

Understanding Children with Cancer

From Shobi Dobi

Cancer - the big "C" word -- "terminal" cancer. We don't say terminal diabetes or terminal bronchitis. This outdated attitude carries a lot of heavy pessimism. Besides let's face it, life is terminal. However, today, most kids survive cancer to grow to adulthood! The progress since the 1960's is that dramatic. The survival rate of acute lymphocytic leukemia alone is up from 0 to 60 percent. However, if you clown with children in the hospital, inevitably you will come across a child that won't make it -- that won't win the battle with cancer.

Bob "Harley" Benson at the Northwest Region COAI Convention gave me a copy of Erma Bombeck's I Want to Grow Hair, I Want to Grow Up, I Want to Go to Boise. Why had I not read this book before? If you work as a caring clown with any population - read this book! Erma Bombeck gets into the child's point of view. She exposes kids' resiliency, attitude, courage and sense of humor when faced with cancer.

Bombeck writes: "These children have a unique approach to their life-threatening illness. Instead of looking backward, they look forward. I discovered that everything in their lives takes on a new importance and that nothing is taken for granted. Not a friendship . . . not a kindness . . . not even tomorrow. No deed goes unnoticed."

"I got a good one for you," she said, changing gears. "There was this girl who had to go quite often for chemo and one time she was kind of fed up, so she had some apple juice in her drawer and the nurse came in and told her to give her a urine specimen. So, the nurse went out and when she came back, this girl had poured a little of that apple juice in that cup and the nurse started to take it out when the girl said, 'It looks so cloudy, I think I'll filter it back through; and she drank it! The nurse like to have had a heart attack."

"You gotta keep your attitude," she continued. "Cancer didn't change my life. I mean, it was just part of my childhood and the only thing it did was to make me more mature."

-- Mellisa in

*"I want to Grow Hair, I want to Grow Up,
I want to Go to Boise"*

We as clowns must be careful how we engage a child about their illness. Most Clowns are not trained therapists -- we are mostly ordinary folks with an extraordinary mission. There are, however, clown therapists who are either Child Life Workers or work with staff as a Clown Therapy Program. [for example *Hubert, the Clown* - David Langdon of Winnipeg, Canada]

What is a Child Life Program?

From the Kaiser Permanente Oakland Medical Center Child Life Department.

The Child Life Program is a therapeutic play and activities program designed to make the hospital experience as positive as possible. It is: (1) to promote the child's normal growth and development while in a health care setting; and (2,) to help the child cope with the stress and anxiety of the overall hospital experience.

The Child Life Specialist:

Prepares the child for health care experiences (for example, during admissions processes and procedures by using developmentally appropriate language. Provide emotional support during procedures.)

Informally assess the developmental needs of the child.

Identify the child's concerns and communicate unique coping mechanisms to other health care staff to facilitate treatment.

Work with families to provide support, clarification of hospital procedures, and reinforcement of treatment plans.

Even if we have no therapeutic training, a little knowledge of child development can give us insight that can help us as caring clowns. Very often the child will tell the clown or a clown's puppet something that the medical staff never hears. This conversation occurs because the clown is there not as an invasive person, but as a friend.

One little 12-year-old girl looked up at Shobi Dobi with frightened big blue eyes (she just found out she was going to lose her leg), "Will it grow back?" Shobi answered "Well, I'm not a doctor, I don't know very much about that." Cop out? I don't think so. I really didn't have the knowledge to talk to her. I could let her express her fears, but it was her Child Life Worker who spoke with her about losing her leg. (Then they brought in a gorgeous 16-year-old girl who had the same illness and the two spoke for three hours!) Children have told Birdie Bird (Shobi's puppet) many of their feelings and fears. These always go back to the Child Care Worker. In one case where I suspected child abuse by a family member and the Child Life worker was not present, I spoke to the head nurse. The clown listens and reports, not listens and tattle tales - we report with discretion.

More than once I have been in a position where it helped to have some knowledge of the general stages in child develop-

ment and what children tend to understand about their illness. While surfing the net, I found some interesting information about cancer and children. In fact, there is even a net site for kids alone where they can write questions about their illness and chat with other kids who are experiencing the same thing. Following are some interesting points I picked up while "surfing."

Children under one year old can't understand what they can't see or touch. They are mostly concerned with being separated from their parents. Over a year old they are concerned with how things feel and how to control things around them. They are most afraid of medical procedures and tests. Many cry or squirm to try to control what's going on.

At around a year and one half, a child begins to think about what is going on around them. Honesty is very important. They should never be told something doesn't hurt when it will. Honesty here helps develop trust. With these young children it is helpful if some choices can be given to them. Do you want apple or orange juice? Do you want to see the clown or not? Blow some bubbles?

The two-year-old is the age where seeing the clown at 15 feet is fine but too close is very often scary. I think it's like seeing a two dimensional cartoon come off the TV or coloring book and become too alive. The resulting confusion is very frightening for them. Stay more than 10 feet away, maybe act shy, or play Peek-a-Boo. If possible, allow them time to observe you clowning with other children until they get used to you.

Children 2 to 7 tend to look at things from one point of view -- their own. They link events to one thing. Like tying illness to a specific event such as staying in bed. Children at this age often think their illness is caused by a specific action. Therefore, getting better will happen automatically or by following a set of rules. They need to be reassured that they did not do anything to cause their illness - that the illness is not punishment for something they did wrong. Puppets are very effective with this age group. Shobi Dobi's *Birdie Bird* has had some pretty wonderful conversations about fears with this age group. Medical procedures with this group can be explained simply, but honestly and realistically by medical staff.

The 2 to 7 year old understands good and bad. The NCI (National Cancer Institute) suggests explaining the disease to this age group in terms of a battle between "good guys' cells" and "bad guy cells." Taking the medicine will help the good guys become stronger so they can beat the bad guys.

Children 7 to 12 years old are starting to understand relationships between events. They begin to see illness as a set of symptoms. They are able to cooperate with treatment. An explanation of cancer to them might go like this. Cancer cells can be described as "trouble makers" that disrupt the

work of the good cells. Treatment helps to get rid of the "troublemakers" so the other cells can work together once again.

Children 12 years and older are able to understand complex relationships between events. Teenagers still define illness by specific symptoms such as tiredness and by limits on everyday activities. Explain cancer to them as a disease, in which a few cells in the body go "haywire." These "haywire" cells grow more quickly than normal cells, invade other parts of the body, and disrupt normal body functions. The goal of treatment is to kill the "haywire" cells. Then the body can function normally again, and the symptoms will go away.

Don't be afraid to ask the child questions. Asking what they think and feel will not create new fears; it will give them the chance to express the fear they already have. Puppets here are a great way to interact with a child.

The key here is always to listen. If you are having trouble being fully present, try looking into a child's eyes and matching their breathing. Often you can calm a frightened child with this kind of presence.

Here is a great website. If you know a kid with cancer they need to visit this site!

Kids Cancer Network

<http://www.kidscancernetwork.org>

In 1992, young cancer survivor Kenon Neal founded Kids Cancer Network to provide "a dose of hope™" for kids and their families isolated by the rigors of childhood cancer treatment.

We are so glad you're here at the KCN website? There are plenty of opportunities on this site to be encouraged! Discover tons of wonderful hard-to-find stuff, and places to: say thanks, get mail, be prayed for, share with thousands, and be creative. Truly a kids cancer network!

Kids Cancer Network designed and sent over 150,000 FUNLETTER activity magazines to children with cancer nationwide before we went online in 2000? now YOU can print out your very own FUNLETTER at home or in the hospital. You are not alone? enjoy a "dose of hope™"!