

LTFU

Long-Term Follow-Up Study

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*For a list of participating centers,
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UNIVERSITY OF MINNESOTA

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Greetings! In this issue of the LTFU Study newsletter we report good news from two recent studies. The studies are based on information you have provided us through your responses to our surveys. They show that, for the most part, our participants are coping very well with some major challenges of survivorship.

You're doing quite well, thank you! Our findings show that most Study participants are emotionally healthy and enjoy life. Some groups may need help in this area, however. As with most health challenges, there are strategies that can help people who are struggling with emotional and psychological concerns.

Fighting fatigue. Unlike everyday tiredness, fatigue isn't relieved by rest. Our findings link fatigue and sleep disturbances with certain types of treatment and also with certain personal factors. If you experience fatigue you should know that there are many things you can do to beat it. We list suggestions throughout this issue.

Dancing through life. Our interview with Study participant Jillian Morris-Jenkins shows what the study results tell. Jillian began dancing as soon as she could walk. Today, she is still dancing, in spite of ongoing fatigue related to childhood cancer and the treatments that saved her life.

Thank you. As always, we want to express our thanks to you, our participants, for partnering with us in these important research efforts.

—Margaret Carbaugh, Managing Editor

FREE Help to Quit Smoking

Today the harmful effects of smoking are known to just about everyone. Smoking is especially risky for survivors, who may have serious health problems made worse by smoking. Examples are lung disease, heart and vessel disease, and secondary cancer. Smoking also increases their risk of these conditions.



We know that quitting is hard. It is even harder if you have been smoking for many years. That's why we have built our smoking cessation program on two therapies known to improve your odds of success:

- *Nicotine patches to help curb cravings and*
- *Telephone counseling to support your efforts to change.*

We will soon be sending out brochures and a letter with additional information about the program. If you smoke and are ready to quit, please sign up to take part in this FREE program. For more details, call 1.877.4SJ.QUIT or visit our web page:

www.stjude.org/breakfreefromsmoking

Study Update

Emotional Health and Health-Related 'Quality of Life'

Most study participants are emotionally healthy and enjoy a positive quality of life. This is one of the important take-home messages of a recent study of emotional health and quality of life. They're able to cope successfully with the feelings of anxiety, fear, and sadness that we all sometimes have. "Quality of life" refers to a person's overall sense of emotional, social, and physical well-being.

What we learned. The survivors in this study were only slightly more likely than were the siblings to report that they had emotional problems or that health-related problems affected the way they felt about their lives. Not surprisingly, the survivors were also more likely to report problems with physical function and general health.

When we looked at specific groups of participants, we found that people in the following groups were more likely than others to have difficulties:

- *Women (women in the general population also report more trouble with emotional health and "quality of life" issues than men do)*
- *Unmarried or unemployed people*
- *People with lower levels of education*
- *People with lower incomes*
- *People who lacked medical insurance*
- *People who had a major medical problem.*

Groups that reported fewer problems were those whose original illness was diagnosed before they were 10 years old and those who had been treated more recently.

Why results are important. This study shows that most Study participants are doing very well years after treatment and that is very good news. It gives us additional evidence of the resilience and coping skills of survivors. The results also tell us about which groups of survivors might need help in achieving a satisfying level of emotional health.

About the study. More than 7000 adult survivors and about 400 siblings provided answers to the surveys for this study. We used the siblings as our comparison group because they

shared in the experiences that the survivors had with illness and treatment. For that reason they were more like the survivors than are people in the general population who have not had cancer.

Dr. Lonnie Zeltzer led the study. Dr. Zeltzer is a professor of Pediatrics, Anesthesiology, Psychiatry, and Biobehavioral Sciences at the David Geffen School of Medicine at UCLA and Associate Director of the Patients and Survivors Program of the UCLA Jonsson Comprehensive Cancer Center. Details of the study were published in 2008 in the journal *Cancer Epidemiology, Biomarkers, and Prevention*.



Add New Energy to Your Life

We all feel tired and struggle with our emotions at times. If fatigue or emotional troubles continue or get worse, see your doctor to rule out a medical cause.

