Healthy living after treatment of childhood, adolescent, and young adult cancer

### Mental Health after Cancer Treatment

#### The Cancer Experience

#### Diagnosis and Treatment

Diagnosis and treatment are difficult times for people with cancer and their families. During diagnosis, children or teens have tests and procedures that are new, sometimes painful and often scary. For parents, the anxiety of waiting for the results of these tests and procedures 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 plan is working or should change. Children and teens 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 their child's cancer will be cured, how to minimize their suffering, and how to make the most of life. Brothers and sisters also worry about, and are sometimes jealous of the sibling 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, people diagnosed 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 stress. 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 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 individuals 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 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 after cancer.

Personal growth can be another reaction to the stresses of life after cancer. 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. Furthermore, they may have been able to find some positive changes in their lives as a result of surviving the cancer 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 difficulties before childhood cancer
- Developing health problems or physical limitations due to cancer treatment
- Low levels of social support
- Parental history of depression, anxiety, or PTSD
- Central nervous system (CNS) cancers (brain or spine) or treatment (radiation to the head/spine or intrathecal chemotherapy)
- 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 daily 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 thorough 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 more than usual or being unable to sleep
- Feeling hopeless
- Thoughts of hurting yourself or others
- Engaging in self-harm behaviors (ie. cutting)
- Alcohol or drug use to avoid unpleasant feelings
- 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

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#### 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 faith.

#### **Treatment Options**

Treatments for depression, anxiety and posttraumatic stress symptoms include counseling in group or individual sessions and, sometimes, 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.psychiatry.org

This site provides guidelines for choosing a psychiatrist.

#### The Anxiety and Depression Association of America www.adaa.org

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

#### American Childhood Cancer Organization www.acco.org

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

#### Childhood Cancer Guides www.childhoodcancerguides.org

This site provides articles related to psychosocial aspects of survivorship.

### Children's Oncology Group www.childrensoncologygroup.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/health/topics/anxiety-disorders

www.nimh.nih.gov/health/topics/depression

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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.

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