



The
National
Children's
Cancer
Society

25 years of serving kids and their families

COMMUNICATING WITH YOUR CHILD DURING THEIR CANCER TREATMENT

COMMUNICATING WITH YOUR CHILD DURING THEIR CANCER



Being open to an open dialogue.

We spend years teaching our children the importance of honesty, and never will this policy be more important than when your child has cancer. Parents of survivors and healthcare professionals alike encourage parents to be truthful with their child at every stage of the survivor journey.

Diagnosis: The truth beats the unknown.

Parents often think they are protecting their child by withholding scary information, but children are usually less frightened when they know the truth about their health. Kids often pick up on their parents' fears and sense when something is wrong. They may piece clues together about not feeling well with frequent doctor visits, and because they don't know the facts, they will worry or possibly imagine things that are not true. An uninformed child may even believe their illness is a punishment for something they did wrong.

It's also important that your child learn about their illness from you. Family, friends or members of your medical team may inadvertently say things that let your son or daughter know about their cancer. Your child may feel hurt or betrayed that you weren't honest with them.

Children who know the truth are less likely to feel stress or guilt, which means they are more likely to cooperate with treatment. Talking about your child's cancer can help your family feel closer and more unified. Childhood cancer affects the whole family, and open communication can make dealing with the changes easier for everyone.

What do I say?

Telling your child they have cancer is a personal matter, so naturally, family, cultural and religious beliefs will come into play. Talk openly to your son or daughter in a way that is age appropriate, and be honest with other siblings about the diagnosis and treatment. Encourage everyone in your family to ask questions and express their feelings.

You will likely question the best way to talk to your child. For starters, who should be present? Some parents prefer to explain their child's diagnosis and treatment with the help of someone from the medical team. Others invite a clergy member from their own church or synagogue to pray with them.

Children are very perceptive though, so it's best to talk about things soon after the diagnosis. Choose a quiet place to talk and use dialogue they will understand. Some parents recommend rehearsing what to say and keeping it less emotional, more matter of fact.

During treatment, knowledge is power.

Your need to communicate openly with your son or daughter will continue throughout treatment. During this time, your child will endure many uncomfortable, even painful situations. Knowing what is going to happen next and why will help him or her feel less out of control and more cooperative. If your child is old enough, let him or her be involved in making medical decisions. As kids gain independence in their teens, they are more likely to cooperate when given the chance to express their opinions.

COMMUNICATING WITH YOUR CHILD DURING THEIR CANCER

Encourage your child to become familiar with all areas of the hospital. A trip to the pharmacy allows them to see how medications are made. Touring the surgery rooms removes an element of the unknown. By empowering a child with knowledge, you'll increase their understanding while reducing their fears.

Keep in mind, no child is going to have a positive attitude all the time. There will be bad days. It doesn't mean that your child is losing strength. It merely means the experience is difficult and they will need your support.

Just Between Us | Survival Tips from other Survivors

"I told my husband to wait to tell Markesha because I wanted my pastor there, and other members of my church to support her, and tell her in a way that a child would understand."
- Annette, Mother of Markesha (Liver cancer)

"Our best advice was from the radiation oncologist. Spencer was 7. The doctor said to tell him then that he was sterile. We were open in discussing that - this is what we are doing and this is what it is going to cause. He grew up with that knowledge...We hit the teen years and had an initial adjustment period, but he's accepted it. I think we got good advice."
- Carrie, mother of spencer (Leukemia)

"We tried to explain things in ways he would understand, like the stem cells are your own personal super hero cells, which will make you strong and grow. We also did our best to be prepared with options that would give him some control if possible...like a specific bandage or way of doing something."
- Linda, mother of Sam (Neuroblastoma)

Treatment ends, communication continues.

