

Emotional Issues after Childhood Cancer

The Cancer Experience

Diagnosis and Treatment

Diagnosis and treatment are difficult times for children with cancer and their families. During diagnosis, children have tests and procedures that are new, painful and often scary. For parents, it is the anxiety of waiting for the results of these tests and procedures that can be the worst part of this time. Learning the diagnosis can be a relief, especially when effective treatments are available. These treatments, though, can be unpleasant for children to have and upsetting for families to watch or give. Tests and procedures are repeated during treatment to find out if the treatment is helping or should be changed. Children with cancer and their parents are frequently at the hospital, sometimes away from other family, friends, home, work or school for long periods of time. Parents worry about whether or not their child's cancer will be cured, how to minimize their child's suffering, and how to make the most of life. Brothers and sisters also worry about, and are sometimes jealous of, the child with cancer. Childhood cancer survivors and their siblings can be concerned about their parents, and keep worries and feelings to themselves to try to protect their parents. As a result, children with cancer, their parents and their siblings can feel angry, lonely, sad and afraid during treatment. Periods of anxiety and depression can occur.

After Treatment Ends

For survivors and their families, the end of treatment can bring new feelings as they come to know the good (and sometimes not so good) outcomes of successful treatment. During treatment, people tend to be concerned with getting through the day-to-day. It is after treatment that people can begin to think about and come to terms with their experience. People can have a range of feelings after treatment ends, and the blend of feelings can be as unique as each person. Survivors and their families often fear that the original cancer will return. Regular testing for recurrent cancer or late effects, and even just talking about possible late effects can cause stressful feelings. The diagnosis of a late effect related to cancer treatment or a new health problem unrelated to childhood cancer can also be sources of distress. Anniversaries of cancer events, such as the date of diagnosis or end of treatment, and life changes such as school entry or the normalization of peer relationships can bring on feelings that include relief and happiness, sadness about the loss of a regular childhood, and guilt over having survived when others did not. Some survivors may feel vulnerable because of their cancer experience, and can be concerned about their health and act with

caution. Parents of childhood cancer survivors very much want to protect all of their children from harm. These protective feelings can increase usual tensions between parents and teenagers over issues related to growing independence, especially in matters that can affect health. Other teens who have had cancer believe that, having survived cancer, they can do anything - and this makes them feel invincible. These feelings can lead some survivors to undertake difficult studies, work or hobbies. The same feelings can lead other survivors to take part in unhealthy or risky behaviors.

Some Reactions to the Stresses of Survivorship

For the most part, childhood cancer survivors and their family members respond well to the stresses of survivorship. Sometimes though, physical problems or other stresses related to childhood cancer and everyday life can sometimes lead to intensely distressing emotions that need medical attention. Some survivors, and their family members, can experience periods of high anxiety that may or may not be triggered by reminders of the upsetting aspects of treatment. They may develop three types of symptoms typically seen in people with posttraumatic stress disorder (PTSD), including (1) unwanted recall of unpleasant memories of cancer, (2) physical or emotional overreactions, and (3) going out of the way to avoid reminders of cancer. For the most part, childhood cancer survivors and their family members do not develop all three types of symptoms and PTSD. Yet one or two of these symptoms can nonetheless get in the way of relationships, school, work and other key areas of daily life in survivorship.

Personal growth can be another reaction to the stresses of survivorship. After years of living with childhood cancer, some survivors and their family members may find that they have undergone meaningful and beneficial changes in themselves, their relationships with other people, and their values as a result of their experiences. It does not mean that these survivors would choose to have had cancer, but that they have been able to find some positive changes in their lives as a result of surviving that stressful experience. Experiencing these positive changes is sometimes referred to as posttraumatic growth.

