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UNIVERSITY OF MINNESOTA

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From the editor

Not enough is known about the long-term psychological effects of diagnosis and treatment for childhood cancer and similar serious illnesses. One of the things we do know, however, is that these events hit every member of a family hard - parents and brothers and sisters, as well as the person being treated. That is the reason we are sending this issue of our newsletter, which focuses on mental health, to our sibling participants as well as to our study participants who were ill. We urge you to share the information in this newsletter with your parents, brothers, sisters, and others who are close to you.

For those of you who might not know, the sibling "control group" is made up of brothers and sisters of study participants who have volunteered to complete our study questionnaires so that we can compare their experiences with the experiences of those who have had a childhood illness. (Some participants were chosen randomly and asked to invite one of their siblings to take part. So, not all participants have a brother or sister in the control group. For more information about siblings, please see the article on page 4.)

Follow-Up 2002. What we have learned so far about the emotional well-being of our participants is mostly positive, as we report in the study update on page 3. However, more detailed information is needed, if we are to help healthcare providers become aware of the lifelong mental health needs of long-term survivors and their families. Later this fall, we will begin sending out our next comprehensive questionnaire. This questionnaire will go out to all participants including siblings. It will contain several sections about mental and emotional health. With your generous assistance we hope to be able to increase our understanding of this important topic. The upcoming questionnaire will be formatted somewhat differently than previous ones. We're sure you will be glad to see that there are no bubbles to fill in. They have been replaced by check boxes.

The LTFU has been going since 1994, more than eight years. That may seem like a long time but compared to some follow-up studies we are just getting started. Health effects which occur over the course of a lifetime take a long time to study. The article on page 4 explains the nature of long-term studies like the LTFU. We hope you will find it informative. The success of the study depends on the continuing participation of all our cohort members. For our part, we will try to make our questionnaires as interesting and as brief as possible!

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Dealing with emotions after childhood illness

by Dr. Melissa Hudson

Trauma and childhood illness

Diagnosis and treatment of childhood cancer and similar illnesses can be traumatic because of the painful, invasive procedures, frequent hospitalizations, and separation from family and friends. These events cause suffering for all family members. At diagnosis, patients worry about whether their disease will respond to treatment and how they will handle the unpleasant side effects of therapy. Parents share these concerns and often feel angry and helpless because they are unable to prevent their child's suffering. Brothers and sisters may become frightened or feel neglected and guilty because they resent the time and attention their parents must give to a sick sibling. All of these difficult feelings typically lessen over time as treatment is completed, side effects go away, and a cure appears likely. Although patients and families handle the stress of diagnosis and treatment in different ways, periods of anxiety and depression occur for almost everyone.

After therapy, worries are not over

Once treatment is completed, persistent side effects may be constant reminders of the stressful events at diagnosis and treatment. The diagnosis of a new health problem, like infertility, that is caused by the treatment can cause discouragement. Returning for check-ups and just hearing about possible late problems can make those anxious feelings return.

Reacting to the stresses of survivorship

For the most part, the majority of patients and family members cope well with the lifelong effects of treatment. Occasionally, however, physical problems and emotional stress may lead to anxiety or depression that requires medical attention. In addition, people can sometimes experience periods of intense anxiety or hyper-arousal triggered by upsetting memories related to treatment. These conditions may be symptoms of post-traumatic stress. They have been observed in people who have lived through painful life-changing events like a war or a natural disaster. (Symptoms of post-traumatic stress are often delayed responses to traumatic experiences that can develop many years later.) In severe cases, depression, anxiety, or post-traumatic stress may affect personal relationships and school or work performance.

When you should seek help

The table at the right lists common symptoms of depression and post-traumatic stress. We strongly encourage patients or family members with symptoms lasting two or more weeks to call their doctor to discuss the need for a referral to a mental health counselor. Because cancer treatments occasionally result in hormone deficiencies or other problems that can affect mood and create these symptoms, we also recommend a thorough check-up by your primary care physician.

