Improving the Pediatric Cancer Care Experience with Palliative Support



Learning Objectives

After reviewing this Guide you will be able to:

- Recognize how palliative care can help your child and family
- Address concerns and preconceived notions about palliative care
- Understand how to request and advocate for palliative care support

Introduction to Pediatric Palliative Care (PPC)

Palliative care can be helpful to children and families regardless of prognosis, given its emphasis on promoting quality of life in the face of a serious illness. Children can receive potentially curative treatment and palliative care at the same time; in fact, PPC can be received as soon as the time of a diagnosis and throughout a child's treatment and beyond.

Pediatric palliative care is a medical specialty that focuses on addressing symptoms of physical and/or emotional suffering in children with serious illness and their families. PPC professionals are experts in communication. They can support you in defining and advocating for your priorities in your child's care, and facilitate conversations between you and the care team.

As one mom of a child with cancer said, "While her oncology team was working to solve for tomorrow, palliative care was working to solve for today."

For more on PPC, see the CPN Guide "Introduction to Pediatric Palliative Care": https://courageousparentsnetwork.org/quides/introduction-to-pediatric-palliative-care.



Benefits of Palliative Care in Pediatric Oncology

Palliative care, when integrated early, can support symptom management and promote quality of life for youth with cancer and their families throughout treatment.

Addressing Physical Symptoms and Side Effects

Cancer and its treatment can cause uncomfortable physical side effects, including nausea and vomiting, different types of pain, fatigue, weight loss, lower appetite, and other symptoms depending on the type of cancer and its associated treatment. It can be very challenging to watch your child struggling with symptoms and feeling unwell because of treatment you hope will deliver a cure.

Typically, your child's oncologist will prescribe medication to improve these symptoms. While many children respond well, unfortunately others may not experience relief. Unmanaged symptoms can cause distress for your child. You may also be upset when witnessing your child's discomfort. A pediatric palliative care provider can review your child's illness and treatment history, listen to your concerns, and collaborate with your child's care team to consider a range of symptom management options for improved relief.

Alleviating Anxiety and Distress

A pediatric cancer diagnosis is abrupt and shocking, disrupting the entire family. Your clinical team may speak about "existential distress." The experience of existential distress is different in every person but can include feelings of loss, meaning, purpose, hope; change in personal identity; a sense of isolation; spiritual questioning and/or worries about mortality; and fear of suffering or untimely death. Children and adolescents can face similar concerns, which they may communicate verbally or exhibit through changes in emotional or behavioral functioning. These will vary depending on the child's age, development, personality, and coping style. PPC providers understand that these reactions can be expected and they can provide a safe space to listen to and validate your concerns without judgment.

For more on spirituality, see the CPN Guide "Spirituality and Caregiving in Pediatric Illness": https://courageousparentsnetwork.org/guides/spirituality-and-caregiving-in-pediatric-illness.

Improving Family-Clinician Communication

Open and honest communication with your child's care team is an essential part of the cancer journey. It is important that you and your child understand the information presented to you, can ask questions without fear of judgement, and can share your concerns as they occur. At times during your child's treatment, you may feel unheard or confused by the many sources of information you are receiving from multiple teams. You may feel that different clinicians are not speaking with one another or that not everyone is "on the same page." Palliative care professionals can help with these concerns. They can convene meetings with all members of your child's care team to clarify information and help you and your child voice your preferences, values, and goals of care.

Promoting Shared Decision-Making

During the course of your child's illness you will be asked to consider options for treatments and to make decisions with your child's clinicians. These can include consenting to a standard treatment protocol, enrollment in a clinical trial, and/or considering options focused on managing symptoms and side effects. As some of these treatments have difficult side effects for your child, the decisions can feel especially hard. The palliative care team is a sounding board to explore these options and weigh the potential benefits and burdens of each approach. They can help you decide what is most important, given your child's condition and your family's goals. These may mean proceeding – or not – with proposed life-prolonging interventions, or making the loving decision together to transition to comfort care only. Conversations and decision-making based on your goals can help you feel more confident and minimize potential future regret for the decisions you have made.

For more on shared decision-making see the CPN Guide, "Framework for Sharing Decision-Making with Your Child's Clinicians": https://courageousparentsnetwork.org/ quides/framework-for-sharing-decision-making-with-your-childs-clinicians.

Supporting Siblings

Your child's illness journey will be a defining feature of their siblings' lives. While it will absolutely be challenging, with adequate support many siblings develop a deep sense of compassion, caring, and understanding for others through their experience.

There is no way to see inside to what a sibling might be feeling, and certainly not all siblings feel or experience things in the same way. Even those within the same family can have very different reactions to living with a sibling who they understand has a serious medical condition; and those reactions can change over time. Your palliative care provider can help

you find developmentally appropriate ways to communicate with your other children about their feelings and changes in their home life. They can also refer you to other clinicians, such as Child Life Specialists, who are skilled in supporting youth affected by illness. Do not hesitate to ask for their guidance.

Palliative Care and Hospice

A family might resist palliative care for their child, because they confuse palliative care with hospice care. Hospice care is for those individuals approaching the end of life, while palliative care can be helpful to children and families regardless of prognosis, given its emphasis on promoting quality of life. Some children receiving palliative care receive palliative care for many years and some are cured or live long into adulthood. For those children whose condition worsens, they may transition to hospice care towards the end of their lives.

To learn more about the differences between PPC and hospice care, see the CPN Guide "Palliative Care and Hospice Care: Understanding the Differences": https://courageous.parentsnetwork.org/guides/understanding-palliative-care-and-hospice-care.

Advocating for Palliative Care

If your child's oncology team does not refer your child for PPC, you can request this additional layer of support. Many hospitals where children are treated for cancer have pediatric palliative care providers and it can be helpful to have a team involved that is not directly responsible for the treatment or management of your child's cancer and other medical concerns. Your child's clinicians are rightfully focused on treating the cancer, whereas PPC clinicians are paying attention to the things that bring joy and meaning to you and your child. They ensure that your child is seen and honored as a whole person, and that you are seen and regarded as your child's #1 advocate.

It is possible that your child's clinical team will question your request for a PPC referral or say that your child does not "need" palliative care because they are in treatment. You can explain that you know that palliative care can be helpful with a number of family support needs (those mentioned above) and highlight that this service is important to improving the care for your child and family.

Conclusion

Pediatric palliative care providers build close relationships with your child and family, supporting you throughout every stage of your child's cancer journey. They are dedicated to easing your child's suffering through symptom relief and emotional support, and they can be invaluable allies in advocating for your child. With a comprehensive understanding of what matters most to you for your child, palliative care clinicians assist you in making decisions that align with your hopes and priorities for your child's care and for your family.