As life moves beyond cancer, you'll need to keep talking honestly with your child. The battle with cancer is difficult for the entire family, and everyone will likely want to put the experience behind them. Try to remember, survivorship is a journey that lasts a lifetime. Your child's illness and treatment may lead to future physical problems, emotional challenges and social concerns. Knowledge about late effects will help your child lead a full, healthy and productive life. Keep the communication open so they can come to you when concerns arise.

Every child will understand their diagnosis in different ways, at different ages. Kids diagnosed as toddlers or preschoolers need new explanations as they mature. It's easy to "move forward" and forget that your child may need new information to process what happened when they were younger.

While the cancer process is often painful and wrought with feelings of helplessness, undoubtedly the experience will have some positive aspects. You'll recognize the support of family and friends, the knowledge of your medical team and pride in the strength and courage of your child. With this journey comes the reminder of how truly precious life is.

RESOURCES

Help for the climb

For additional resources, visit beyondthecure.org or talk to a member of your child's medical team.

Medical

National Cancer Institute

800-4-CANCER cancer.gov
Provides state-of-the-art information about the treatment of individual types of cancer, clinical trials and late effects.

CureSearch

800-458-6223 curesearch.org
Funds research and provides information to those affected by childhood cancer.

Chemo Care

chemocare.com
Provides information about chemotherapy and side effects.

Insurance/Legal

HealthCare.gov

healthcare.gov
A government sponsored web site on healthcare information.

Patient Advocate Foundation

800-532-5274 patientadvocate.org
Solve insurance and healthcare access problems.

Social Security Administration

800-772-1213 ssa.gov
Provides answers to questions regarding social security benefits.

Support, Advocacy and Financial Assistance

The National Children's Cancer Society

800-5-FAMILY theNCCS.org
Emotional support, advocacy, education, and financial assistance to parents of children with cancer and an online community for parents and survivors.

American Cancer Society

800-ACS-2345 cancer.org
Information on parental issues such as coping with diagnosis, understanding the health care system, financial and insurance information, and transitioning your child back into school.

Association of Cancer Online Resources (ACOR)

acor.org
Electronic support groups to patients, caregivers, and survivors.

Cancercare 800-813-HOPE cancercare.org Individual and group counseling both on-line and via their toll-free counseling line.

Supersibs

888-417-4704 supersibs.org
Support for brothers and sisters of children with cancer.

First Hand Foundation

816-201-1569 applications.cerner.com/firsthand
Financial assistance for treatment, equipment, displacement and vehicle modifications for children with health problems.

United Healthcare Children's Foundation

952-992-4459 uhccf.org
Financial help for medical services such as speech, physical or occupational therapy, prescriptions, and medical equipment such as wheelchairs, orthotics and hearing aids.

Healthy Living

American Institute of Cancer Research

800-843-8114 aicr.org
Offers specific nutrition information for the cancer survivor.

SmokeFree

877-448-7848 smokefree.gov
Help for those who want to quit smoking

Sun Safety Alliance

703-481-1414 sunsafetyalliance.org
Provides information on sun safety.

Learning Disabilities

National Center for Learning Disabilities

888-575-7373 nclld.org
Solutions and opportunities for individuals with learning disabilities.

Survivorship

Beyond the Cure Survivorship Program

Sponsored by The National Children's Cancer Society
800-5-FAMILY beyondthecure.org
Information on all aspects of cancer survivorship, a late effects assessment tool and college scholarships.

Livestrong

866-673-7205 livestrong.org
Awareness, advocacy and support for the cancer community.

