

LTFU
Long-Term Follow-Up Study

SurvivorShip

Fall 2007



LTFU

Long-term Follow-up Study of Adults
Who Had Serious Illnesses as Children

1.800.775.2167

E-mail: ltfu@stjude.org

www.stjude.org/ltfu

LTFU Steering Committee

Barry Anderson

Greg Armstrong

John Boice

Stella Davies

Dennis Deapen

Lisa Diller

Sarah Donaldson

Daniel Green

Sue Hammond

Melissa Hudson

Wendy Leisenring

Anna Meadows

Ann Mertens

John Mulvihill

Joseph Neglia

Kevin Oeffinger

Roger Packer

Steve Qualman

Les Robison

Charles Sklar

Marilyn Stovall

Louise Strong

Yutaka Yasui

Lonnie Zeltzer

SurvivorShip

Margaret Carbaugh,
Managing Editor

Margaret.carbaugh@stjude.org

Melissa Hudson,
Medical Editor

Melissa.Hudson@stjude.org



Thank You for Partnering with Us in Research

From the scientist's workbench (or workstation) to the patient's bedside—progress in medicine grows out of high quality research. Today, more than ever, successful research calls for a team effort, with each team member playing a vital role. For more than a decade, the most valuable players on our team have been you—and the 17,000 other participants who continue to make the Long-term Follow-up Study a success.

In the near future, we plan to add another 20,000 participants to your ranks, thanks to funding from the National Institutes of Health. Like you, this group received a diagnosis and successful treatment for cancer or another serious illness during childhood. To help us answer important questions about your health, we have chosen to focus on people who received treatment from 1987 to 1999. In this way, we can better understand how changes in medical care may affect your future health.

Growth in the study comes at a crucial time. Many adults like you are now entering their midlife years and beyond, the time when health risks related to previous treatment may show up. Also, long-term risk may be increased by unhealthy behaviors and other health problems that commonly occur as we all grow older. An understanding of these risks will help the medical team prevent or detect these health problems early on, when efforts to help you can generally do the most good. In this expanded issue of our LTFU newsletter, we have highlighted several projects to showcase the impressive amount of information that has been gained through our collaborative efforts. For those who were willing to share their stories, we are also grateful.

As we go forward together, we will take even greater strides toward understanding the long-term health issues of survivors of serious childhood illnesses. On behalf of my medical and scientific colleagues throughout North America, we sincerely thank you for your remarkable contributions to the effort.

*Warm regards,
Les Robison, PhD*



Midlife and beyond. Growth in the study comes at a time when many study participants are entering midlife. This is the time when adults like you need to be even more watchful of their health and risks related to previous treatment. The person shown here is undergoing a series of tests to evaluate his health status.

In This Issue

We share what we have learned from study results to help you stay healthy.

- 4-5 General Health**
Living with Chronic Health Problems
- 6-7 Second Cancers**
Increasing the Odds of Early Detection
- 8 Reproductive Health**
Understanding Risks to Family Planning
- 9 Mobility**
Moving Past Physical Limits: Keep Active to Stay Healthy
- 10-11 Insurance Access**
Getting the Health Insurance Coverage You Need
- 12-13 Emotional Health**
Staying Healthy in Mind and Spirit
- 14-15 Education**
Reaching Educational Goals after Childhood Illness



Seth Dixon, BMC, St. Jude

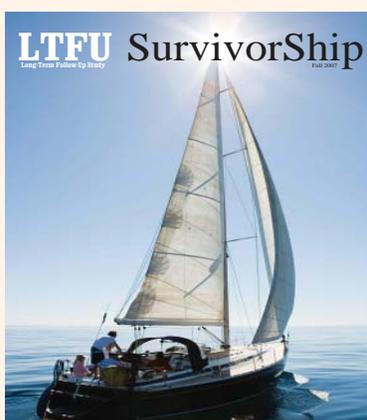


SurvivorShip has been published by the Coordinating Center of the Long-Term Follow-up Study in Memphis, Tennessee. In this special publication, we have highlighted key study findings from the past 14 years.