If you have trouble sleeping . . .

Set up a bedtime routine.

Go to bed and get up at the same time each day.

Limit alcohol and caffeine, especially in the evening.

Try to eat your evening meal at least 2-3 hours before you go to bed.

Try meditation to turn your mind away from the concerns of the day.

Switch off the tv and the computer an hour before bed time to give your mind a chance to unwind.

Diet and exercise really can help . . .

Eating a wide variety of foods and lots of fresh veggies and fruit ensures that you get the nutrients you need to support physical and emotional health.

To sneak extra vegetables into your meals, finely chop broccoli, carrots, or celery and add to pasta sauce, meat-loaf, or burgers.

Try fish for lunch or dinner once or twice a week. Some evidence suggests that the healthy fats in fish like salmon and tuna can have a positive effect on emotions.

Exercise boosts both energy and mood. Ask your doctor about the right amount and type of exercise for you.

Treat depression . . .

Fatigue, anxiety, and trouble sleeping can be symptoms of depression. If you think you might be depressed, talk to your doctor about getting help.

PLEASE SEND US YOUR E-MAIL ADDRESS

Please update your contact information by going to our website: www.stjude.org/ltfu. Click on the link on the left side of the web page labeled Contact Info Update Form. We would especially like your e-mail address, if you have one.

Thank you!

Fatigue and Sleep Problems

Fatigue—one of the most common side effects of cancer and treatment—can stick around for months or years after treatment ends. Unlike everyday tiredness fatigue, isn't relieved by rest. Because it may affect every aspect of your life, we asked Study participants to describe their experiences with fatigue and related problems.

What we found. Survivors reported only slightly more fatigue or sleep problems than did members of the sibling

Mind-Body Medicine . . .

“focuses on the interactions among the brain, mind, body, and behavior, and on the powerful ways in which emotional, mental, social, spiritual, and behavioral factors can affect health,” according to the US National Center for Complementary and Alternative Medicine (NCCAM).

You can find additional information about mind-body medicine and other fresh approaches to wellness on the NCCAM website:

<http://nccam.nih.gov/>

comparison group. Also, their experience with fatigue and sleep problems did not differ significantly from that of the general population of healthy adults who have never had cancer.

However, about a fifth of the survivors in this study did report that they were dealing with fatigue. These people were likely to have a history of radiation therapy, to have heart or lung problems, or to also be depressed. Women and people

who were not married also reported problems with fatigue. Seventeen percent of survivors reported problems with sleep and 14 percent reported having daytime sleepiness. Health factors linked to daytime sleepiness were heart problems, obesity, and depression. These factors were similar for survivors and for siblings in the comparison group.

Questions for future research. Many participants in the LTFU Study completed treatment years ago. Because the results of this study were generally positive, we now wonder whether cancer- or illness-related fatigue decreases over time. Longer follow-up studies of adults who received treatment for childhood cancer and similar illnesses will help us learn whether this is true. As people get further away from the time of their original treatment, we would like to ask them about fatigue and sleep again.

About the study. This is the largest study done so far on the topic of cancer-related fatigue and sleep among adults who had cancer or a similar illness during childhood. The results are based on survey responses from more than 1800 survivors and 500 sibling participants in the LTFU Study. The study was led by Dr. Daniel Mulrooney, a pediatric oncologist at the University of Minnesota. Details were published in the journal *Sleep*.



Dr. Dan Mulrooney

Comments by Dr. Lonnie Zeltzer: “Mind and body . . . what affects one affects the other”



Dr. Lonnie Zeltzer

The period of time during diagnosis and treatment of a serious childhood illness such as cancer is probably the toughest that patients and families ever live through. Years after treatment ends, former patients may continue to face delayed treatment effects—both physical and emotional. The good news is that fatigue, sleep problems, anxiety, and depression can all be treated.