BIBLIOGRAPHY

- Arroyave, Whitney D., Elizabeth C. Clipp, Paige E. Miller, Lee W. Jones, Dianne S. Ward, Melanie J. Bonner, Philip M. Rosoff, Denise Clutter Snyder, and Wendy Demark-Wahnefried. "Childhood Cancer Survivors' Perceived Barriers to Improving Exercise and Dietary Behaviors." *Oncology Nursing Forum* 35.1 (2008): 121-30. Print.
- "Childhood Cancer: Late Effects of Cancer Treatment." *Cancer.org*. American Cancer Society, 19 June 2009. Web. 15 Dec. 2010.
- Cohen, Jennifer, Claire E. Wakefield, Catharine A. K. Fleming, Rebecca Gawthorne, Linda C. Tapsell, and Richard J. Cohn. "Dietary Intake after Treatment in Child Cancer Survivors." *Pediatric Blood & Cancer* (2011): N/a. Print.
- Hunsinger, Deborah Van Deusen. *Pray without Ceasing: Revitalizing Pastoral Care*. Grand Rapids, MI: William B. Eerdmans Pub., 2006. Print.
- Hudson, Melissa M., Sally Wiard, and Allison Hester. "Health Link: Finding and Paying for Healthcare after Treatment for Childhood Cancer." *Survivorshipguidelines.org*. Children's Oncology Group, Mar. 2006. Web. Jan. 2011.
- Jalonick, Mary C. "Food Pyramid Out, 'My Plate' in for Healthy Eating." *Boston Globe* 2 June 2011. *Boston.com*. Boston Globe. Web. 22 Sept. 2011.
- Kadan-Lottick, Nina S., Leslie L. Robison, James G. Gurney, Joseph P. Neglia, Yutaka Yasui, Robert Hayashi, Melissa Hudson, Mark Greenberg, and Ann C. Mertens. "Childhood Cancer Survivors' Knowledge About Their Past Diagnosis and Treatment." *Journal of the American Medical Association* 287.14 (2002): 1832-839. Print.
- Keene, Nancy. *Educating the Child with Cancer: a Guide for Parents and Teachers*. [Kensington, Md.]: Candlelighters Childhood Cancer Foundation, 2003. Print.
- Keene, Nancy, Wendy Hobbie, and Kathy Ruccione. *Childhood Cancer Survivors: a Practical Guide to Your Future*. Beijing: O'Reilly, 2007. Print.
- Klassen, Anne F., David Dix, Michael Papsdorf, Robert J. Klaassen, Rochelle Yanofsky, and Lillian Sung. "Impact of Caring for a Child with Cancer on Single Parents Compared with Parents from Two-parent Families." *Pediatric Blood and Cancer* (2011). *Onlinelibrary.wiley.com*/. Wiley, 19 Jan. 2011. Web. Spring 2011.
- Landier, Wendy. "Health Link: Introduction to Long Term Follow Up after Treatment for Childhood, Adolescent, or Young Adult Cancer." *Survivorshipguidelines.org*. Children's Oncology Group, Oct. 2008. Web. Dec. 2010.
- Learning & Living with Cancer: Advocating for Your Child's Educational Needs*. White Plains, NY: Leukemia & Lymphoma Society, 2006. Print.
- MacLellan, Scott Neil. *Amanda's Gift: One Family's Journey through the Maze of Serious Childhood Illness*. Roswell, GA: Health Awareness Communications, 1999. Print.
- Martin, Terry L., and Kenneth J. Doka. Men Don't Cry-- Women Do: *Transcending Gender Stereotypes of Grief*. Philadelphia, Penn.: Brunner/Mazel, 2000. Print.
- Nutrition and the Cancer Survivor*. Washington DC: American Institute for Cancer Research, 2001. Print.
- Oeffinger, K. C., and M. M. Hudson. "Long-term Complications Following Childhood and Adolescent Cancer: Foundations for Providing Risk-based Health Care for Survivors." *CA: A Cancer Journal for Clinicians* 54.4 (2004): 208-36. Print.
- "Questions to Ask My Doctor about My Cancer." *Cancer.org*. American Cancer Society, 27 Apr. 2011. Web. Spring 2011.
- Raiss-Dana, Deborah. *Diamonds or Dust: Keeping Your Marriage Together When Your Child Fights for Life*. 2004. Print.
- Weiner, Susan Lipschitz, and Joseph V. Simone. *Childhood Cancer Survivorship Improving Care and Quality of Life*. Washington, D.C.: National Academies, 2003. Print.