



# Complex Child E-Magazine

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## Palliative Schooling by Susan Agrawal

My daughter Karuna currently receives comprehensive palliative care services due to her life-limiting medical condition and chronic pain. While we have implemented these services well within the home, we have found that the school system is not at all used to or accepting of a palliative care model for education. As such, we have struggled for years to try to get my daughter a proper education.

### **Applying Palliative Principles to School**

Anyone with a progressive or life-limiting condition is likely to encounter problems at school. Special education laws, schools, and educational processes in general are designed with forward progress in mind. Children work toward benchmarks, acquire skills, make progress, and meet goals. It is very challenging when your child is going in the opposite direction, such as losing ground cognitively or academically, becoming physically sicker, or experiencing frequent ups and downs due to his or her condition. Goals, priorities, and practices must be adapted appropriately, when steadily moving forward is not possible.

Unfortunately, creating a palliative plan for school is not an idea that has received much attention from either the medical or educational fields. Apart from one very old study on French children dying from cancer, there has been virtually no research in this area. There are some book excerpts that address the subject, but most focus more on the aspect of death instead of applying the principles of palliative care to the school environment. One article tells the tale of taking a child to preschool, and gives a practical example of the process.<sup>1</sup> Despite the paucity of research or available materials, education is an issue that most palliative care programs and participants address on a regular basis.

Palliative care has several principles that are applicable to education. These include:

- 1) Pain and symptom relief, including relief of physical, social, psychological, and spiritual pain
- 2) Enhancing the quality of life of a child
- 3) Promoting the values, beliefs, and desires of the child and family
- 4) Making ethical choices
- 5) Providing holistic, family-centered and community-centered care

How does this relate to education? First off, education is a natural part of most children's lives. As such, going to school represents the norm for most children, and more often than not, children truly want to attend school. Attending school allows a child to have some normalcy in his life. It potentially can improve social, psychological, and spiritual health, which in turn can greatly enhance a child's quality of life.

Of course, going to school may also present challenges, such as an increased risk of infection or injury, which must be taken into consideration. On the whole, however, the positives outweigh the negatives for most children attending school. Getting out of the house, enjoying a change in environment, interacting with friends, working together with teachers and therapists, and of course learning are just some of the many benefits provided by school. School can relieve boredom, promote hope and optimism, and help to establish a sense of normalcy, especially for children who may live for many years.

### **Adaptations for Palliative Schooling**

Setting up an educational plan for a child with a life-limiting illness will be a challenge, especially if the child's disease is progressive. Each child is very unique and will need individualized help. There are some general practices, however, that do apply to most children.

1. Develop an IEP or 504 plan for the child with your school district. IEPs are individualized educational programs that are tailored to the specific needs of a child. If a child has a deficit in any area, or is so significantly health-impaired that all of her education is impacted, an IEP is necessary. For children who need accommodations but not help accessing the curriculum, a 504 plan is sufficient. Either plan should include an extensive health plan for the child.
2. Develop an attendance plan. Most children receiving palliative care will have problems with attendance. Some children may need to miss school for treatments or hospitalizations. Other children may only feel up to going to school one or two days a week. Some children may only be able to attend half days. A plan should be in place to allow for homebound schooling or tutoring as needed or desired. For children who are more limited, allowances for frequent absences, shorter days, or a modified schedule may be necessary.
3. Create rest breaks. Almost all children will need their schooling program modified to deal with fatigue issues. Many families include built-in naps or rest breaks in their children's plans.
4. Provide personnel and training to meet the child's health needs, such as nursing care, emergency plans, and other similar medical preparations.
5. Provide equipment to ensure the child's health, comfort and safety. Some children may need specialized positioning equipment or other devices, such as a nap mat or bed, in order to attend school. Many children require air conditioning on the bus and school. Some children may need a quiet place to calm down.

6. Allow children to work at their own pace, completing assignments as they are able. A spiral curriculum, which revisits the same material after a time, may be helpful for many children.<sup>2</sup>

It is important, however, that the child's illness not be used as an excuse, either by the child, family, or the school district. Children should be held to the same expectations as their peers, whenever possible. Similarly, school districts should not refuse to allow a child to attend school because of substantial medical needs, a need for nursing care, or fear of the child being injured or dying.

## **Goals and Programs**

As a matter of example, we can look at my daughter Karuna's current situation. Karuna currently has three standard palliative care goals: to stay out of the hospital as much as possible, to be pain-free, and to have a good, happy quality of life. Her team has done a wonderful job in helping us realize these goals.

But how do these goals apply when it comes to school? Obviously, the most important goal relating to education is quality of life. In our case, we also want Karuna to be able to learn to communicate her wants and needs, both to provide her with adequate pain control when needed, and to make her happy.

We asked, and are continuing to ask, two questions in order to establish our goals:

1. What makes this child happy at school?
2. What does this child need to learn in order to be healthy and happy?

By having your child and your family answer these two simple questions, you will find out what is truly important to your child, and what is most important in his or her education. Your child's program and goals should all be designed around the answers to these questions.

In our case, the answer to question one is social interaction, having friends, and getting out of the house. In preschool, Karuna's favorite activities were art, music, sensory time, and gym. As such, we try to focus on these aspects to provide Karuna with as much happiness as we can. For example, Karuna was transferred to a class with a much higher cognitive level so that she would have other children with whom she could communicate and interact. We have had less success in providing her a program with her favorite activities, as she only attends school half days and typically misses these subjects. This is something we continue to work on, as school districts are not inclined to write goals or change schedules based on one child's happiness.

As for question two, we are less interested in her learning her letters or how to add, and more interested in her learning to communicate with us to express her wants, needs, and medical issues. The majority of her academic goals, therefore, are designed around

communication and social interaction. Other children, however, may find that pursuing a standard curriculum, whether they will eventually use the skills they master or not, may provide personal satisfaction and a sense of hope.

It has definitely been a challenge to write goals and benchmarks that support palliative care goals, while still allowing the school to include legally required measurable goals that complement the standard curriculum. We would love to include goals such as, “Karuna will make several friends, play with them, and enjoy the experience of friendship.” But schools must create goals that are measurable and related to the curriculum. This goal then becomes, “Karuna will participate in a communication exchange with a peer using her communicator or other available methods, 4 out of 5 trials.”

Schools will likely need a lot of assistance in this area. They tend to be unfamiliar with palliative care principles, and they will most likely have a lot of trouble creating a plan for your child that both meets the requirements of special education law, and creates the atmosphere and situation you desire for your child.

## **Getting Help**

It is of the utmost importance to discuss the overall philosophy of palliative care and how it influences the educational process with your child’s school team. It may be valuable to have a member of your palliative care team write a letter, attend a meeting, observe your child, or talk on the phone with school teachers or administrators. Your palliative care team is designed to advocate for your child and his or her needs, and they are very experienced in sharing the philosophy of palliative care.

Palliative care is always a process, with goals and needs changing as the child’s condition changes. Similarly, applying a palliative philosophy to the educational system will be a process. It is likely to be very unfamiliar to schools and administrators, and may take quite a bit of individualization and work to achieve what is best for your child and family. But when done well, it can truly enrich your child’s life.

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<sup>1</sup> Mary Elizabeth Ross, Judith Hicks, and Wayne L. Furman, Preschool As Palliative Care. *Journal of Clinical Oncology* 2008;26(22):3797-9.

<sup>2</sup> Personal communication with Donna Noble.