Understanding Palliative Care and Hospice Care



🗱 INTRODUCTION

At some time during your child's illness a clinician may suggest a palliative care consult. You may or may not have heard the term palliative care, and you may worry about what this means.

In the United States, pediatric palliative care (PPC) is different from hospice care. PPC can include, but is not only about, end-of-life care. This guide will introduce you to these two specialties: how they are alike and how they are different.

Palliative Care

Palliative care is an extra layer of support that focuses on the psychological, social and emotional well-being of the child and family. It also addresses physical symptoms that may be particularly hard to treat. The goal is always comfort and relief of suffering.

If or when palliative care is recommended, it does not necessarily mean that your child is dying or likely to die. **Palliative care can be provided at the same time as treatments hoped to be curative for your child's illness.** It has been shown to improve quality of life, and helps your child live as fully as possible for as long as possible.

If your child has a serious illness with an uncertain outcome, you or your child's provider may feel that you may benefit from meeting with a palliative care specialist. Palliative care clinicians are specialists in thinking "out of the box" and looking at ways to support your child and family

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holistically. The PPC team offers strategies for symptom management, whether it is for physical or psychosocial distress; they offer ideas for making each day be as good as it can be; they offer guidance for clearly communicating with all of your child's providers. The team may follow your child to different inpatient units, to clinics, a private practice and/or home.

Some children receive palliative care for many years. Some children receiving palliative care are cured or live long into adulthood. Some children receiving palliative care transition to hospice care *if* their condition worsens. Transitioning to hospice care allows for more services in the home.

Hospice Care

Hospice care is an extension of palliative care and focuses on end of life. For hospice enrollment, and to qualify for insurance coverage (private or Medicaid), a physician must certify that the child may die within the next six months if the disease follows its natural progression; however, this time limit can and often is renewed, especially because with children there is often much uncertainty about their prognosis or disease trajectory.

Hospice care is delivered through a specialized interdisciplinary team of professionals and hospice volunteers. Hospice most often provides care in the home, with members of the team coming for short visits that are coordinated with your schedule. The schedule can be flexible and you can decide how best to work with the team. Nurses are available on an on-call basis 24 hours a day, including weekends and holidays, to help problem-solve and to visit if needed.

Hospice pays for and secures any medication or equipment related to comfort, often delivering them to your home. Therefore, all medications, durable medical equipment, and medical supplies that are related to non-curative treatments are covered and managed by hospice.

Concurrent Care

In the past, when families selected hospice care they had to forgo disease-directed treatment. This meant that to qualify for hospice, the child could not also receive treatments to try and cure the disease. This changed in 2010 with the passage of federal legislation called the Concurrent Care for Children Requirement (CCCR). CCCR allows any child who is under 21 years of age and who is eligible for Medicaid or Children's Health Insurance Program (CHIP) to be enrolled in hospice and receive treatments that may be considered curative. Unlike adult hospice, pediatric hospice allows children to continue with all interventions and treatments while also getting the support of the whole hospice team for the child and family. When hospice is suggested for a child, it provides additional benefits for the whole family.

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How Are Palliative Care and Hospice Care Similar and Different?

What do palliative care and hospice care have in common? Both provide care to those with serious illness, to offer relief of complex symptoms and reduce suffering from physical and/or psychosocial distress. Both are provided **in addition to** treatments and interventions that your child is already receiving. Both provide support for the family as a whole, and coordinate closely with others as the family desires. Children can move between palliative care and hospice and even graduate from both. However, there are distinct differences between the two, illustrated here.

	Palliative Care	Hospice Care	Concurrent Care (Children enrolled in hospice who receive Medicaid are eligible for concurrent care)
When should it be considered?	Palliative care is an added layer of support offered to a child and family when a diagnosis of a serious illness with an uncertain outcome has been made. It may be offered at diagnosis or at any stage of the illness.	Hospice is offered when quality (not quantity) of life becomes the number one priority; when there are no further medical interventions to treat the underlying illness. The focus is on manage- ment of physical and psychosocial symptoms and suffering. Hospice requires a physician's order that a child has a life expectancy of less than six months if the disease follows its natural progression; however, this order may be renewed.	Concurrent care for children is part of the federal Affordable Health Care Act allow- ing children (under 21 years old) insured by state Medicaid or a Chil- dren's Health Insurance Program to be enrolled in hospice care while still receiving ongoing or new treatments that are disease-directed.
How does it work?	Palliative care is provided through a consultation with a specialized team or through your child's primary provider. Palliative care is con- cerned with the whole child (physical, emo- tional, spiritual) and the whole family.	Hospice is supportive care without curative intent, provided when the patient's disease is no longer responding to medical treatment or when the child/ family has elected not to pursue further disease-directed treat- ments.	A child must be enrolled in hospice services for concur- rent care to be in effect. A physician must certify that the child may possibly die within six months due to the serious illness; or, again, in certain states that timeframe may be extended.

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Who pays for the service?	Palliative care is paid for by insurance or in some states through a Medic- aid program or self-pay. Health insurance plans may differ.	All expenses related to the terminal diagnosis are covered by Medi- care, Medicaid and most private insurance.	Each state implements concurrent care differ- ently. This provision does not define treatments that are considered potentially curative and therefore are subject to interpretation. Your case manager or social worker will assist with this.
Where are services delivered?	Palliative care may be delivered in the hospital, in outpa- tients clinics or in the home by a community palliative care team.	Hospice is usually provided in the home. There are some hos- pice houses that are able to care for a child and family through the end of life.	
Who provides the care?	Palliative care is provided by special- ly-trained clinicians. The team may include physicians, nurses, so- cial workers, child-life specialists, chaplains?, music/art/or massage therapists.	Hospice care is pro- vided by an interdis- ciplinary team that comes to the home. This may include a physician, nurse, so- cial worker, chaplain, home health aide, bereavement special- ist, volunteers, and sometimes a child-life specialist, music and/ or massage therapist.	

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What are the services?	Palliative care teams usually do not provide direct medical care (e.g., writing prescrip- tions, ordering physical therapy, calling other specialists). The child keeps their primary care specialist and subspe- cialists.	The hospice team gen- erally becomes the sole provider of services such as nursing and medical equipment. The team may be a part of the same agency, and work with, the palliative care team. They also often work with the primary care provider to ensure continuity of care for the family.	
What is the benefit?	Focus is on quality of life, relief of distress- ing physical, spiritu- al and psychosocial symptoms	Hospice continues the palliative care plan and includes the option of increased visits and the ability to assess and treat the child's symptoms while remaining at home. Bereavement services are also offered before and after death.	



Hearing the term "palliative care" for the first time may feel scary or threatening. Some parents fear that accepting a palliative care consult or hospice service signals that they are giving up hope; however, hope is always present. Understanding the benefits of palliative and hospice care will allow you to access what best supports your child and family.

Resources:

Information for parents and professionals www.nhpco.org