



# Complex Child E-Magazine

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## An Introduction to Pediatric Palliative Care

by Scott Millard

Life or Death. Good versus Evil. Isn't that how we have been taught to think of it? We have been conditioned to equate death with losing, and because of this we seek out any treatment available to extend life as long as possible. But what if the length of days were not the primary measure of a life? What if the quality of our days was more important than the quantity of them?

This is where Palliative Care comes in. Palliative Care is about life--quality of life. It is often misunderstood and misrepresented as being about death, and often wrongly thought of as just another term for hospice or end of life care, but that is not at all what it is about. It is about life. At its essence, Palliative Care is about adding life to days when days cannot be added to life.

One of the primary reasons that Palliative Care is not discussed or implemented more frequently or earlier--when it can have greater benefit for the patient and his family--is because we mistakenly equate Palliative Care with dying. As a society we don't like to talk about death, especially when it comes to children, so we avoid the conversation. Often, people think having a conversation about death and dying will cause us to lose hope. In my experience this is not the case. Typically, once we start talking about the possibility that a child might not reach adulthood, we begin to uncover what is really important to a family. Instead of dashing their hopes, we can help them to begin living a more focused and full life, maximizing the days they have, no matter how many of those days there may be.

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

The Association for Children's Palliative Care (ACT) defines Palliative Care for children and young people with life-limiting conditions as an active and total approach to care. It begins from the point of diagnosis or recognition, and embraces physical, emotional, social and spiritual elements through to death and beyond. It focuses on enhancement of quality of life for the child/young person and support for the family. It includes the management of distressing symptoms, provision of short breaks, and continues through death and bereavement.

There are two key points that are important to highlight about this definition. First, it defines the target population for Palliative Care services based on the condition only, and

not the progression of symptoms. This is a critical distinction between Palliative Care and hospice services. Second, Palliative Care is a holistic approach to care for both the child and his family, which places priority on the enhancement of quality of life.

### **Why Should You Consider Palliative Care?**

Advances are continually being made in every field of science and technology, and the body of medical knowledge is expanding at a rapid pace. Every day there is some new test or treatment being developed. Palliative Care does not preclude curative treatment, but if you judge the quality of a life to be at least equally as important as the quantity of life, it does require different questions to be asked and different priorities to be considered.

When implementing Palliative Care you must remember that just because you CAN do something doesn't mean you SHOULD do it. Before considering a test or beginning a new treatment, you and your child's medical team should ask two questions:

1. What will we do differently if we know the answer?
2. Will the treatment improve our child's--and our family's--quality of life or just prolong it?

### **Remember the Child**

Often, the focus is on the problems and issues, trying to understand and keep track of the different treatments and machines that our children are reliant on to sustain their lives. But sometimes the actual person--that precious little life--can easily get lost.

I really believe that losing sight of the person is one of the huge risks in the increasing specialization of medicine. Each specialist develops tunnel vision for his part of the body, and before you know it, the child with complex health care needs becomes nothing more than a collection of parts. They are a heart, lungs, kidneys, brain, blood, immune system and so on. But what happened to the person? What happened to the child?

One day when we were feeling just a little bit overwhelmed by the crazy life we were living, the physical therapist working with our son said something very simple and profound to us. He said something that would re-focus us and change our perspective forever. He simply said, "Always remember that he is more like other kids than he is different from them, just treat him like a kid."

A key goal of Palliative Care should be to reintegrate the person into regular life. It puts the child and his family back at the center of the picture instead of the disease, symptoms or treatments. If implemented correctly, Palliative Care should cause us to consider the whole person and the effects of everything we do on the person as a whole.

## **When Should I Consider Palliative Care for my Child?**

How do you know when to start the discussion about Palliative Care? As the above definition implies, the discussion is best begun at the time of diagnosis of a life-shortening condition. In their guide for discussions on child and family wishes, the Service Improvement Network Project, an ACT initiative, suggests doctors (and parents also) begin by asking themselves the following questions:

1. Would you be surprised if this child died prematurely due to a life-shortening illness?
2. Would you be surprised if this child died within a year?
3. Would you be surprised if this child died during this episode of care?
4. Do you know what the child's and family's wishes are for the end of life?

The first question is the best because it focuses on the condition only and not the progression of symptoms. If the answer to any of these questions is NO, then a further discussion about Palliative Care services is appropriate.

## **How is Palliative Care Best Implemented?**

Caring for a child with complex health care needs at home is an exhausting and often isolating experience. As parents, you know that all of the medical stuff is only a small part of what has to be coordinated to ensure your child gets the care and services he needs. Most parents of children with complex health care needs are coordinating medical care, social services, and educational and community based supports. It can very quickly become a full time job.

Instead of being mom and dad, you become nurse, therapist, insurance specialist and care coordinator. And most of you are trying to do all of this without the backup of short break respite care or other practical support services like integrated care coordination.

Palliative Care is best implemented by an integrated interdisciplinary team. If multiple medical professionals or service providers support your child, the identification of an unbiased care coordinator is crucial. Because every child and family is unique, Palliative Care services are most effective when they are "needs-led." Services should be provided on the basis of the needs of the patient and family, and not based on a standard set of services that is offered to each family. Also, because the needs of both your child and family may change over time, this must be an ongoing dialogue and not a one-time discussion.

## **What Types of Services Should Palliative Care Include and Where Should They be Delivered?**

Palliative Care is a holistic approach to the care of both the child and his family, which

may include:

- Specialized short-break care (Respite)
- 24-hour access to support resources
- Provision of information, support, education and training for caregivers
- Practical help, advice and information for the entire family (including siblings, grandparents and the extended family)
- Specialty therapies including play, music and art therapy
- Care coordination

An important aspect of Palliative Care is to think beyond the hospital and outpatient clinic. Palliative Care services, including end-of-life care, are best delivered in the home environment. When that is not possible, services should be delivered in a purpose-built, home-like facility, such as what we are working to provide through Connor's House, a facility and service model we are working on building in the mid-Atlantic area.

Unfortunately, this is still the exception in the United States, as over 82% of childhood deaths occur in the hospital. Honestly, our hospitals and hospital-based medical teams are excellent at many things, but they are not typically well-suited to provide care for seriously ill children once the acute phase of treatment is over. Our medical technology and clinical competence may be among the best in the world, but medical care, especially at the end of life, has to be about more than just the latest technology and clinical competence.

We are working through Connor's House to make a better reality attainable for other families, but we cannot do it alone. Our goal is not to replace any existing service. Our goal is to fill a gap that exists in our current system by providing a much needed addition to the range of services currently offered to children with complex health care needs and those that care for them. Our goal is to help address these gaps by creating a place where the children and their families will be offered friendship, practical and moral support, and, most importantly, respite care for short periods. This will allow them the opportunity to recharge their batteries and summon the strength necessary to carry on caring for their children at home.

The following are some resources where you can learn more about pediatric Palliative Care.

#### Palliative Care Resources

- Connor's House  
<http://www.connorshouse.org>
- The Association for Children's Palliative Care (ACT)  
<http://www.act.org.uk/>
- The American Academy of Pediatrics

<http://www.medicalhomeinfo.org/health/Palliative.html>

- The American Academy of Hospice and Palliative Medicine  
<http://www.aahpm.org>
- National Hospice and Palliative Care Organization  
<http://www.nhpco.org/>
- The Initiative for Pediatric Palliative Care  
<http://www.ippcweb.org/>
- Children's Hospice and Palliative Care Organization  
<http://www.childrenshospice.org/>
- International Children's Palliative Care Network  
<http://www.icpcn.org.uk/>
- Children's Hospice International  
<http://www.chionline.org/>