Risk Factors

Several factors can affect the development of depression and anxiety with symptoms of posttraumatic stress after diagnosis and treatment of childhood cancer, including:

- Female gender
- Adolescent or young adult age
- Prior trauma

- Mental health or learning problems before childhood cancer
- Low levels of social support
- Parental history of depression, anxiety, or PTSD
- Cancer of the brain or spine (central nervous system - CNS)
- Cancer treatment to the CNS (radiation to head, chemotherapy into spinal fluid)
- Treatment with Hematopoietic Cell Transplant (bone marrow or stem cell transplant)

When to Seek Help

People with distress that (1) lasts two weeks or more, and/or (2) interferes with their ability to do key home, school or work tasks, should call their healthcare provider to discuss the need for a referral to a mental health professional. Because physical health problems can cause these same symptoms, a through check-up by your primary healthcare professional is recommended if they occur. Some possible signs that help is needed can include:

- Changes in appetite and weight
- Crying easily or being unable to cry
- Constant tiredness and low energy level
- Sleeping a lot
- Not sleeping well
- Feeling hopeless; thoughts of death, escape, suicide
- Increased irritability
- Decreased interest in activities that had been pleasurable in the past
- Unwanted recall of painful aspects of cancer
- Feeling extremely fearful, upset or angry when thinking about cancer
- Physical reactions (rapid heart rate, shortness of breath, nausea) when thinking about cancer
- Avoiding health care visits
- Refusing to talk about cancer

Share Your Concerns with Your Healthcare Provider

If you experience distress, discuss it with your primary health care provider or childhood cancer specialist. Your distress may be related to your cancer experience, worries about late effects, or other events in your life. In any case, there is treatment. Talking with others about your fears and worries is a first step in gaining control over them. In addition to receiving help from a health care provider, some people also find support through support groups, participation in activities at their place of worship, or their sense of spirituality. Support can help survivors and their families manage difficulties in useful ways.

Treatment Options

Treatments for depression, anxiety and posttraumatic stress symptoms include counseling in group or individual sessions and medication. Medication usually works in combination with some form of counseling. Mental health professionals (including mental health nurse practitioners, psychiatrists, psychologists, and social workers) provide treatment for depression and anxiety in a variety of community settings. Your primary healthcare provider can help you find a suitable mental health professional in your community.

Resources

Support is available to childhood cancer survivors and their families who have anxiety and depression after treatment. These are just a few of the many resources available:

American Cancer Society (www.cancer.org)

This site provides web-based support network, other programs and services, and stories of hope for cancer survivors and their families.

American Psychiatric Association (www.healthyminds.org)

This site provides guidelines for choosing a psychiatrist.

The Anxiety Disorders Association of America (www.adaa.org)

This site provides information that can help people with anxiety disorder find treatment and develop self-help skills.

Lance Armstrong Foundation (www.laf.org)

This site provides information and tools through this site that people living with cancer can use to "live strong".

Candlelighters Childhood Cancer Foundation (www.candlelighters.org)

This site offers education, support, service, and advocacy for childhood cancer survivors, their families and the professionals who care for them.

Cure Search (www.curesearch.org)

This site provides parents and families with information related to specific cancer type, treatment stage and age group as well as tips on navigating the health care system, getting and giving support, and maintaining a healthy lifestyle.

National Institute of Mental Health (www.nimh.nih.gov)

This site provides general information about anxiety or depression, available treatments, finding a mental health provider, and access to research reports and other relevant information. See these specific areas of the web site:

www.nimh.nih.gov/healthinformation/anxiety/menu.cfm

www.nimh.nih.gov/healthinformation/depression/menu.cfm

Patient Centered Guides (www.patientcenters.com/survivors)

This site provides a list of follow-up clinics for childhood cancer survivors and articles related to psychosocial aspects of survivorship.

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Additional health information for childhood cancer survivors is available at
www.survivorshipguidelines.org

Note: Throughout this *Health Links* series, the term "childhood cancer" is used to designate pediatric cancers that may occur during childhood, adolescence, or young adulthood. *Health Links* are designed to provide health information for survivors of pediatric cancer, regardless of whether the cancer occurred during childhood, adolescence, or young adulthood.

Introduction to Late Effects Guidelines and Health Links: The "Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers" and accompanying "Health Links" were developed by the Children's Oncology Group as a collaborative effort of the Late Effects Committee and Nursing Discipline and are maintained and updated by the Children's Oncology Group's Long-Term Follow-Up Guidelines Core Committee and its associated Task Forces. **Disclaimer and Notice of Proprietary Rights**

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