



Hospice & Palliative Care Network OF MARYLAND

Hospice and Palliative Care FAQ's

Frequently Asked Questions

Hospice and palliative care are philosophies of care. The two practices share the same core principles. The Network's mission is to promote the provision of quality hospice and palliative care in Maryland. Delivered by teams of clinicians, volunteers, and, if desired, faith based leaders, hospice and palliative care services offer medical care, pain relief and most importantly - hope.

Q: What is hospice?

A: Hospice is not always a place – but rather, a philosophy of care (including palliative care) extended to patients and families approaching the final months of life. When the cure of a serious illness is no longer an achievable goal, hospice professionals partner with a patient and family members to promote physical, emotional and spiritual comfort. Hospice care is most often provided wherever a patient calls home, surrounded by family, friends and memories.

Q: What is palliative care?

A: Palliative care provides relief from the pain and symptoms associated with a serious illness. Care may be provided and/or managed by an advanced practice nurse (one who has achieved additional medical training and education) or, a physician who has achieved certification in hospice and palliative care.

Palliative care is appropriate during any phase of a serious illness, the goal of which is to empower the patient (and family) to enjoy the best possible quality of life.

Q: What is the difference between hospice and palliative care?

A: There are more similarities than differences between hospice and palliative care. Palliative care is appropriate for those living with the complications of chronic illness, as well as for the frail or elderly. Hospice is an appropriate choice when the focus of the illness turns to comfort - and closure - during the final months of life.

Palliative care focuses on pain relief, and is appropriate during any phase while coping with a life limiting illness. Hospice care is often provided when a patient's diagnosis is measured in months, instead of years.

Q: Are hospice services only appropriate for people who are coping with the final days (very end) of life?

A: No. Hospice services provide resources, education and guidance as early as the diagnosis of a serious illness. As the disease progresses, hospice providers can walk alongside a patient and family to match the level of care and comfort required.

Q: What services/caregivers does hospice provide?

A: The interdisciplinary team of clinicians, hospice professionals, volunteers, and clergy members provide physical, emotional and spiritual support to patients and families navigating the final stages of a serious illness. Team members typically include:

Medical Director:

Each hospice employs a medical director responsible for the overall medical component of the hospice's patient care program. He or she is called to ensure each patient receives the appropriate medication and care necessary to control the symptoms of the disease. The medical director will serve as the patient's advocate in the absence of the attending physician, or, when the attending physician's perspective is not in harmony with the hospice's philosophy.

Attending Physician:

An attending physician leads the patient's care team. He or she works closely with the hospice medical director and other hospice professionals to create a plan of care consistent with the patient's and family's wishes. If a patient does not designate an attending physician, hospice providers will do so.

Registered Nurse:

A registered nurse coordinates the care provided by the hospice team. Experts in pain relief and symptom management, hospice nurses work with the care team to promote physical, emotional and spiritual comfort for the patient and family. Hospice nurses offer training and education to family caregivers, nursing assistants, and others in the areas of medication management, patient safety, and day-to-day care. The hospice nurse also coordinates the delivery of supplies and equipment needed to manage the patient's physical needs in the home environment.

Social Workers:

Social workers provide advocacy to the patient and family during this sensitive time, helping navigate important decisions and facilitate communication. Skilled in lending emotional counseling and psychological support, social workers point patients and families to appropriate information regarding insurance coverage, financial assistance, and community resources to complement care.

Clergy:

Many hospice services partner with members of the faith community across all denominations to provide spiritual counseling, support and visitation to patients and families. Often, clergy work onsite where hospice care is provided in a hospital, nursing home or assisted living center.

Volunteers:

Volunteers are vital members of the hospice team. They assist families with the varied responsibilities involved with caring for a loved one at end-of-life. Hospice volunteers provide companionship, help with shopping and errands, extend respite for primary care givers, and more. Hospice volunteers receive extensive training to understand the special needs of patients and families.

Hospice Aides:

Hospice aides bring skills to address the basic care needs of patients. The plan of care (composed by the hospice nurse) is based on the specific needs of each patient, and may include bathing, feeding, dressing, light housekeeping, and more.

Therapists:

Occupational, speech, and physical therapists are often recommended to assist the patient in maintaining optimal physical functionality and safety.

Pharmacist:

A hospice pharmacist determines the appropriate dosage, strength, quantity, and frequency of medication to relieve the pain associated with a serious illness. Hospice nurses typically administer medication, and often train family caregivers to work in tandem.

Bereavement Counselors:

Family members and friends of a patient coping with the end-of-life often require their own support system. Bereavement counseling and services vary according to hospice programs, but are typically available to family and friends of the deceased - and the broader community - for up to 13 months following the death of a loved one. Most programs are designed to support the bereaved through the year of "firsts" - celebrations, birthdays, anniversaries and seasonal holidays without a loved one. Support is delivered across varied disciplines such as one-on-one counseling, support groups, educational forums, and retreats.

Q: Who makes decisions for hospice patients?

A: A patient enrolled in hospice makes decisions for him or herself until the time that he or she is no longer able. Patients are strongly encouraged to designate a health care agent ([link](#)). Typically, this person is a family member or close friend who understands and supports the choices and preferences, and promises to communicate decisions on the patient's behalf when they are no longer able.

In the state of Maryland, the surrogacy law is very clear ([link](#)) as to who has the authority to make decisions on a patient's behalf if a health care agent is not appointed. Additionally, patients are encouraged to compose an advanced care directive . These legal documents outline instructions for doctors and family members in making critical health care decisions when a patient is no longer able. Communicating wishes in writing ensures that they will be respected and honored.