We were surprised that so few participants reported long-term problems with sleep and fatigue. Some early research among people who were treated for cancer during adulthood shows that they continue to struggle with fatigue and sleep problems for years after the end of therapy. Not so for the participants in the LTFU Study. We are also happy to see that Study participants overall report better emotional health and quality of life than do members of the general population. It's clear that no one goes through treatment for childhood cancer or other serious childhood illness without being touched in some way. But many people manage to grow and gain new meaning in life as a result of these stressful experiences.

We may think of fatigue as a purely physical condition and anxiety or depression as entirely emotional. But we really cannot split the mind and body into two separate parts—what affects one affects the other. There are many ways to help your body and mind work together to reduce the negative effects of stress. A number of strategies can be learned, such as biofeedback, hypnosis, yoga, or meditation. In meditation, one learns how to focus breathing while noticing the present rather than worrying about the past or the future. In fact, many childhood cancer survivors talk about how the experience has made them notice and appreciate the present moment, rather than waste time worrying.

In addition to stress management strategies that are good for everybody, getting help for anxiety or depression can improve a person's satisfaction with life. It's not a sign of weakness but of strength to seek help as needed. Exercise and spending time in ways that give you pleasure are all equally important for maintaining good psychological and physical health, reducing fatigue, improving sleep, and enhancing quality of life.

Notes from Participants

Despite Fatigue Jillian Dances Through Life



Jillian, age 3, shortly after treatment

Blessed as a child with natural grace and plenty of energy, Jillian Morris-Jenkins began dancing as soon as she could walk. Today she is still dancing even though she gets tired easily and sometimes has trouble getting enough sleep. Her sleep problems and fatigue are related to childhood cancer and the treatments that saved her life.

A chance discovery when she was two years old helped save Jillian's life. While changing her diaper, her aunt noticed a lump on Jillian's chest. Doctors diagnosed it as advanced stage neuroblastoma. They treated Jillian's cancer with head-to-toe high-dose radiation, chemotherapy, and blood transfusions. Two major surgeries followed — and finally a bone marrow transplant.

Jillian is now a young adult and her cancer has never come back. She has had to deal with other medical conditions and delayed effects of therapy, however. Ongoing fatigue and sleep problems bother her the most.

To help get a good night's sleep Jillian tries to go to bed and get up at the same time every day. "Even with an alarm clock I have the worst time getting up in the morning," she says. "On week nights I sleep at least six to seven hours but I feel as if I haven't slept at all."

Jillian's doctor, Dr. Jacqueline Casillas, is an LTFU Study investigator. Dr. Casillas sees Jillian at a clinic for adult survivors of childhood cancer at the UCLA Livestrong Center of Excellence for Survivorship Care.

Dr. Casillas is very aware of Jillian's problems with sleep and fatigue. She's referred Jillian to the Integrative Oncology Center at UCLA. Integrative oncology is the combination of conventional cancer treatments with complementary and alternative therapies

that have proven to be useful. Experts at the center will put together a plan to help increase Jillian's energy and recommend relaxation techniques to help with sleep problems. Dr. Casillas may also refer Jillian to sleep experts. These professionals can review Jillian's sleep patterns to find out if she gets enough undisturbed sleep. They would inform her about good sleep hygiene practices, such as avoiding sedatives and alcohol and avoiding going to bed on a full stomach.

It's well-known that exercise can be a useful tool for combatting fatigue. Jillian regularly visits a gym to work on strength training. Walking and dancing help her squeeze in extra aerobic exercise, which is crucial to heart and lung health. To keep her routine exciting she is considering adding belly dancing to the mix!

In spite of her fatigue, Jillian works full time and takes graduate courses in fashion merchandising. She has an active social life and goes out dancing or travels with friends every chance she gets. She also spends plenty of time with her family.

"I see fatigue mostly as a sign that I'm trying to do too much," Jillian says. Giving up graduate school is not an option so, when she has to, Jillian lets other things go. When she needs to rest, she says "I must make time for it." In the future, Jillian plans to launch an online shopping site for petite women like herself (she's 4'7"). Part of the proceeds would go to a foundation to help families of children with cancer. "This may be my way to give back," she says.

Editor's note. If you would like to receive additional information about getting a good night's sleep, please contact us at:

ltfu@stjude.org



With Dr. Jackie Casillas