

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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Spring is here! Across much of the country, days are getting warmer and longer. It's time to clean up yards and flowerbeds. It's also a great time to uproot bad habits and replant the seeds of healthy living. Helping you in this effort has been our goal since the LTFU Study began. With each issue of the newsletter we work to bring you the tools you need to manage your health, as well as to report on the advances we are making in understanding survivorship.

Complementary and alternative medicine use. In this issue we look at a health trend that has grown into a movement over the last 20 years or so. During this time, a steady stream of people—including many LTFU Study participants—have been turning to various forms of complementary and alternative medicine (CAM) to deal with some of their health concerns. To find out more about CAM, read the study update on page 2 and Dr. Hudson's comments on page 3.

Follow-Up 2007. Thank you to those who have already returned your Follow-Up 2007 survey. If you have not yet completed your survey, please do so soon. As always, we will use what we learn from your responses to the survey questions to help adult survivors like you stay healthy.
—Margaret Carbaugh, Managing Editor

We Need Your Help!

Many of you may recall providing DNA to us in a mouthwash sample during the early days of the study. The DNA from those samples is still being used in research. Now, we have a need for additional samples to continue our work.

Research on the DNA of participants is an important part of the LTFU Study. This type of research won't yield quick results—in fact it can take many years—but it is crucial to understanding the health impacts of cancer and treatment on adult survivors.

To prepare for these new research studies, we need to ask for samples from you again. From cheek cells found in your saliva, we can extract DNA molecules—the building blocks of your genes. We will use the DNA molecules from your sample and from samples provided by other LTFU Study participants to learn more about the health issues facing survivors like you.

Providing a sample takes just a few minutes. The process is easy and does not hurt. As always, our studies are confidential. This means that researchers never know your name.

Our Coordinating Center team is now sending out the sample collection kits, along with instructions and a pre-paid mailer to send the kit back to us. Please help us with this important project. Thank you!

Study Update

Complementary and Alternative Medicine Use by LTFU Participants

From acupuncture to Zen, use of complementary and alternative medicine grows



Dr. Ann Mertens
led the study

To deal with long-term treatment effects, some survivors are turning to age-old remedies such as acupuncture. Others are exploring the health benefits of NewAge alternatives like crystals and magnets. More and more, these and other forms of complementary and alternative medicine (CAM) are finding a place alongside mainstream medicine. CAM means treatments that are used in addition to (complementary) or instead of (alternative) conventional medical treatments. To learn more about CAM use among LTFU Study participants, we designed a survey to explore possible links between use of CAM and people's symptoms, prior treatment, current health, and personal factors such as age, sex, and race. The survey was completed by 9,984 survivors and 2,474 siblings.

What we learned. We were a little surprised at what we learned. Those who had serious childhood illnesses such as cancer face unique health issues. So, we thought that survivors might use CAM more often than did other adults. Instead, we found that survivors are very similar to other adults in the types of CAM they use and in how often they use it.

About 40 percent of the study participants reported that they used some type of CAM for specific disease- or treatment-related symptoms in the previous year. These rates are in line with what has been reported by cancer patients in other studies.

Participants in the LTFU study tended to use CAM in addition to conventional medicine, rather than instead of it. Those who used CAM were more likely to be women, non-Black, and over the age of 30. They also had higher levels of education. Male survivors used herbal remedies more often than men in the sibling group did. Female survivors tended to use biofeedback and hypnosis or guided imagery more often than did the males.

What does it mean? Key points are shown in the box below. The survey responses raised an important question that we hope to explore in future research. Are survivors turning to CAM because conventional medicine is not meeting their needs?



Study participants used...

Acupuncture	Biofeedback
Crystals/Magnets	Energy-based therapies
Herbal remedies	Hypnosis/guided imagery
Massage	Meditation and relaxation
Therapeutic touch	Yoga/Tai Chi/Qi Gong/ special exercise

Participants reported having ...

Arthritis	Back and neck pain
Digestive problems	Fatigue
Headaches	Psychological distress
Insomnia	(Anxiety/depression)

Results were recently published in *Pediatric Blood and Cancer*. The study team was led by Ann Mertens, PhD, of Emory University, Atlanta, Georgia.

Editor's note: Health professionals who practice conventional medicine do not usually consider CAM treatments to be standard medical approaches. LTFU Study researchers are not endorsing the use of any CAM therapy. We are simply reporting on the study results.

Key points...

- Study participants should explore with their doctors possible CAM therapies that might benefit them.
- Participants need to tell doctors about their CAM use because some types of CAM might interfere with conventional medical treatments or increase the chance of side effects.
- Participants need to learn about the potential risks and not just the benefits of any CAM treatments they are considering.

Exploring New Paths to Health

Based on what you have told us, complementary and alternative medicine is widely used by LTFU study participants. What this fact means is not so clear. About 40 percent of study participants have tried some form of CAM. This percentage mirrors CAM use by the general population. It is also in line with reports by groups

“Be aware of the possibility that CAM therapies might interfere with conventional therapy or increase the likelihood of side effects.”

of other survivors of serious childhood illness like cancer.

Because of the widespread interest in CAM the National Cancer Institute (NCI) has funded studies of the risks and benefits of some CAM therapies. For example, one study is looking at the use of massage therapy to relieve cancer-related fatigue. Another is testing how well acupuncture can control symptoms of colorectal cancer.

Although the NCI is looking into the use of CAM, very few CAM therapies have yet been adequately tested to prove that they are safe and that they work. For this reason, we urge you to talk with your clinical team about the risks and benefits of any CAM therapies you are using or thinking about using. Above all, be aware of the possibility that CAM therapies might interfere with conventional therapy or increase the likelihood of side effects. For more about CAM in cancer treatment, check out the National Cancer Institute’s website (www.cancer.gov/cancertopics/pdq/cam).