Treatment options

Mental health counselors work in a variety of settings that may vary in each community. Counselors may be social workers, psychologists, or psychiatrists. Some families prefer to start with counseling services offered by a clergy person at their place of worship. Another option is to ask your family doctor to help you find a mental health counselor. Treatments for depression and anxiety include individual or group counseling and medication. Medications are usually given by a medical doctor like a psychiatrist or a primary care physician working with a counselor. Medication usually works best in combination with some form of counseling.

Share your concerns with your doctor

If concerns about complications after treatment are causing feelings of anxiety or depression, discuss these feelings with your family doctor or your cancer specialist to find out if they are related to your treatment. Sometimes anxiety may result from other events in your life not related to your illness. In any case, ask your doctor about what you can do to reduce the risks of health problems as you get older. It is important to remember that many people who have never been treated for a serious illness commonly suffer from anxiety and depression, and even from post-traumatic stress. Help is available to treat these problems. Seeking help can be a powerful first step in overcoming them.

SYMPTOMS OF DEPRESSION AND POST-TRAUMATIC STRESS

Symptom	Depression	Post Traumatic Stress
Overeating, weight gain	X	
Poor appetite, weight loss	X	
Crying easily or unable to cry	X	
Chronic fatigue, poor energy	X	
Sleeping a lot	X	
Difficulty making decisions	X	
Hopelessness/thoughts of death, escape, suicide	X	
Difficulty sleeping	X	X
Difficulty concentrating	X	X
Increased irritability	X	X
Decreased interest in activities	X	X
Re-living painful memories of illness		X
Becoming upset, scared, or angry when thinking about illness		X
Physical reactions (like rapid heart rate, nausea) when thinking about illness		X
Staying away from medical visits		X
Refusing to talk about illness		X

Study update: mental health

Most people treated for cancer or a similar illness in childhood are psychologically healthy. That is the good news recently reported by LTFU study investigators in the medical journal *Pediatrics*.

The research team analyzed questionnaire responses from a group of our study participants. The group included 5736 adult survivors of childhood leukemia, Hodgkin's disease and non-Hodgkin's lymphoma and 2565 members of the sibling control group.

The researchers looked at the participants' responses to questions about depression and physical distress. They found that:

- ❑ Most people in the study did not have symptoms of depression or distress. This finding supports other research suggesting that the majority of survivors are psychologically healthy and coping well with the effects of their past illness and treatment.
- ❑ The proportion of study participants who reported symptoms of depression was similar to that in the general population. Scientists estimate that between three and ten percent of young adults ages 18 to 44 have symptoms of major depression.
- ❑ Survivors were more likely than siblings to have symptoms of depression or distress.
- ❑ Women, both survivors and siblings, were more likely than men to have symptoms. This is also true in the general population.
- ❑ Both survivors and siblings who experienced life difficulties such as unemployment, low-income, and lack of education were more likely than other participants to have symptoms, as is true for the general population.
- ❑ Participants who had intensive chemotherapy were more likely than other participants to have symptoms. However, there is probably no physical link between intensive chemotherapy and psychological difficulties. Instead, the researchers speculated that people who had intensive chemo were more likely than others to suffer significant life disruptions during treatment. Multiple hospitalizations, long absences from school, and restrictions on activities related to chemotherapy might all play a part in disposing these participants to experience psychological distress in adulthood.
- ❑ No other treatment-related factors were strongly associated with depression or distress.

It is gratifying to see such positive results on such an important subject. It's very good news that most of you are doing so well. However, if you are having mental or emotional difficulties, please remember they are nothing to fear or to be

ashamed of. Many people, including those who have never had a serious illness, have these sorts of problems. They are very treatable. A good place to start is with your family doctor, who may refer you to a counselor. Be sure to let him or her know about your childhood illness and treatment.

