Insurance

Most people receiving hospice care are covered by the **Medicare Hospice Benefit**. This benefit covers almost every aspect of hospice care with very little out-of-pocket expense to the patient or family. Most private health plans and Medicaid (MassHealth) also cover hospice services.

Who Is Eligible

Hospice is for people who are seriously ill and whose remaining lifespan is estimated at **six months or less**. Two (2) physicians, a hospice physician and a patient's physician, if there is one, must certify a patient's eligibility for hospice care. Eligibility for continued care is reassessed at time intervals specified by Medicare. A patient may continue receiving hospice care even if he or she lives longer than 6 months, as long as the hospice physician certifies that the patient still meets eligibility criteria for hospice care.

How to Begin

Anyone can initiate contact with a hospice program. A patient or family member may call a hospice to inquire about services or may call the patient's doctor to ask about hospice care and for a referral to a hospice program. Once a hospice nurse visits the patient and determines that he/she meets the hospice eligibility guidelines, hospice care can begin.

Choosing a Provider

There may be several hospices that provide care in a community, or perhaps only one. Patients and/or family members may seek out the opinions of those they trust, including doctors or other healthcare professionals, social workers, therapists, clergy, or neighbors or friends who have had experience with a hospice care provider. Websites may provide some information, but it is important to call, or even meet with providers to ask questions about their programs before making a decision. For a list of hospice providers in your area, consult the locator at Hospice & Palliative Care Federation of Massachusetts (hospicefed.org).

Included in Hospice Care

Depending on a patient's illness and related conditions, the plan of care a hospice team creates can include any or all of these services:

- Items needed for pain and symptom management, including prescription medications
- All medical, nursing and social services (i.e. social work support)
- Durable medical equipment such as a hospital bed, wheelchair, walker, commode etc.
- Most medical supplies, such as bandages and catheters
- Physical therapy services
- Occupational therapy services
- Speech-language pathology services
- Dietary counseling
- Personal care aide services
- Spiritual and grief counseling for the patient and family
- Volunteer support, if desired and available
- Short-term inpatient care for pain and symptom management
- Inpatient respite care

Some hospice care programs may provide additional complementary therapies such as:

- Pet therapy/visits
- Music therapy
- Art therapy
- Massage therapy
- Reiki (a type of energy therapy)
- Comfort Touch®
- Aromatherapy



NOT Included in Hospice Care

When signing on to hospice care, you will be notified of non-covered items, services and medications. Such items include:

- Anything unrelated to the patient's hospice diagnosis
- Any care that is not approved and arranged by the hospice care team
- Aides to care for a patient more often or for a longer time period than approved by the hospice care team
- Treatment at a hospital (or ambulance transportation) unless it is **unrelated** to the hospice diagnosis (such as a fall)
- Treatment and medications for curing the terminal illness
- Room and board at a care facility
- 24-hour continuous care, except in rare circumstances approved by a hospice care team

When a Patient Can Receive Hospice Care outside the Home

Short-term inpatient care may be approved for pain and symptoms that cannot be managed at home. This care must be provided in a Medicare-approved facility, such as a hospice facility, hospital, or skilled nursing facility that contracts with the hospice.

Inpatient respite care is also available so that caregivers can rest. A hospice provider arranges respite care for patients in a Medicare-approved facility, such as a hospice residence, hospital, or skilled nursing facility. Respite stays can be **up to 5 days** each time and can be offered on an occasional basis.

Note: If a patient/ family makes the decision to move the patient to a hospice residence or nursing home for care, Medicare continues to cover hospice services, but **does not cover room and board**.



The Primary Caregiver

Many assume that hospice provides all of the care for a patient. However, while a patient is receiving hospice care at home, **the patient's family unit remains the primary caregiver.**

The hospice team of specialists is involved in the treatment of a patient and educates the family about the patient's medical condition and how to care for the patient's needs.

A hospice nurse will visit the patient at least once every 14 days, and usually more frequently, as the patient's condition requires. A hospice aide may be assigned to visit in order to bathe and provide personal care for the patient, at intervals determined by the hospice team.

A family may decide to employ additional private in-home care at their own expense, and hospices can provide a list of local care agencies. It is important to remember that the main responsibility for caring for the patient remains with the family for as long as the patient is receiving hospice care at home.