Previous issues of the LTFU Study Newsletter have reported on a wide range of topics. Our goal has been to give you the tools you need to live a healthy and happy life. Copies of all previous issues are now available on the LTFU Study website. You can download them from www.stjude.org/ltfu/newsletters.

Editors

Margaret Carbaugh and Melissa Hudson



Living with Chronic Health Problems

Quick Facts

What are the study's current findings?

- Survivors had more chronic problems than did siblings.
- The incidence of chronic health problems goes up over time and does not level off. This is true, even after 30 years.
- The survivors most likely to have a severe health problem had had one of the following conditions in childhood:
 - Bone tumor
 - Brain tumor
 - Hodgkin's disease
- Women and those who were older at original diagnosis were more likely to have any health problem, to have multiple problems, and to have severe problems.

What is the study's future goal?

Because health care visits with cancer specialists are less frequent over time, we need to educate family and general practice doctors about the chronic health problems of long-term survivors.

Why is this important?

Education of family and general practice doctors will be key to our efforts to help you stay healthy over time.

We compared how often survivors and siblings report chronic health problems and how severe the problems are.

Chronic health problems such as high blood pressure and diabetes seem to be the price we pay for living longer these days. The cost may be higher in adults who have had childhood cancer or a similar illness. Compared with members of a sibling group (brothers and sisters), they face higher risk of adult health problems *and* more severe health problems.

Results of a recent LTFU study on this topic are important for several reasons. They stress once again that the risk of chronic health problems is based on the specific treatment received for childhood illnesses. This is why we continue to drive home the same message: *You need to know the details about the treatments you received and share them with your doctor.*

The “good news” health story of the past 20 years or so is the dramatically improved cure rates of diseases like cancer and our ability to manage many chronic health problems. When we catch the problems early on, we further improve our odds of success. You can do your part with regular follow-ups and health screenings.

As the table shows, survivors were more likely than were members of the sibling group to have a chronic problem and to have severe or life-threatening problems.

	Chronic Health Problem	
	Any Problem	Severe Problem
Survivors	62%	27%
Siblings	37%	5%

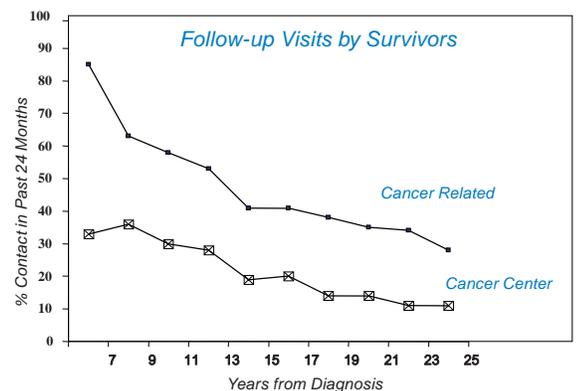
Some of the chronic problems commonly reported by survivors were vertigo (problem with balance), underactive thyroid, difficulty swallowing, hearing loss, and chronic cough or shortness of breath.

Having a second (new) cancer or heart disease topped the list of severe problems. Severe problems were more likely to develop in survivors who had received radiation therapy combined with chemotherapy drugs that affect the heart, lungs, ovaries, or testicles.

We based our findings on data about 137 chronic health conditions reported by 10,397 survivors and 3,034 siblings. Results were published in *The New England Journal of Medicine*, 1572-82, October 2006.

As Time Goes By ...

Fewer than 20% of survivors have follow-up visits at a cancer center or with a cancer specialist. Survivors are less likely to have this type of follow-up over time, although risk of problems goes up over time.



Move at Your Own Pace; Stay in Touch with Other Survivors

In this story, Jon tells how he copes with ongoing health problems and shares his favorite resources. Among them are a support group he helped to start. “Our message is simple,” he says: “You are not alone.”

Because of chronic fatigue and other ongoing health problems, 28-year-old Jon lives with his parents and works part time while he charts his future.

