Frequently Asked Questions about
Pediatric Hospice and Pediatric Palliative Care

Developed by the New Jersey Hospice and Palliative Care Organization Pediatric Council

Items marked with an (H) discuss hospice care. Items marked with (PC) discuss palliative care.

1. What is hospice care? (H)

Considered to be the model for quality, compassionate care for people facing a life-limiting illness or injury, hospice and palliative care both involve a team-oriented approach to expert medical care, pain management and emotional/spiritual support expressly tailored to the person’s needs and wishes. Support is provided to the person's loved ones as well.

Hospice believes that each of us has the right to die pain-free and with dignity, and that our loved ones will receive the necessary support to allow us to do so.

- Hospice focuses on caring, not curing. In most cases, care is provided in the person’s home.
- Hospice care also is provided in freestanding hospice centers, hospitals, nursing homes and other long-term care facilities.
- Hospice services are available to patients of any age, religion, race or illness.
- Hospice care is covered under Medicare, Medicaid, most private insurance plans, HMOs and other managed care organizations.

(Definition from National Hospice and Palliative Care Organization)

2. What is palliative care? (PC)

To palliate means to make comfortable by treating a person’s symptoms from an illness. Hospice and palliative care both focus on helping a person be comfortable by addressing issues causing physical or emotional pain or suffering. Hospice and other palliative care providers have teams of people working together to provide care. The goals of palliative care are to improve the quality of a seriously ill person’s life and to support that person and his/her family during and after treatment.

Hospice focuses on relieving symptoms and supporting patients with a life expectancy of months not years, and providing support to their families. Palliative care, however, may be given at any time during a person’s illness, from diagnosis onward. Most hospices have a set of defined services, team members and rules and regulations. Some hospices provide palliative care as a separate program or service from hospice.

(Definition from National Hospice and Palliative Care Organization)

3. “What does hospice care provide and what will they do?”

“Who will be involved in my child’s care?”
“What can hospice do for my child and my family?” (H)
Hospice provides an interdisciplinary team of professionals who will work with your child, your family and your physician. The team will provide skilled care focused on keeping your child and family as comfortable as possible and will assist in maximizing your child’s and family’s quality of life by working with child and family to identify realistic goals.

More specifically:

- A registered nurse will act as case manager to coordinate the plan of care with the interdisciplinary team. Nurses will visit regularly to monitor the child’s condition and work with your doctor to modify the plan of care as needed to keep the child comfortable. The nurse will also teach you to provide the necessary care, answer questions about the child’s symptoms or changing condition and provide support during difficult decision making and crisis periods. The hospice nurse is available to officially declare the death without the need for emergency services. A hospice nurse is available 24 hours a day, seven days a week.

- Social workers are available to assess how the child and family are managing physically, emotionally and financially. The social worker can help with issues related to coping, decision making and communication and as well as assist in accessing community resources if needed. Social workers or others can also provide bereavement counseling.

- Hospice aides assist in providing physical care for the child and free up time for caregivers to meet personal responsibilities.

- Chaplains are available to provide spiritual counseling. The chaplain provides open, non-judgmental listening and appropriate intervention according to the family’s needs, spiritual/cultural traditions, and values. If the family desires, the chaplain can assist families to connect with clergy of their own faith, and can assist with making arrangements or officiating at funeral or memorial services.

- Medical equipment will be provided (e.g. hospital bed, wheelchair, oxygen, etc.).

- Medications related to the terminal illness and for symptom control will be provided.

- Access to specialized therapies and services (such as physical therapy, occupational therapy and nutritionists) as needed, depending on the child’s condition.

- Hospice physicians will work with the child’s own physician to provide expertise in pain and symptom management and end of life care if needed.

- Volunteers provide a variety of services, such as spending time with the ill child while primary caretakers run errands or meet other responsibilities. Volunteers may also participate in activities that provide meaning and enjoyment, such as playing a game or reading a book to your child.

4. Where is hospice care provided? (H)

Most hospice care is provided at the child’s home or wherever the child is receiving care. If at some time during your child’s care there is a symptom that is difficult to manage, or if you are very stressed and need a short break from caring for your child at home, short term hospitalization may be arranged. Respite care may also be an option.

5. What is “inpatient” hospice care? (H)

Inpatient hospice care refers to hospice care that is provided in a hospital setting or in an inpatient hospice unit. This level of care is for a short period of time, and typically only when a patient’s symptoms are difficult to manage at home; the team develops a plan for comfort and return to the home.

6. What does “pediatric” mean? (H, PC)
Pediatric means “pertaining to infants and children.”

7. How does pediatric hospice differ from adult hospice? (H)

Typically, hospice services are focused on adult care. Some hospices are well equipped to care for pediatric patients; others may lack the expertise and specialized resources to do so. Pediatric hospice services are provided by staff who have the skills and experience to recognize and meet the unique needs of seriously ill children and their families.