Q: Who pays for hospice services?

A: Care provided by hospice services is fully covered by Medicare, Medicaid, and most private insurers. A full explanation of coverage should be made available to the patient during an initial visit by the hospice team if insurance information has been provided prior. Many hospice organizations are non-profit, and will provide care regardless of an individual's ability to pay . Financial policies, however, vary by organization.

Q: Where hospice services are provided?

A: Hospice care is provided primarily (about 90% of the time) wherever the patient calls home. This may be a private residence, a nursing home, an assisted living community, or a residential hospice house. The primary goal of care is to ensure the patient enjoys the best possible quality of life, in close proximity to loved ones.

Periodically, a patient may develop a symptom that requires frequent nursing assessment that exceeds the level of care available at home. Two care options are available to address these changing needs. The first is to transfer the patient to a hospital or an inpatient hospice facility (not every program has one) for acute inpatient hospice. A second option is to initiate continuous care. In this instance the hospice will provide an interdisciplinary team member to be present with the patient in the home setting until the symptom is resolved.

On occasion, family members need a break from care giving responsibilities. Perhaps to attend to personal business or health concerns, accommodate travel out of town, or simply to catch up on rest, and refuel. Respite care for the patient is typically available for up to five days to allow a caregiver to take a well-deserved break. Respite care may be provided in a hospice inpatient facility, or, at a hospice or nursing facility with which the hospice has a contractual arrangement. Respite care can be utilized more than once.

Q: When is the right time to inquire about hospice services?

A: Commonly, a patient is eligible for hospice services when the patient's goal has changed from pursuing treatment and/or a cure, to comfort and care; or when the life expectancy is measured in months rather than years.

Transitions in care are more integrated now than during an earlier point in history. Today, patients may receive active disease treatment, not for curative intent, but to assertively manage symptoms while concurrently receiving hospice services. Every hospice program has specific admission criteria and guidelines. Please ask for assistance. They're there to help you make the best choice.

Generally, most hospice providers expect the following:

The patient's medical prognosis has progressed to the final stages. This means the attending physician has determined medical intervention is no longer effective in curing the disease.

The patient's life expectancy is now measured in months, if the disease follows its normal course.

The patient/family has made a decision to cease curative treatment, and is ready to shift the focus to comfort and care.

The patient has an attending physician who agrees to a comfort oriented approach to care and agrees to collaborate with the hospice team.

The patient lives within the geographic location served by the local hospice program.

Q: How do we know the best hospice care provider to choose?

A: The Hospice & Palliative Network of Maryland (HPCNM) does not endorse one program or service over another. The state of Maryland is a "certificate of need" state, so programs can provide care according to geographic location. It is important to ask which programs serve your area. Other key questions to pose include: Is this program Medicare certified? Is the program accredited by an outside organization such as The Joint Commission or Chaps. What percentage of the hospice's staff is certified in hospice and palliative care? Will the hospice make a visit to explain services and the cost of care?

Q: What equipment is needed at home when caring for a hospice patient?

A: Patients may require home medical equipment such as hospital beds, oxygen delivery systems, a wheelchair or a walker, or, a bedside commode. All necessary equipment is ordered by the hospice care team, and covered under most insurance plans.

Q: How can we manage pain when nothing works?

A: Pain management is a priority for the entire hospice team. This is what hospice does best. Hospice care teams and pharmacists work together to tailor a medication plan specific to the type and intensity of pain with which the patient is coping. Pain management plans often require adjustment to maintain comfort as the disease progresses.

Your hospice nurse will be able to anticipate patient needs and communicate with the physician regularly to ensure that requirements for medications are met. Hospice staff members are available 24-hours a day to answer questions and guide care to manage symptoms.

Q: If my child is diagnosed with a serious illness, where can I find help? Can we pursue curative care and hospice care?

A: Pediatric professionals blend the care of seriously ill children perhaps even better than their adult counterparts. Children often continue to receive aggressive treatment of their disease while receiving the support of the hospice team at home. This is referred to as "concurrent" care, and allows established care providers to invite the expertise of the hospice staff to the care team members that support the child and family. Not every hospice program is staffed with pediatric providers. This is an important question to ask when hospice services are being considered.

Q: What if a hospice patient’s condition improves?

A: If a hospice patient’s condition improves or stabilizes, the patient may be recommended for discharge from hospice care until a time when his/her condition requires resuming care. Being discharged or ‘graduating’ from hospice does not in any way pose a barrier to accessing services at a later point in time.

Q: Are there situations where family members do not want to share with their loved one they are under hospice care?

A: Well-intentioned family members sometimes want to protect loved ones from hearing difficult news. While we want to honor the integrity of the family’s wishes, our mission is to empower everyone involved with information. People who are seriously ill often feel more secure, respected and affirmed when they understand their prognosis. Hospice team members can help family members navigate those conversations.

Q: Does a family member who is caring for a hospice patient have rights to time off work?

A: Under the Family Medical & Medical Leave Act (FMLA), employees are entitled to a certain amount of unpaid leave, with benefits intact, to care for a family member in need. Check with your employer for your company’s policy.

Q: How is HPCNM funded?

A: As a 501©3, non-profit member organization, the Network receives financial support from membership dues paid by the hospice and palliative care organizations we support. Further, HPCNM depends on the generosity of private donations. If you would like to make a donation, please visit our website at www.hnmd.org, or mail your tax-deductible donation to:

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