A survivor of acute lymphoblastic leukemia (ALL) and a brain tumor, Jon has moved more slowly toward independence than he would have liked at times. But one of the key lessons he has learned as a survivor of two bouts of cancer is that he has to move at his own pace.

“I am able to do *most* things,” Jon says. “But I can only work part-time.” School progress was also slowed by chronic fatigue and problems with memory and other learning issues. As a result, it took 8 years for him to graduate from college with a degree in sociology.

“Being able to get things done and keeping up in college was a struggle for me,” he says. “Sometimes, I feel as if I’m just being lazy or unmotivated. Other times, I realize that I’m experiencing normal side effects of the treatment, especially the brain radiation.”

Despite fatigue and other late effects, Jon plans to complete a master’s degree and work in family counseling. For now, he’s finding ways to give back to others by starting a young adult survivors’ group with Tanya, another LTFU study participant. “We’re just getting off the ground,” he says. “At present, we have local meetings and schedule monthly events.” “Eventually, we plan to host an online chat group for young adult survivors.”

“Although there are many groups for survivors, there aren’t too many that target young adults,” Jon says. “During the best of times, young adulthood can be confusing and difficult. Add on the issues of cancer survivorship and long-term effects and you’ve got a pretty heavy load.” He adds, “Plus, most people who survived a serious illness like cancer have already had a lot to cope with as kids.”

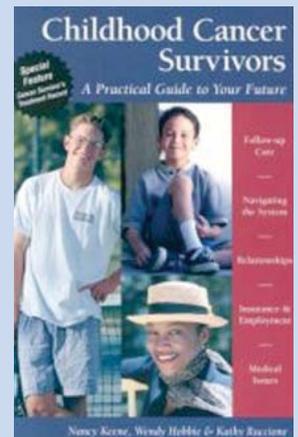
Jon knows because he’s been there. At the age of 6, he experienced a relapse of his ALL, originally diagnosed at the age of 2. Doctors tried to beat it with additional rounds of chemotherapy. When that didn’t work, he underwent total body irradiation and bone marrow transplantation. Then he experienced what he calls a “miracle.” The bone marrow of his younger sister matched his perfectly. As a result of receiving a perfectly matched bone marrow transplant, Jon did not experience graft-versus-host-disease, a common side effect, and he recovered more readily than he would have otherwise.

After surgery to remove a brain tumor at the age of 15, Jon received cranial radiation. A few years later, he completed high school and began college at the same time as his graduating class. It wasn’t until his third year of college that he began to find the work too difficult and was first checked for problems with learning and other late effects. Since then, he has received ongoing medical care to manage the late effects of his cancer and treatment.

RESOURCES

Jon shares the tips and resources that have helped him get through the tough times.

- Young Adult Survivors’ Group
www.cancersurvivorsunite.org
(1.267.738.8760)
- When he has questions about his cancer or treatment effects, Jon refers to a well-worn copy of the book *Childhood Cancer Survivors: A Practical Guide to Your Future*.
- With this book, Jon keeps a handy treatment summary listing diagnoses and dates, types, and amounts of treatment. If you don’t have a summary like this, contact your follow-up clinic.



Also, did you know that the Children’s Oncology Group offers a template to help you organize your personal treatment summary? It is available in Appendix I of the LTFU guidelines at www.survivorshipguidelines.org.

- As a survivor you have certain legal rights you need to know about. These are outlined by laws such as the American with Disabilities Act and the Family and Medical Leave Act. You can read about these laws at the U.S. Department of Labor website.
www.dol.gov/esa/whd/fmla

Increasing the Odds of Early Detection of a Second Cancer

Quick Facts

What are the study's recent findings?

- Most survivors did not have a second cancer. Risk was greater for some treatment groups than for others.
- Risk increased every year after diagnosis.

What is the study's future goal?

Some study participants are now 20 and 30 years past diagnosis. Their continued participation will allow us to look at rates and risk factors for late-occurring second cancers.

We also want to look at lifestyle issues that affect risk, such as sun exposure.

Why is this important?

Study of these late cancers will let us give you more details about screenings and ways to stay healthy.

