



The
National
Children's
Cancer
Society

25 years of serving kids and their families

COPING WITH YOUR CHILD'S CANCER

COPING WITH YOUR CHILD'S CANCER



Finding hope and strength in what you've lost.

A cancer diagnosis seems to change life almost overnight. Normal, everyday routines are often replaced with an overwhelming sea of changes and uncertainties. Survivors and their families experience significant losses, and with those losses, grief often follows. These feelings are often overlooked in the face of illness. But like the emotional concerns that come with your child's diagnosis, it's important to find ways to cope with the grief these losses have caused.

It's normal to mourn your old life. Parents often grieve for their "healthy child," knowing their child's medical history will now always include cancer. Others feel a loss of control, security or confidence in their futures. And for many, it's difficult to give up the feeling that they can shelter their children from hardship. Innocence has been replaced with fear and sadness.

Many families have not yet been exposed to significant hardships, and seeing a child face the threat of death changes one's perspective on the world. All these losses and feelings are real and valid. But in spite of these life changes, it should comfort you to know that there is life beyond childhood cancer. Over 300,000 survivors today are living proof.

Grief can't always be anticipated.

Some losses that accompany cancer are unexpected. Just as every child's treatment is different, every person will experience unique losses and reasons to grieve. There is no standard, but it helps to remember you are not alone.

Many survivors and their families are faced with these personal losses:

Hair- Though an obvious external loss, it can mean different things for different people. For some parents, it's a constant reminder of the cancer and the loss of their healthy child.

Fertility- The loss or possible loss of fertility is a side effect of some treatments.

Amputations- To save a child's life, an arm or leg sometimes must be amputated or enucleated. This will change how he functions long after the treatment is over.

Learning ability- Some cancers and treatments affect the brain in ways that make it more difficult to learn, even after treatment is completed.

Energy and strength- A child may not be able to participate in favorite activities due to weaker body strength and physical energy.

Childhood- Many parents feel that the cancer experience turns their child into an "old soul."

Personality- The stress of the cancer experience and side effects of some medications can cause significant changes in a child's personality.

Normal activities- Things that were previously considered normal-school, sports, social events, church, vacation, even visiting friends and family- may be lost or greatly reduced during treatment. **Attention to other children-** Often, the demands of the sick child gives parents less time to spend with their other kids.

Freedom- Parents and children frequently have to adjust to a lifestyle that allows less freedom and spontaneity.

Income- It is common for a parent to reduce work hours or leave a job to care for the child with cancer.

Time for adult relationships- Many parents find they must sacrifice some attention from their marriage or other friendships to care for their sick child.

Community connections- Some friendships stay strong throughout treatment, but some parents report a falling away of support and a feeling of isolation.

Deaths of other children with cancer- Meaningful friendships are forged with other children and families facing cancer. Some of these kids will not survive their disease or treatment.

COPING WITH YOUR CHILD'S CANCER

Everyone copes differently.

Though the cancer experience is overwhelming for everyone, each person must ultimately find their own way to cope. Grief experts and authors Martin & Doka discuss people's different styles of grieving. "Intuitive Grievers" experience feelings very intensely, often finding it helpful to express their feelings by sharing their experiences and crying. Intuitive Grievers can also have times of confusion, difficulty concentrating, disorganization, exhaustion and anxiety. For people who grieve this way, it's especially important to recognize what has been lost and find ways to express your feelings.

For those who are "Instrumental Grievers," grief may seem less intense. Their grief impacts how they think, and there is often a reluctance to talk about their feelings. Parents who grieve this way tend to focus on problem-solving and taking as much control of the situation as possible. Sometimes, their energy levels can be even higher than normal as they gear up for problem solving.

People can have one style of grieving or a mixture of both, but every individual must find ways to lessen their grief. Parents in the same family may have different ways of coping with their grief. One may prefer to deal with situations and losses as they occur while their spouse may need to anticipate possible problems and come up with ways to deal with them ahead of time. Sometimes, parents need outside support to find ways to be supportive to each other.

The losses you experience do matter. As a parent, you can't ignore these real feelings and experiences or they eventually will sap you of the energy you need to care for your sick child, your family and yourself.

Just Between Us | Survival Tips from other Survivors

"As a parent, the hardest thing for me to deal with was the feeling of guilt I carried. You have to let go of that."
- Shana, mother of Mackenzie (Rhabdomyosarcoma)

"As we watched, I saw all that life has to offer unfold before me. I saw joy, excitement, fantasy and dreams. I also saw a touch of loss of innocence and the recognition that not everything is as wonderful as it's cracked up to be. But even with that, I saw how the heart of a child can still find love and faith."
- Scott, father of Amanda (Lymphoma)

Let go. And hold on.

Parents who have learned to cope well with childhood cancer have usually learned two things: to let go and to hold on. When parents learn to let go, they begin to recognize that there are things simply out of their control. Ultimately, the success or failure of cancer treatment is outside anyone's control. Accepting this and other matters you have little power over leaves you with more energy to focus on the things you can control.

Those who "hold on," have learned to not let cancer and its treatment take any more from life than it has to. Don't give up anything that you can keep unless you decide it's no longer worth your while. Priorities can shift and some things may no longer feel like they are worth your time. But never allow the disease to make you feel like it's all you have, or all you are.

Holding on means working to not let cancer have the last word in your life or the lives of your children. In the midst of this difficult time, life offers gifts and growth. Some parents find themselves getting smaller, trapped in fear, grief and bitterness. Those who grow have found ways to let go, while also seeing the beauty of holding on. You have the freedom to choose how cancer will affect you and your family. Open yourself up to wherever the journey takes you.

Content contributed by Greg Adams, LCSW, ACSW, CT- Director for Good Mourning, Arkansas Children's Hospital

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.

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.