*"Psychological outcomes in long-term survivors of childhood leukemia, Hodgkin's disease, and non-Hodgkin's lymphoma" can be found in **Pediatrics** Vol 110 No 1 (July 2002) pages 24-52.*

Dr. Brad Zebrack: researcher, cancer survivor

Brad Zebrack, the lead author of the paper discussed above, is a research fellow at the UCLA School of Medicine and an investigator with the Long-Term Follow-Up Study. Before he became a researcher he was a pediatric oncology social worker at Children's Hospital in Oakland, California.



Dr. Zebrack is also a long-term cancer survivor. In 1985, at the age of 25, he was diagnosed with Hodgkin's lymphoma. His experience with cancer and treatment led him to his interests in both social work and research. His research focuses on the impact of cancer on survivors and their families. He has published several articles on quality of life among survivors of childhood cancer.

Both as a social worker and as a researcher, Dr. Zebrack has found that serious illness and treatment can have positive as well as negative effects. Many survivors he has spoken with feel that their experiences have helped them to become better people. "In spite of the physical challenges that continue through their lives, they still often find that cancer can be a source of motivation," he says. In 1989, Dr. Zebrack and his wife Joanne completed a year-long 11,000-mile bicycle trip around the United States. The purpose of the trip was to inspire young people treated for cancer and similar illnesses to have confidence in their ability to lead productive and satisfying lives in spite of their illness and treatment.

Comments or questions?

Call our toll-free line:

1-800-775-2167

Survivors and siblings make history!

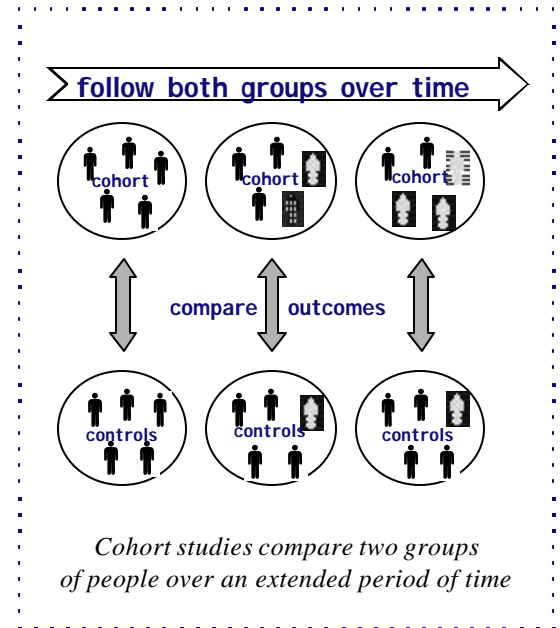
Did you know that the survivors and their siblings who are participating in the Long-Term Follow-Up (LTFU) Study are making medical history? Our study is the largest ever of survivors of childhood cancer and similar illnesses. It joins the ranks of many other famous cohort studies that have led to major medical discoveries. (Please see box below.)

What is a cohort study?

A cohort study is a study that compares a group of people who share a common characteristic with another group that does not have the characteristic. The common characteristic might be a medical condition, a treatment, or even a behavior, like smoking. The participants in the LTFU Study share a common history of treatment for cancer or a similar illness during childhood or adolescence. The comparison group is also known as the control group. For best results the people in the control group should be as similar as possible to the group being studied. In our study, a certain number of participants were randomly chosen, like a flip of a coin, to invite one of their siblings (brothers and sisters) close to them in age to be in the control group for the cohort.

Why were siblings chosen for the LTFU control group?

Siblings make a good control group because they typically grow up in the same environment as the cohort participant. The sibling control group is similar to the LTFU cohort in almost every way except they did not receive treatment for cancer or a similar illness in childhood. If survivors in the LTFU cohort have different health outcomes compared to their brothers and sisters, these results can provide strong evidence about how cancer treatments affect long-term health. Siblings in our control group are very important to the success of the study. In fact, the validity of study results depends on sibling participation, now and in the future.