Important Notes

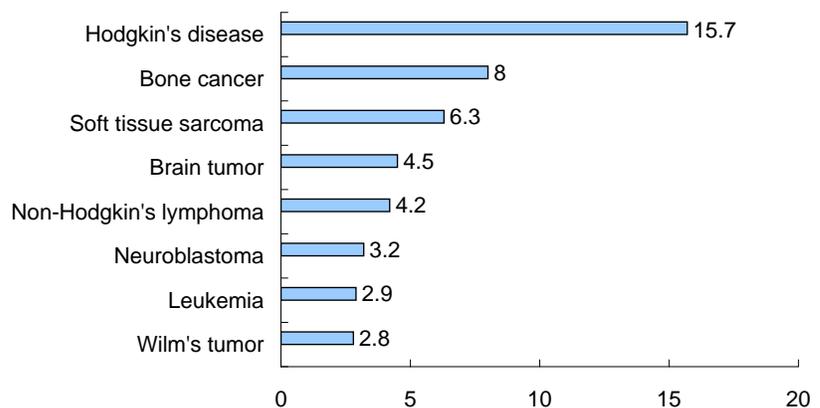
In studies conducted after this one, we are starting to look at the data of survivors whose disease was diagnosed 20 and 30 years ago. We are seeing more cases of nonmelanoma skin cancer and benign brain tumors. Rates of breast cancer also keep rising.

We recommend that women who received radiation therapy to the chest area begin breast cancer screening 8 years after radiation or at age 25, whichever comes last. Like other survivors, they should avoid tobacco and protect their skin from excessive sun exposure.

We determined rates and risk factors for second cancers among those who had childhood cancer.

For all of us, the risk of cancer inches up as we move into our middle years and beyond. Adults who had a childhood cancer face a higher risk of a new (second) cancer.

Study results suggest that overall risk of a second cancer is quite small compared to the number of people cured. However, some groups face greater risk than do others. Radiation therapy and chemotherapy using alkylating agents or anthracyclines were linked to a higher risk of second cancer. Alkylating agents are drugs such as procarbazine, cyclophosphamide, and nitrogen mustard. Anthracyclines are drugs like doxorubicin and daunorubicin. Increased risk was also linked to being a female survivor of cancer and having had cancer at a younger age. Those who had certain types of cancer, such as Hodgkin's disease, had a higher risk of a second cancer than did those who had other cancer diagnoses. See the graph for details.



Percentage (%) with Second Cancer 20 Years After Diagnosis

Second cancers were most common in the breast, thyroid, brain and bone, especially in those who received radiation therapy to these areas of the body. Breast cancer developed only in women.

Results help us see which groups need to be followed more closely. Continued, frequent follow-up and screening to detect early signs of a second cancer will increase the odds that any new cancer will be diagnosed at an early stage. You can further improve your odds by performing regular self-exams. See the box on the next page for resources.

We based our findings on a group of 13,581 study participants. We looked at questionnaire responses and pathology reports. Treatment data such as doses of chemotherapy and levels of radiation were found in the medical records of patients.

Results of other LTFU studies support these conclusions about risk factors: Among those who had breast cancer in one study, all but two had received radiation therapy to the chest. Among those who had nonmelanoma skin cancer, 90% had received radiation therapy, and 90% of the skin tumors were in the area that received radiation.

The studies are reported in the *Journal of the National Cancer Institute*, 618-29, April 2001; *Annals of Internal Medicine*, 590-7, 2004; and the *Journal of Clinical Oncology*, 3733-41, 2005.

Monitor Body Changes; Have Regular Check-ups

Michele's story stresses the value of self-exams, combined with clinician exams and mammograms. It also shows why you need to know details of your past treatment to manage your current health issues.

Technology gives us great tools," says Michele, "but they're not 100 percent accurate." That's why Michele, now in her early 40s, also stresses the value of self-exams and clinician exams. Twice, self-exams have helped identify signs of cancer early on, when treatment is generally able to do the most good.

