

People often say that being a parent is the hardest job. For parents or caregivers of children diagnosed with a serious medical condition, the job of parent/caregiver takes on a set of unique challenges. These caregivers are faced with having to deal with some of the most difficult questions. Questions like, “Am I making the best decisions for my child?” “How do I best address my child’s pain/discomfort?” “When do we stop pursuing interventions?” and “How are we going to get through this.” It is questions like these that make having an extra layer of support within a medical team, incredibly helpful. This extra layer of support can come in the form of a palliative care team. Yes, palliative care is for kids too!

Many may think of palliative care and associate it with adults and the end stages of an illness, but palliative care is for all people living with a serious illness, regardless of age and regardless of the stage of the illness. It seeks to address and provide relief to symptoms brought on by the illness, as well as tend to the needs of both the patient and the full family unit. Illness does not discriminate by age, and neither does palliative care. Pediatric palliative care works to address the pain and suffering of the youngest members of our society, and their families.

As noted above, illness does not discriminate by age. According to the CDC¹, congenital and serious illnesses were among the leading causes of death in children in the United States under the age of 14 from 1999-2020. The top diagnoses included congenital disorders, cancer, respiratory diseases, and heart diseases. While this statistic focuses on what led to these children’s death, the more important point to take note of is that these children *lived* with these illnesses. They lived with illnesses that may have meant, among other things, that they endured frequent medical appointments, numerous hospitalizations, and countless procedures. They lived with illnesses that caused their caregivers to ask those difficult questions highlighted above.

Many caregivers have hopes and dreams for their child’s life. When their child is faced with a serious illness, some of these hopes become out of reach while others remain. These may include the hope that your child is comfortable and does not suffer, that they experience joy, or that they are known by their family. These hopes, or goals, can guide a family as they navigate decisions along their child’s medical journey. Each decision that caregivers make impacts how their child is living, what their quality of life is like. Quality of life is not any one thing, but rather, is subjective and based on a family’s goals for their child. Palliative care in pediatrics aims to walk alongside families as they are faced with decisions regarding the medical care for their child. It aims to listen to families, to support them, to address not only their child’s suffering, but their suffering as well. It seeks to look beyond the diagnosis, and focus on the child, who they are as an individual, and who they are to their family.

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¹ <https://www.cdc.gov/nchs/fastats/child-health.htm>