

Cancer in the Parent or Caregiver: How to Help the Child Cope

McKenzie Pediatrics 2011

Faced with a diagnosis of cancer, parents and caregivers wonder what, when, and how to tell children about the illness. They also have questions about how the child will cope, both in the immediate aftermath, and long term.

One in four cancers are diagnosed in patients younger than 55 years old – an age group likely to be raising children. While treatments have improved for many cancer types, and patients often live longer with cancer even when a cure is not achieved, children may be exposed to a parent's serious illness for a substantial period of time. Therefore, it is important for parents to understand how to help the child, even while going through their own traumatic period.

Each family's unique circumstances make it impossible to provide a "one size fits all" model for talking to children about a parent or caregiver's cancer diagnosis. However, the parents should follow the HONEST model for communication with children:

Home: Find a private place to talk, with ample time, and bring the family together

Open-Ended Questions: Ask about a child's observations of changes at home or in the parent, as well as what they understand so far about the illness. Talking openly sets up a model for the family of coming together around difficult challenges, supporting each other, and problem-solving together.

Name The Illness: Give honest, age-appropriate information about the diagnosis, disease progression, and treatment. Call it "cancer". Describe what cancer is, and what type it is. Don't minimize it; make it clear that it's different than a "owie" or a "tummy ache".

Emotions: Ask about and normalize the child's range of feelings

Specify Impact: Describe how the illness and treatment will impact the child's life, and discuss plans to minimize disruptions. Take care not to flood children with too many details that are scary and unhelpful.

Touch Base Often: Follow up regularly with each child when they are most likely to talk

Parents and caregivers should also apply the following general principles in the weeks and months after informing a child of their parent's diagnosis:

1. Continue to communicate honestly, in an age-appropriate manner. Children are quite likely to overhear adult conversations. If not directly included, they may feel betrayed, excluded, unimportant, and/or confused.
2. Protect family time (see below)
3. Maintain normal routines as much as possible. When these can be preserved, children tend to cope more easily; when many routines are regularly disrupted, children may show more signs of stress. And don't remove children from their usual afterschool activities. Reduce the number, if necessary...keep one or two activities consistent, rather than many sporadic.
4. Optimize and organize supports (family, friends, faith-based)

What are some ways to protect family time?

1. Create a “cancer free” zone around children. Avoid the “all cancer, all the time” household. Encourage others to approach you, not the children, for information and updates. Ask friends to visit and call when children are occupied elsewhere, otherwise a child may hear the same story repeatedly. Limit phone calls during family time, particularly during meals. If you have an answering machine, turn the volume low or off during family time.
2. Use technology wisely. Update family and friends efficiently by using phone trees, email distribution lists, or Web sites/social pages.
3. Think flexibly about connecting with children. Find new activities to enjoy together if it's difficult to engage in old favorites. Focus conversations on normal life as much as possible – school, homework, activities, and friends. Do not assume that a child's distress is always related to cancer...children experience stress for a variety of everyday reasons.

What are some ways of optimizing and organizing supports?

1. Designate a friend or family member to coordinate rides, meals, and so on from people who have offered.
2. Consider using free Web sites (www.lotsahelpinghands.com) on which family needs can be posted and approved guests can sign up to provide help
3. Elicit children's preferences about substitute caregivers.
4. Weigh the pros and cons of various arrangements of helpers, such as extended family living at home, a rotating schedule of guests, or daily help from people living elsewhere.
5. Ask about children's preference about when and to whom they would like to talk about a parent's illness at school – if they even want to talk to anyone. Communicate these wishes to school personnel.
6. Engage in regular communication with one point person at school to quickly catch any emerging problems. Guidance counselors, teachers, school psychologists, and nurses may be helpful resources.

Finally, learn to recognize the signs of concern in children: a persistent change in mood or behavior for more than 2 weeks; a change in functioning at home, at school, or at social activities (including sports); increased conflict with or withdrawal from peers or parents; and safety-concerns such as risk-taking, impulsivity, or suicidal thoughts. Seek mental health guidance ASAP if any of these signs are noted.

Here's a memorable “poem” to bring comfort to those afflicted with, or affected by cancer. We hope that it helps:

What Cancer Cannot Do

Cancer is so limited...
It cannot cripple Love

It cannot shatter Hope
It cannot corrode Faith
It cannot destroy Peace
It cannot kill Friendship
It cannot suppress Memories
It cannot silence Courage
It cannot invade the Soul
It cannot steal eternal Life
It cannot conquer the Spirit.

-Author unknown