When she was just 16, Michele first noticed an enlarged lymph node on her collarbone. After a checkup, her pediatrician referred her to a children's research hospital. There she underwent removal of the lymph node and spleen — a part of the lymph node system. Tissue from both were analyzed for diagnosis and staging of her condition, early stage Hodgkin's disease. She also received chemotherapy and radiation therapy to the chest and abdomen.

More than 10 years after treatment for her initial cancer, Michele's attention to physical changes once again paid off. While showering one day, she felt a pea-sized hard nodule during a breast self-exam. She was able to trace the edges of the nodule through her wet soapy skin. Although it was not seen on a mammogram, the nodule was picked up on an ultrasound exam.

At the time, Michele had been working as a nurse at a children's oncology hospital. She had kept up with current research, including studies about the risk of second cancer—especially breast cancer—after Hodgkin's disease. Awareness of risk prompted Michelle to take immediate action.

Within days, a surgeon removed the lump from her breast. Analysis of laboratory results confirmed that it was cancer.



Seth Dixon, BMC, St. Jude

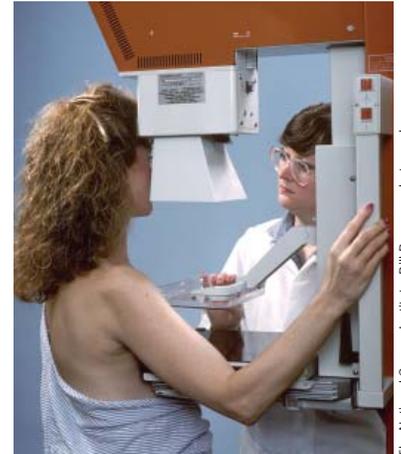
Periodic careful exam of moles can help detect early signs of skin cancer such as changes in the moles' color, size, or shape.

Michele had initially planned a lumpectomy and treatment with radiation and chemotherapy.

She changed her mind after a discussion about risk with her doctor. "I had concerns that the combined amounts of radiation to the chest area would do more harm than good. So I opted for a bilateral mastectomy [removal of both breasts] and reconstructive surgery."

Keeping up with her health issues tops all the other items on her "to-do" list. In addition to her annual follow-up exams, Michele makes sure to have all the clinical screenings recommended for her age and other risk factors. To keep informed about her risk, she refers to a well-worn copy of her medical records, which she carries with her to doctor office visits.

She says she also benefits from talking with other survivors about her experiences and has just started a survivors' support group at her church.



The National Cancer Institute, Bill Branson, photographer.

Mammograms can help detect early signs of cancer in the breast.

Resources

You need to perform regular self-exams to become familiar with your body—especially areas that received radiation therapy. In this way, you can detect early signs of skin cancer. The following websites provide helpful information.

Instructions for Conducting Skin Self-Exams [Skin Cancer Foundation]

<http://www.skincancer.org/prevention/self-examination.htm>

An Interactive Tool for Breast Self-Exam [Susan G. Komen for the Cure]

www.cms.komen.org/komen/index.htm

1. Click the tab **About Breast Cancer** for a list of topics.
2. Choose **Early Detection and Screening**.
3. Then scroll down for the interactive breast exam.

Understanding Risks to Family Planning

Quick Facts

Early Menopause

What are the study's current findings?

- Early menopause was more common among those who had cancer (8%) than among members of the comparison group of siblings (<1%).
- Almost 30% of women who received alkylating agents plus abdominal or pelvic radiation as treatment for a serious childhood illness had early menopause.

What is the study's future goal?

In the Follow-Up 2007 survey, we plan to repeat questions about menopause to better understand the risk factors for this complication. We also plan to look at ways in which genetic factors affect reproductive health after chemotherapy and radiation therapy. Plus, we plan to look at genetic factors that may predict who may have early menopause.

Why is this important?

We need to increase our understanding of which women are more likely to experience early menopause. In this way, we can better plan ways to protect them from some of the health effects that go along with menopause and assist them with their family planning.

Resources

Fertile Hope
www.fertilehope.org

American Society of Reproductive Medicine
www.asrm.org

We compared results for women who had serious childhood illnesses such as cancer with those of a comparison group of siblings.