How long does a cohort study run?

Because most cohort studies are looking at long-term effects on health, they typically run for many years. For example, the Framingham Heart Study has been running for more than fifty years. It now includes information from two generations of citizens

of the town of Framingham, Massachusetts. Cohort studies with good participation rates by the cohort and control group yield the most accurate results. We are very grateful for your continuing participation in the LTFU Study. You are helping researchers better understand the effects of treatment for childhood cancer and similar illnesses on the long-term health and quality of life of survivors.

SOME FAMOUS COHORT STUDIES

Framingham Heart Study

Started in 1948 to study heart disease and its risk factors. Has enrolled two generations of citizens of the town of Framingham, MA. Reported on the association of type "A" behavior with heart disease; discovered the effects of LDL and HDL cholesterol; found cigarette smoking increases heart disease risk. <http://www.framingham.com/heart/>

Nurse's Health Study

Started in 1976 to research risk factors for major chronic diseases in women. Has enrolled 122,000 nurses. Studies oral contraceptives, diet and lifestyle risk factors for chronic disease. Demonstrated associations between obesity and heart disease and between alcohol consumption and breast cancer. <http://www.channing.harvard.edu/nhs/>

Minnesota Twin Family Study

Started in 1983. Has enrolled more than 8000 pairs of twins and their family members. Compares identical twin pairs raised together to those separated at birth and raised in different families. Has published findings suggesting that certain inherited personality traits can influence the risk of getting a divorce. <http://www.psych.umn.edu/psylabs/mtfs/>

Future of the Long-Term Follow-Up Study

The Long-Term Follow-Up Study began in 1994. So far, we have sent out two comprehensive health surveys. Ninety percent of our participants have already returned these first two surveys. Many of you have also given us additional information about such topics as pregnancy outcomes, health care access, and sexual health. Later this fall we will begin sending out our third comprehensive survey. After that, we will continue to contact you every two to three years.

We hope you find your participation enjoyable and that you will join us in making medical history for many years to come. Thank you!

Identifying a counselor

- ✓ Mental health counselors may be found in private practice, group practice, faith-based counseling services, or community health centers.
- ✓ Ask your family doctor or others for recommendations.
- ✓ Choose a counselor with a master's degree (MS or MSW), a doctorate (PhD) or a medical degree (MD).
- ✓ Choose a licensed counselor.
- ✓ Check the credentials of the counselor. They may be trained in social work, psychology, or medicine.
- ✓ If medication is needed, a psychiatrist or primary care doctor working with a counselor will be needed to prescribe it.

Paying for mental health services

- ✓ Check details about mental health coverage on your insurance policy.
- ✓ Does the policy require a referral from your primary care physician?

- ✓ What percentage or amount of services is covered?
- ✓ Is a co-pay required at the time of service?
- ✓ Do you have to choose a counselor from a provider list?
- ✓ If you have Medicaid or Medicare benefits, check the list of providers in your community who accept these benefits.
- ✓ If you do not have insurance, check with your state or county health department to see if you are eligible for coverage by other state or federally supported insurance plans.

Communicating with your counselor

- ✓ Be sure your counselor is aware of the details of your cancer treatment. If you don't have information about your cancer treatment, call or visit your oncologist to obtain it.
- ✓ If you do not feel that you are able to relate well to your counselor after 2-3 sessions, let him or her know and look for a new counselor.

MENTAL HEALTH SERVICES LOCATOR

The Center for Mental Health Services (CMHS) Knowledge Exchange Network of the U.S. Department of Health and Human Services provides a state-by-state mental health services locator at the following web address:

<http://www.mentalhealth.org/databases/>

They also provide free information about mental health at their toll-free telephone number:

800-789-2647

**If you would like more information, please call our toll-free study line:
1-800-775-2167**