8. Why should we choose palliative care? (PC)

Palliative care is an approach to care in which an interdisciplinary team of professionals will work with your child, your family and your physician to provide skilled care that will be focused on keeping your child and family as comfortable as possible. The team will assist in maximizing the quality of life of your child and family by working with child and family to identify realistic goals. Palliative care is appropriate for any child with a complex chronic illness and complements with the medical management of child’s condition.

9. How can palliative care help my child and my family? (PC)

The palliative care interdisciplinary team can help you and your family keep your child comfortable throughout the course of his/her illness or treatment in many ways. More specifically:

- A registered nurse will act as case manager to coordinate the plan of care for your child with you, your child’s physician and the interdisciplinary team. Nurses will monitor your child’s condition, teach you how to provide care for your child, answer questions about your child’s symptoms and changing condition and provide support during difficult decision making and crisis periods.
- A social worker will assess how your child, you and your family are managing physically and emotionally. The social worker can help with issues related to coping, decision making and communication. The social worker can also assist in accessing community resources if needed.
- Home health aides assist in providing physical care for your child and provide some respite care for you to be able to meet personal and other family responsibilities.
- Chaplains are available to provide spiritual counseling. The chaplain provides open, non-judgmental listening and appropriate intervention according to the family’s needs, spiritual/cultural traditions and values. If the family desires, the chaplain can assist families to connect with clergy of their own faith.
- Volunteers provide a variety of services, such as staying with child while primary caretakers run errands or meet other responsibilities. Volunteers may also participate in activities that provide meaning and enjoyment, such as playing a game or reading a book to your child.

10. Who provides the care for my child? Who is “in charge” of my child’s care? (H, PC)

Both hospice and palliative care services involve an interdisciplinary team. It is the parents and child, working with their physician and the team, who determine goals of care and make decisions about the plan of care.
11. While on hospice, can my child still see his/her pediatrician, regular doctor or go to the clinic where he/she has been treated? If my child is on hospice, do I need to change doctors? (H)

Your child may continue to see their primary physician as often as necessary. The need for visits to specialists or consultants would be discussed upon admission to hospice program, or as there are changes in your child’s condition.

12. When is a referral for palliative care appropriate? (PC)

A referral for palliative care is appropriate any time after a child is diagnosed with an illness or condition that necessitates relief of the symptoms of suffering.

13. Who should determine if my child should receive hospice services? (H)

If your doctor determines that treatments will not restore or maintain your child’s health, hospice care may be suggested. If your doctor does not suggest hospice but you observe significant decline in your child’s condition, you should ask about being referred to hospice. If your child has already been receiving services from a palliative care program, the staff of that program can assist in accessing hospice services for your child and might even be able itself to provide hospice care.

14. Is hospice only for patients with cancer? (H)

No, hospice is available to anyone in need of end of life care, regardless of the type of illness.

15. Does being on hospice mean that my child is dying? (H)

Children are on hospice only if their physician believes, in his/her best medical judgment, that the child is likely to die of their illness and that there are no treatments available that can provide a cure, that a child’s illness is likely to progress and that child in is the last months of their life.

16. Can my child stay/die at home? (H)

Yes, if that is your choice. With hospice care, hospitalization would be considered only if needed to control symptoms that became difficult to manage at home. Once the symptoms are under control, the child could return home. Respite care may be an option for brief periods to provide families with a needed break.

17. Does choosing hospice mean that I am giving up hope? (H)

No, it does not mean that parents are giving up hope. Hope changes to a focus on symptom management and increased quality of life and time with family members. It does mean that while hoping for the best, parents are preparing for the worst and are putting in place a plan to keep their child as comfortable as possible. The hospice team will help the family care for the child, cope with changes that occur in the course of illness and prepare for the child’s death.
18. What does symptom management mean? (PC, H)

Symptom management is aggressive treatment for pain or any distressful symptom that develops as a result of illness or treatment to help keep your child as comfortable as possible.

19. Do I have to have a DNR (Do Not Resuscitate) in place to receive hospice or palliative care? (PC, H)

No, a DNR does not have to be in place to receive hospice or palliative care, but a DNR order complements hospice’s philosophy of neither extending or shortening lifespan through extraordinary means.

20. Do I have to choose between hospice and curative treatment for my child?

As of September 2010, children receiving benefits under Medicaid may continue to receive regular medical treatment for their illness even after they elected hospice care. For other children, parents should speak to their insurance company to determine coverage.

21. Who pays for hospice care? Does my insurance cover this care? (H)

Medicaid and most major insurance carriers pay for hospice care for minors. The hospice office will contact your insurance carrier to determine the services covered by your plan.

22. Who pays for palliative care? Does my insurance cover this care? (PC)

Coverage for palliative care services for children in the United States, and New Jersey specifically, is a work in progress. There is not a clear answer to this question because palliative care is a focus of care that considers what a child and family need to manage and live with a child’s chronic complex condition and families needs vary greatly in what is needed. Often a palliative care consult can be done during a hospitalization and recommendations made with reimbursement and coverage issues addressed at that time. A palliative care focus of care may be offered by home care agencies as part of the services already being provided by the agency and as needs are determined coverage and payment issues will be addressed. When inquiring about services available through different programs, you should ask about costs of care and coverage.