Early Menopause

In one article, we reported that early (before age 40) menopause was more likely in women who had received radiation therapy to the pelvic area, alkylating agents, or both as treatment of a serious childhood illness such as cancer. See the figure to the right. Early menopause was also more likely in women who had a diagnosis of Hodgkin's disease or those who were older at follow-up.

Results are important because study participants can refer to them as they plan careers and families.

Women who have a high risk for early menopause may decide not to delay child-bearing, but to start their families in their young adult years. Also, women who go through menopause at a young age need to know that they may be at increased risk for other health problems such as osteoporosis, which are linked to early menopause.

We based our findings on data from 2,819 study participants and 1,065 members of a comparison group of siblings. Results were published in the *Journal of the National Cancer Institute*, 890-6, July 5, 2006.

Early Births

In another study, we found low birth weight among children of women who survived childhood cancer. We concluded that the low birth weight was due to the children being born early (that is, before 37 weeks in the womb). The children of the women who survived cancer were about twice as likely to be born early as were the children born to a comparison group of people who never had cancer.

When we looked at the data more closely, we saw a clear relation between higher rates of babies being born early and with low birth weight and higher doses of radiation to the mother's uterus during childhood cancer treatment. This was especially true for women who received radiation to the uterus before their first menstrual period.

Full results were published in the *Journal of the National Cancer Institute*, 1453-61, October 18, 2006.

Treatments Linked to Early Menopause

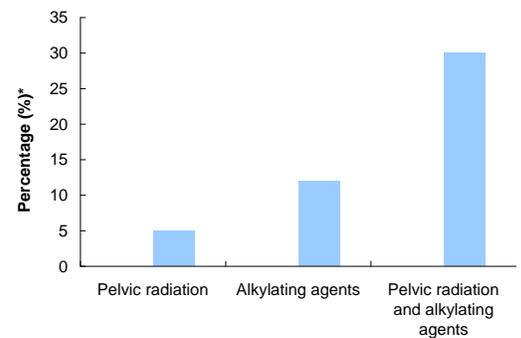


Figure shows the percentage of women who will have early menopause by age 40 based on treatment.

Risk of Early Births

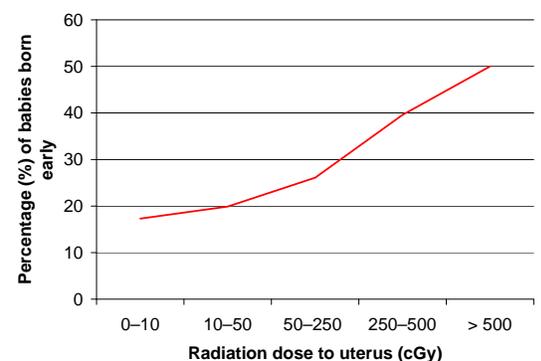


Figure shows the relation between radiation dose and early birth.

Moving Past Physical Limitations: Keep Active to Stay Healthy

Quick Facts

What are the study's current findings?

- About 20% of survivors have problems with physical abilities, like walking, moving around the house, or climbing a flight of stairs.
- Survivors are twice as likely as siblings to report these problems.
- Survivors of brain and bone tumors report the most difficulty.
- Survivors who received treatment with radiation are more likely to report physical limitations.

What is the study's future goal?

In the 2007 questionnaire, we ask more detailed questions about your physical abilities. We want to determine whether they interfere with your life, and if so, how. We also want to find out whether the number of persons with physical ability problems increases with age.

Why is this important?

Knowing details about your problems with physical activities and how they affect your life will help us develop interventions to address these problems. Also, it will encourage policy makers to provide appropriate resources to address these needs.

