



# Complex Child E-Magazine

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## Choosing Palliative Care: Not Just for the Terminally Ill by Susan Agrawal

Most of us are familiar with Hospice Care for children and adults in the very last stages of life. But many families know less about Palliative Care, a similar specialty that may be extremely helpful for children with life-threatening chronic conditions whose quality of life is profoundly affected by their disorders. In my daughter's case, Palliative Care took her from a child who never smiled because of her constant pain and turned her back into a child who is thriving and enjoying life, despite the complexities of her condition.

### **What is Palliative Care?**

A paper advocating for its existence describes it as, "the science and art of lessening physical, psychosocial, emotional and existential suffering."<sup>1</sup> It is intended to be offered to children with life-threatening conditions from the moment of diagnosis all the way through the entire illness, regardless of whether the child dies or is cured. The American Academy of Pediatrics (AAP) position paper on Palliative Care emphasizes that death is very difficult to predict for many children, and Palliative Care should be offered to *all* children with life-threatening conditions.<sup>2</sup> It should not be reserved for children who are imminently dying or who have decided to stop pursuing curative medical care.

The most important thing to know about Palliative Care is that it is possible to receive full medical services, including treatments that may lead to a cure, while also receiving Palliative Care. Palliative Care is designed to improve the quality of life of the child, support the family, and help the child and family make difficult decisions about issues such as what treatments to try and which interventions are appropriate. As the AAP position paper states, "The goal is to add life to the child's years, not simply years to the child's life."<sup>3</sup>

A Palliative Care team typically includes one or more physicians, nurses, spiritual counselors or chaplains, and other professionals, such as music or art therapists, child life specialists, psychologists, and social workers. Palliative Care uses these specialists to treat the entire family, including siblings, and the child's extended "village," which might include other doctors, teachers, therapists, friends, classmates, or home nurses.

Palliative Care programs provide a variety of services. Some of these may be medical in nature, including alleviating pain and managing other symptoms that interfere with quality of life like nausea, vomiting, depression, and anxiety. Other services may include discussions with the family and child on what tests and treatments are appropriate. While some families will choose to try all types of testing, no matter how invasive, others may

choose to limit testing to noninvasive tests such as blood work or X-rays in order to reduce the child's suffering. Similarly, some families will decide to try very difficult treatments such as chemotherapy, while others will decide that invasive and debilitating treatments are not appropriate for their child. The doctors, nurses, and other professionals in a Palliative Care program can help families make these decisions, as well as write formalized Advanced Directives that lay out what emergency treatments the child will or will not receive. Other Palliative Care services include counseling, education, spiritual support, care coordination among the child's doctors, therapists, and nurses, specialized therapies like music and art therapy, and referral to services such as respite care or home nursing.

### **When should a family consider Palliative Care?**

Palliative Care is appropriate for any child with a life-threatening disorder, poor prognosis, or whose condition is severely impacting his or her quality of life. Most programs accept children with a wide variety of diagnoses, which may include advanced cancer, metabolic or mitochondrial diseases, end-stage renal failure, HIV, cystic fibrosis, advanced neurological disorders, certain genetic or congenital disorders, advanced gastrointestinal disorders, and other similar life-threatening conditions.

My daughter entered a Palliative Care program on the recommendation of her Gastroenterologist when it became clear that she had minimal function in her gut and would be dependent on TPN (IV nutrition) for the remainder of her life. She suffered from excruciating constant pain, she was not sleeping well, and she was making little progress in school or therapy. Just getting through the day was extremely difficult for her. While most specialists did not want to try narcotics with my daughter due to her already poor gut function and chronic respiratory issues, Palliative Care helped us come to the decision that narcotics were necessary for her quality of life, even if it meant she needed more respiratory interventions and would lose more gut function. They have also helped to manage many of her chronic neurological and urological issues to provide her with more daily comfort, and worked with many of her other specialists to help make the best decisions for her care.

While my daughter is currently doing well, we know that her Palliative Care program will take us through the difficult years that we expect will come eventually, such as when her liver fails from long term TPN usage or when we see a further decline in her health.

Palliative Care is not that widely available to children at this time. While most hospitals now have some sort of hospice program, many of them do not have full Palliative Care programs. Even those that do provide Palliative Care often only offer these services to children who are clearly terminal in their last six months of life. Other hospitals may offer Palliative Care primarily to children in one program, usually oncology, instead of allowing all children with life-threatening disorders to have access to these vital services. In some cases, hospitals may require a Do Not Resuscitate order or a pledge to stop life-prolonging treatment in order to provide a child with Palliative Care. While these limitations are in part due to a lack of funding and reimbursement for Palliative Care

services, as well as a shortage of trained and experienced pediatric specialists in this area, they ultimately deprive children and families of vitally important care and services.

It is important to choose a Palliative Care program that meets your family's needs. Just as not all doctors are a right "fit" for all families, not all Palliative Care programs may meet your needs. You may want to look at programs based in the hospitals in your area, as well as independent programs, to find one that meets your specific needs.

Palliative Care has returned my daughter's smile to her face, something no other medical specialty has been able to accomplish. While her Palliative Care treatment probably will not lengthen her years here on earth and may actually shorten them slightly, it has definitely increased the quality of her life, allowing her to enjoy each day, attend school, and live at home with her family.

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<sup>1</sup> Children's International Project on Palliative/Hospice Services Administrative/Policy Workgroup of the National Hospice and Palliative Care Organization. "A Call for Change: Recommendations to Improve the Care of Children Living with Life-Threatening Conditions." Alexandria, VA, 2001, 1.

<sup>2</sup> American Academy of Pediatrics Committee on Bioethics and Committee on Hospital Care [hereafter AAP], "Palliative Care for Children." *Pediatrics* 2000;106,2:351-7. Reaffirmed 2007.

<sup>3</sup> AAP, 353.