Supporting Caregivers

Hospice care is patient-centered and the unit of care includes the family. Hospice specialists help patients and their families discuss their goals and make decisions about end-of-life care. The hospice team teaches the family how to care for their loved one and educates both the patient and family about the end of life.

Social services and spiritual support are offered to the patient and family, along with grief counseling during and after a patient's time in hospice care. Trained volunteers may visit a patient for companionship, and may provide a short respite visit for a caregiver, help pick up groceries and run other errands.

Other Help for Caregivers

Massachusetts provides additional support and services for qualifying patients and families at minimal cost. Your hospice social worker can help connect you with available programs. Consult your town website and local Council on Aging for possible available services in your area.

Local community groups, houses of worship, family and friends can also be a vital resource for help during your loved one's illness and time receiving hospice care. Often, the caregiver's community and family network are eager to run errands, pick up groceries, and help with laundry, cooking and meals.

Hospice Social Workers

A hospice social worker can be helpful with a great variety of non-medical activities to support a patient and family. The social worker is available to the patient and family to discuss the emotional challenges of serious illness, help prioritize a patient's goals, provide grief support and help anticipate needs and problem-solve to decrease anxiety and stress.

The social worker can assist with healthcare decisions, advance care planning and directives, legal matters and access to other community resources. Other tasks commonly undertaken by social workers include facilitating family meetings and discussions, funeral planning, applying for Medicaid, transfers to or from a nursing facility, help navigating bill payment issues, immigration issues and more.

24/7 Care

Hospice care is available "on call" after the administrative office has closed, seven days a week, 24 hours a day. Hospices are required to have nurses available to respond to a call for help within minutes, if necessary. Some hospice programs have chaplains and social workers on call as well.

Hospice Chaplains

The chaplain or spiritual counselor provides an additional layer of support for patients and families. People of all faiths or no specific faith can request visits from the spiritual care member of the hospice team. Hospice chaplains or spiritual counselors are non-denominational and their involvement with a patient and family does not need to be religion-focused. They are trained to help patients and families discuss issues such as fear, loss, forgiveness, anger or spiritual questioning. They can arrange a visit by a local rabbi, priest or minister if requested. They can also provide companionship, facilitate family discussions and provide emotional support to the patient and family.



Palliative and Hospice Care for Children

In Massachusetts, the Pediatric Palliative Care Network (PPCN) was created to ensure access to **palliative care** services for any child up to their 19th birthday, who has a life-threatening illness that could limit normal life expectancy. There is no requirement that a child have a 6-month prognosis and patients may receive curative treatment at the same time (concurrent care). Pediatric palliative care, also called Pedi Pal, is provided by community-based hospice organizations that are contracted by The Massachusetts Department of Public Health. The Pedi Pal program is a state-funded program free of cost to families. There are no income limits or citizenship requirements.

Pediatric palliative care specialists provide an extra layer of support to the family and work alongside a child's existing medical team to enable the family to care for their child at home. Comprehensive care is offered to meet the complex medical, nursing, psychosocial and spiritual needs of the child and the entire family. The care team coordinates all aspects of a child's care, often relieving families of the need to make frequent, stressful hospital visits. Additional services, such as music and art therapy are available and child life specialists can support the child and any other children in the home. If a child needs to be hospitalized, some larger hospitals can provide pediatric palliative care during the course of a hospitalization.

All health plans in Massachusetts, including MassHealth and private insurers, include a pediatric **hospice benefit**. Coverage for services is insurance provider-specific, so care must be taken to work with a child's insurer to understand coverage limitations, age requirements and deductibles. Generally, pediatric **hospice** services are covered for children and youth up to their 19th birthday. Children must have a 6-month prognosis, however they may also receive curative or other treatment at the same time (concurrent care). Coverage provided by MassHealth is usually more comprehensive and follows Medicare guidelines.

The MetroWest Boston area is primarily served by 2 hospice organizations that provide palliative and hospice care for children at home:

[Care Dimensions Pediatric Hospice](http://caredimensions.org) - Care Dimensions (caredimensions.org)

[Good Shepherd Community Care Programs](http://gscommunitycare.org) - Good Shepherd Pedi Pal (gscommunitycare.org).

For possible additional providers, consult the locator at:

[Hospice & Palliative Care Federation of Massachusetts](http://hospicefed.org) (hospicefed.org).