Resources

National Council for Support of Disability Issues
www.ncsd.org

The National Center on Physical Activity and Disability
www.ncpad.org

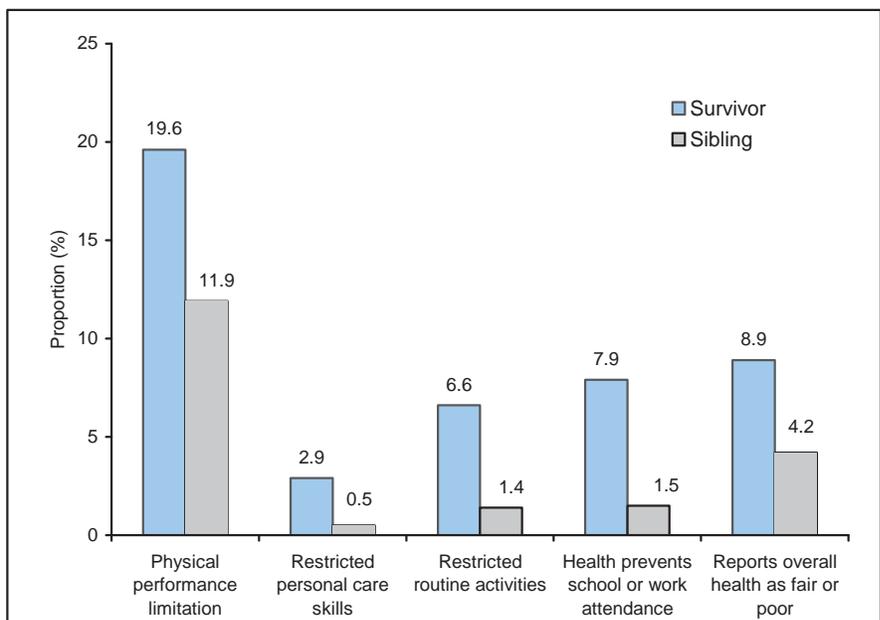
World Association of Persons with Disabilities
www.wapd.org

We compared physical abilities of a group of siblings who never had cancer with the abilities of those who had specific types of childhood cancer.

We looked at how often adults who had serious childhood illnesses such as cancer had physical limitations. Also, we looked at whether physical limitations were affected by the specific type of cancer, the treatment, or the late effects of the illness itself.

We found that most survivors manage to get around on their own and do all the things they need to do to take care of themselves in their day-to-day lives. As shown in the figure, about 20 percent of study participants who had childhood cancer reported life-long problems with physical abilities, such as walking, moving around their house, or climbing a flight of stairs. A history of treatment with radiation and lasting problems with brain, bone, muscle, heart, or lung function also increased the likelihood of reporting problems with physical abilities.

Such problems may make it more difficult for survivors to attend work or school. Also, they may have problems completing such routine activities as shopping or housework. Some may even need a caregiver to help them with bathing, dressing, and other aspects of self-care.



These findings are important because they tell us how many adults who had childhood cancer may need additional or ongoing rehabilitation. They also provide information about the types of services such individuals may need to fully participate in home, work, and community activities.

Curing serious childhood illnesses such as cancer does not end all of the challenges faced by those affected. The potential for continued difficulty with movement and full participation in life at home, work, and in the community requires long-term follow-up and access to rehabilitation services.

Full results are in *The Annals of Internal Medicine*, 639-47, November 2005.

Getting the Health Insurance Coverage You Need

Quick Facts

What are the study's current findings?

- Many survivors still lack health insurance.
- Survivors with insurance have had a harder time getting insured than have members of the comparison group of siblings.
- Survivors are more likely than members of the sibling group to be covered through Medicaid or public assistance.
- Survivors pay more for insurance than do members of the sibling group. Also, they have more restrictions and exclusions on their policies.

What is the study's future goal?

A future survey will allow us to determine what types of exclusions survivors face and how their employment choices are affected by insurance-related concerns.

Why is this important?

Knowing more about survivors' experiences with insurance will help us find ways to help you get the best coverage you can.

Insurance Tips

For more insurance tips, see LTFU social worker Sally Wiard's article in the spring 2003 Study newsletter:

www.stjude.org/ltfu/insurance

We looked at the rates of insurance coverage among study participants and at the problems experienced with health insurance.