Our other study update, discussed at right, looks at physical activity among LTFU Study participants who had acute lymphoblastic leukemia (ALL). While the health benefits of most CAM therapies are not proven, few forms of therapy can beat the benefits of regularly getting a move on.

Something as simple as a brisk walk each day can help you cope with stress. Exercise can lessen the effects of depression and anxiety. It can also help you sleep better. Surprisingly, most people feel they have more energy, not less, when they exercise regularly, so exercise also helps you feel less fatigued. Regular physical activity can lead to better heart and lung function, increased strength, and greater flexibility. It is key to healthy weight, adequate lean muscle mass, and strong bones.

For fun ways to work more physical activity into your life see the box at right. If you have health problems that limit the amount of physical activity you can do, ask your healthcare team what kinds of activity or adaptive exercise might work for you. Even small amounts of activity can produce big benefits for just about everybody.

ALL Survivors and Physical Activity

Regular physical activity—a key to healthy living for everyone—is even more important for people who had a serious childhood illness such as cancer. Yet results of a recent LTFU study showed that survivors of childhood acute lymphoblastic leukemia were less likely than the general population to meet Centers for Disease Control (CDC) guidelines for physical activity. The CDC guidelines are based on solid scientific data. They recommend more than 30 minutes of moderate physical activity on 5 or more days per week or 20 minutes of vigorous

activity 3 or more days per week. In the general population, 48 percent did not meet CDC guidelines; among survivors of childhood ALL, almost 53 percent did not. Researchers concluded that being less active puts survivors at greater risk of conditions such as heart disease and osteoporosis.



Dr. Oeffinger

Results were published in *Cancer Epidemiology, Biomarkers & Prevention*. The study was led by Dr. Kevin Oeffinger, Memorial Sloan-Kettering Cancer Center, New York.

Spring into Action

Try all of these every day for one week...

- Park farther from your building (if weather permits).
- Walk up and down a few flights of stairs.
- Use break time for a brisk walk around the block.

Try one of these each day for a week...

- Wake up early and take a stroll before breakfast.
- Play with a hula hoop or skip rope.
- Listen to some oldies and bop your way to a cleaner house.
- Walk to the library or the park.
- Clean out flower beds or mow the grass.

Reflect and connect the dots...

- Each evening, relax and reflect on how you have spent just one day of your life. Did you enjoy walking to the park? Did you find that you had more energy when you increased your activity?
- Chart how you feel on a scale of 1 to 10.
- At the end of the week, connect the dots on your graph to see your progress.

Congratulations—and keep moving!

Notes from Participants

Taking Charge of Your Health

The remarks below are taken, with permission, from the comments that LTFU study participants have made on their surveys. Thank you for your feedback and for allowing us to share it with other adults who had serious childhood illnesses such as cancer. And thanks to *all* of you who have written personal comments on your surveys and who continue to take part in the LTFU Study. I assure you that the information you provide does make a difference in the lives of many people, as shown in the comments we have shared here.

—Dr. Melissa Hudson



Several people wrote about research findings reported in the LTFU Study newsletter that prompted them to discuss specific health concerns with their medical team:

“I appreciate the findings you provide to study participants in the newsletter. Your alerts regarding the possibility of thyroid cancer from radiation therapy prompted me to discuss a ‘pressure’ I felt in my neck with my doctors. The pressure turned out to be the result of a benign nodule on the thyroid called a Hürthle cell tumor.”

—Janet, 52 years old, Hodgkin’s disease

“After reading one of your newsletters, I discussed some of the results with my doctor in light of some health concerns I had. She ordered an ultrasound and found benign nodules on my thyroid.”

—Theresa, 47 years old, liposarcoma

Others wrote to express gratitude for being where they are today:

“I am very blessed. I am healthy and actively enjoying my life. I love taking part in this study. I hope the information I provide helps.”

—Linc, 39 years old, rhabdomyosarcoma

“I appreciate your continued concerns regarding my health and your follow-ups. I am a survivor/thriver from my cancer for 37 years now with no recurrences. I am very blessed. I also enjoy the newsletters sent to me. Although I have not met the people featured in most of the articles, I feel that I know what they are going through or have gone through. We are very lucky to have specialists like you in our corner and taking care of us.”

—Deborah, 52 years old, osteosarcoma

Your experiences highlight the importance of being aware of the risks you face, based on the treatment you received.

They also show why you need to be on the lookout for early signs of potential problems. As you know, efforts to help you can generally do the most good when problems are detected in early stages. That’s why it’s important not to ignore signs like the pressure that Janet felt.

Congratulations on taking charge of your own health. You and other study participants have a right—a responsibility, really—to ask your doctors about your health concerns. Equally important, you have a right and a responsibility to share with them any information that may have some bearing on your health.

—Dr. Hudson

Coming Up—Camp Mak-A-Dream



Would you rather be rafting, fishing, or just relaxing outdoors? At Camp Mak-A-Dream, set in the western Montana wilderness, you can do all of this while you learn how to stay on top of your health. This year, Camp Mak-A-Dream is offering

two conferences for survivors. The Young Adult Survivor Conference (YASC), will be held May 14-19. This conference is for people in their 20s and 30s who have completed cancer therapy. It is focused on the late effects of treatment, dealing with the healthcare system, and ways to stay healthy. The second conference is called the Young Adult Conference (YAC). This conference, held June 19-26, is for anyone ages 19-25 who currently has or has had cancer.

There is no cost to register, or for meals or lodging. Travel scholarships are available for those who have never been to either conference.

For more information, visit www.campdream.org or contact Shirley (phone: 406.549.5987; email: Shirley@campdream.org).

Thank you, LTFU Study participants, for being our research partners for the past 14 years!