Pediatric Palliative Care

Pediatric palliative care is designed to support infants and children with serious illnesses and their families.

What Is Palliative Care?
Because each disease, patient, and family is unique, palliative care will also look different from case to case. The first meeting with a palliative care team often starts with, “Tell me about your child.” The team may want to know more about what things bring joy to a child, sources of suffering, and how the child and the family are coping. Palliative care teams offer expertise in complex symptom management and communication. The palliative care team strives to be an extra layer of support, especially as health conditions change and tough medical decisions may arise.

How Does a Palliative Care Team Get Involved?
Palliative care is a subspecialty team, and patients are typically referred by other physicians. The referral may be made at any age or stage of illness. At some centers, palliative care may meet with parents prenatally if an infant is expected to have a serious illness. Because serious illnesses can mean many things, palliative care may become involved at the diagnosis of an illness or later, after a patient has had signs of decline (including hard-to-manage symptoms).

Common Members of the Palliative Care Team
Teams may vary by hospital, but common palliative care team members include physicians, nurse practitioners, nurses, social workers, chaplains, and child life specialists. Each of these team members has special training and a common focus of addressing suffering and coping.

Elements of Palliative Care
One of the overall goals of palliative care is to maximize meaningful experiences and minimize the suffering of children and families facing serious illness. A lot of palliative care is focused on open communication, including discussions about hopes, worries, and goals of care. The palliative care team may revisit these discussions as the illness changes over time. Once the team better understands a child and their family, they can advocate for their needs, such as for intensive symptom management or improved collaboration with the medical teams. Palliative care teams help anticipate and prepare for worst case scenarios so that families are not making tough decisions in a moment of crisis.

Clearing Up Some Common Misconceptions
Palliative care is not the same as hospice. Hospice care is a healthcare program designed for patients who likely have a prognosis of less than 6 months to live. Hospice care is predominantly focused on patient comfort and time outside the hospital. Palliative care can include hospice (at one end of the spectrum) but is often involved much earlier in an illness and can be for those still pursuing disease-directed treatments.

Palliative care is not about giving up nor does it mean there is nothing more to do. Palliative care recognizes that there are still some limits to what medicine can achieve and that there is a difference between interventions that are done to a child rather than for a child. However, palliative care clinicians continue to hope for the best while helping to prepare for the rest. The team hopes to understand the child’s and family’s goals so they can live the way they want to.

FOR MORE INFORMATION
Palliative care: https://getpalliativecare.org/whatis/pediatric/