23. How can I best help all my children -- my ill child as well as my other children? Does my child need to know the prognosis? How do I help my child understand? (H)

The pediatric hospice team considers your child and family as a unit of care. During your child’s illness, team members will provide supportive services to your child and your family members, including your other children. All family members should understand the ill child’s condition and the services being offered. The situation should be discussed with children in an age-appropriate manner. Children often comprehend and accept more than their parents think they do. Absence of information is sometimes more frightening than knowing the facts. Everyone should have the opportunity to ask questions and express their concerns and fears. The hospice team will provide support and guidance in working with you to determine how best to open up these lines of communication with your family members. The
social worker and nurse may be helpful in working with you on these issues. Some hospices have art therapists, child life specialists, pet therapy or music therapists to assist in helping children express their feelings and emotions.

After your child’s death under hospice care, bereavement support is offered to your family for at least 12 months. These services can take a variety of forms, including telephone calls, visits, support groups and written materials about grief. Individual counseling may be offered by the hospice or the hospice may make a referral to a community resource. Some agencies have bereavement services specifically designed for grieving children.

24. The doctor said “there is no more treatment” and I am afraid that I won’t know what to do if my child gets sicker at home. How would I find out what to do? (H)

While the doctor may believe that there is no more curative treatment to be offered, pediatric hospice programs aggressively treat the child’s symptoms, have a plan for managing symptoms that may develop and provide around the clock access to skilled nurses. Nurses can answer questions over the telephone for guidance or visit the home whenever necessary. The team also supports the family members emotionally -- if they are worried, upset or concerned about what to do for their child in a particular situation.

25. My child has many doctors but sometimes I get conflicting messages. How do I make decisions when I am confused? (PC, H)

The hospice or palliative care team will support informed decisions made about your child’s care by you and your doctors. The team can be very helpful to you by discussing the messages you are getting from your doctors and what they mean in terms of how the different choices would affect your child’s and your family’s quality of life. At times, the team can help you by answering your questions, by helping you figure out the questions you need to ask your child’s doctors so you can more fully understand their recommendations, or by participating in patient care discussions with you and your child’s doctors.

26. What do I do if my child is uncomfortable or in pain? (H)

There will always be a plan in place to manage pain or symptoms. You should contact your hospice nurse or on-call nurse at any time when your child is in pain or uncomfortable.

27. What is the need for pain management in children? (PC, H)

When serious illness causes pain and distressful symptoms, it is essential that health professionals with expertise in pain and symptom management work with parents in the care of their child. A child’s comfort is always a priority when quality of life is being defined -- adequate pain control is the first priority that must be met before the patient’s other life goals can even be addressed.

28. What do I do if there is an emergency? (H)

One of the priorities of the hospice team will be to help you understand your child’s condition, the meaning of any changes that occur and what you might expect to happen as your child’s disease progresses. Their goal is for you to be well prepared in terms of what to expect and what to do when various changes occur in your child’s condition. Of course, a child who is in pain or uncomfortable is considered a very urgent matter for the hospice team and a nurse is available 24 hours a day, seven days a week for advice by phone or a visit to your home if needed.
29. Why does the doctor think I need these services? (PC)
Physicians refer their patients for palliative care services when it is time to consider incorporating quality of life goals into the plan of care. This will ensure that they receive expert pain and symptom management, the medications and home care supplies needed as well as other supportive services to enhance quality of life. Counseling resources will be able to support you and your child in making personal choices that will affect quality of life.

30. Why do I/we need these services when we take care of our own child? (PC, H)
These services assist and support families in caring for their ill child. Supportive care and counseling can help families deal with the many social, spiritual and psychosocial needs that often come with caring for a seriously ill child.

31. What is the availability of pediatric hospice services? (H)
Specialized pediatric hospice programs may or may not be available in your area. There may also be some pediatric home care or palliative care programs in your area that are not specifically affiliated with a hospice, but which may have expertise in providing the care that your child needs. Your state hospice agency (NJHPCO in New Jersey) can assist you in finding resources in your area – click here for a list of hospices in New Jersey that have self-identified their capacity to provide pediatric hospice.

32. How can I find out about pediatric palliative care in my community? (PC)
The availability of pediatric palliative care services will vary from community to community. Your child’s physician or hospice may be able to help you identify these resources. For further assistance, feel free to contact NJHPCO at 908-233-0060.

33. How does my child get admitted to services? How is a referral made? (H, PC)
Admission to a hospice or palliative care program begins with a referral from your child’s physician. Once the referral has been made, a member of the team (most likely a nurse or social worker) will contact you to set up a time to meet, discuss your needs, answer your questions and develop a plan to care for your child. As a parent, you may certainly contact agencies about their services and how they might help your child and family. The agency may be able to help obtain the needed referral from your child’s physician.