

# Listen to the Children and Honor Their Pain

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The title of this article comes from the philosophy that children need to be heard during the traumatic experience of illness or death of a family member. In this article, I will present a continuity of care model that supports children and their families from the point of diagnosis through to three years postdeath, should remission not occur. This model integrates the arts and has evolved through a process of listening to what children say they need to cope and adapt to the multiple transitions that a serious illness or death imposes on their lives. Grief is defined as any change or loss that causes sadness or anxiety. We use this definition throughout the spectrum of illness so that a child can be prepared for loss and death within a framework of hope while maximizing a healthy adaptation response. Dealing with grief is considered a necessary life skill.

All of the programs at Arthur G. James Cancer Hospital have evolved through feedback obtained from children and their families. We use the arts for healing because children do not have the cognitive development to express their fears and emotions with words. Art therapists, artists, mimes, quilters, storytellers, dancers, musicians, and photographers help children express themselves. A group of children of any age cannot sit in a circle and tell you how they feel about illness or death. However, if children are given the means to express themselves through art, the richness of the expression of pain and its subsequent healing can be quite remarkable.

Using the arts permits and encourages a child to express his or her feelings and open up to therapeutic intervention. The arts also help adults to express themselves more openly, and they give the entire family an opportunity to share emotions that they do not know how to talk about.

## Literature Review

In their book, *How to Help Children Through a Parent's Serious Illness*, McCue and Bonn (1994) wrote, "With all our advanced techniques for treating serious disease, for saving or prolonging life, we in medicine have forgotten one very important affected group: the children of our patients" (p. 1). Yet, according to the National Cancer Institute and U.S. Census Bureau, approximately 129,089 children had a parent diagnosed with cancer in 1998 (Birenbaum, Yancey, Phillips, Chand, & Huster, 1999). The grief literature indicates that children who lose a parent at an early age may suffer from an inability to develop intimacy, depression, drug abuse, and failure in general life skills. Rait and Lederberg (1989) focused specifically on children of patients with cancer. They identified these children as a hidden high-risk group whose problems were minimized by overwhelmed parents and were invisible to healthcare staff. This study noted increased incidences of psychological symptoms such as changes in cognitive development and self-esteem and acting-out behavior.

Call (1990) concluded that children do not receive adequate support either during a family member's illness or after a fam-

ily member dies and stressed the need for healthcare workers to be flexible and creative when working with this population. Lewis (1986) went further by writing that "linear staged models of the family's response to cancer as espoused in the clinical and theoretical literature, need to give way to more dynamic models that depict the family moving through multiple transitions each of which are characterized by such things as uncertainty, role changes, existential concerns, tensions, and emotional strain" (p. 271).

## Continuity of Care Model

During the past 10 years, I have developed a continuity of care model that meets these expectations of a more dynamic model similar to the one described by Lewis (see Figure 1). Through feedback from the children asking to return to programs and classes, we felt that they should be allowed to come back as often as they needed throughout the illness continuum. We serve more than 250 children each year. As I tell parents when they first call me to get information about our programs, life is full of change and loss. Even though they wish they could spare their children this difficult journey, they have no choice but to embrace it as an opportunity for growth. The following describes the different components of the continuity of care model that I designed as part of children's programming at Arthur G. James Cancer Hospital.

## Kids Can Cope, Too!

This is a six-week program designed to help children cope with the serious illness of a loved one from the point of diagnosis through end of life. We serve children aged 2–19 and separate them within age-related groups: ages 2–7, 8–12, and 13–19. Although the majority of the children have parents, grandparents, or siblings with cancer, the group is open to any child who is experiencing serious illness in the family. We have had families with AIDS, diabetes, and heart disease, among others. Also, patients with cancer do not need to be treated at the Arthur G. James Cancer Hospital for their children



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King is the 22nd recipient of this lectureship, which recognizes a healthcare provider who has made a substantial contribution to the psychosocial aspects of cancer care.

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