Our findings showed that many individuals who survived serious illness during childhood have more difficulty getting health insurance than do members of a comparison group of siblings. Many survivors still lack insurance, and those with insurance have had a hard time getting it. These findings are important because lack of coverage often blocks survivors' access to ongoing medical care, including cancer-related care. In our study, survivors without insurance were less healthy overall. They also had more mental health problems and physical problems such as chronic pain than did those who had insurance.

Researchers looked at survivors and siblings in two groups: those younger than 18—who are covered by their parents' insurance—and those 18 and older at diagnosis. Racial and ethnic minorities (blacks and Hispanics) were more likely to be uninsured. Younger survivors were more likely to be insured if their cancer had recurred or if they had had a second cancer. Uninsured survivors older than 18 were likely to have a lower income and educational level. The chance of having insurance increased with annual household income for everyone in the study.

In both age groups, survivors had more difficulties in getting health insurance than did members of the sibling group. Also, they were more likely to report exclusions and restrictions on policies and to pay more for coverage. See the table. Survivors were also less likely than were the siblings to be covered through work or a parent or spouse's policy. More received insurance through Medicaid or public assistance than did members of the comparison group of siblings.

The next step is to find out what types of exclusions survivors face and how their employment choices are affected by insurance-related concerns. With this information, researchers can help survivors overcome some of the barriers to full insurance coverage, which is an important factor for healthy living.

Full study results were published in the issue of the *Journal of Clinical Oncology*, 9187-96, Dec. 20, 2005.

Insurance Coverage Among Survivors and Siblings

	Insured	Insured, but Had Problems with Policy Exclusions, Extra Cost, or Difficulty in Obtaining Insurance		
		Exclusions	Extra Cost	Difficulties
Survivors	89%	5%	2%	29%
Siblings	91%	1%	<1%	3%

Study Insurance Options; Hold Onto Benefits

Fran's story illustrates the lengths to which study participants sometimes go to get or keep employer-sponsored insurance.

Fran learned early on that she had to hang onto her health insurance and not lose coverage, even for a day. She was just 2 years old when she received a diagnosis of Wilms' tumor in 1970.

Fortunately, her father had employer-sponsored insurance that covered the surgery to remove the affected kidney and the treatment with radiation and chemotherapy. Within a year, a spot appeared on her left lung, which was also treated with radiation and chemotherapy.

It was during her college years that Fran had to deal with the first late effects of her disease and treatment. As a result, she underwent several surgeries and was hospitalized for a month. Rather than withdraw from college, she decided to take a one-year leave of absence. During this time, she remained covered by her father's insurance.

"The insurance company tried to argue that I was no longer covered because I was over 18 and not in school," she says. "My parents went to bat for me, and the insurance company backed down without a huge fight."

"I can't imagine what would have happened to my family financially, or to my health, if we had lost insurance in the middle of my treatment."

Within a few years, the need to retain coverage weighed in Fran's decision-making again. Shortly after graduation from college, she wanted to quit a job that provided her with group insurance. She found out that she could convert her company's

insurance to a private policy. But it had a hefty price tag: \$2,000 a month! Rather than come up with the monthly premium, she moved up the date of her wedding to ensure uninterrupted coverage through her husband's plan.

"I feel as if every life decision—when to marry, what to study, what jobs to look for and take, and where to live—have been affected by insurance and access

"I feel as if every life decision—when to marry, what to study, what jobs to look for and take, and where to live—have been affected by insurance and access to health care."

to health care."

Looking to the future, she says, "I'm hoping that maybe we are at a tipping point where enough Americans will demand a more equal health coverage system."

Insurance Resources

Check out the following for help with insurance.

- www.cancersurvivorsproject.org
[Select Quick Info/FAQs, Choose item 12.]
- What Cancer Survivors Need to Know about Health Insurance. National Coalition of Cancer Survivors
www.canceradvocacy.org/resources/publications
- Chapter 6, From Cancer Patient to Cancer Survivor: Lost in Transition, 2006. Institute of Medicine.
www.nap.edu/catalog.php?record_id=11468
- Childhood Cancer Survivors: A Practical Guide to Your Future
www.oreilly.com/medical/survivors/news/insurance.html

- *HIPAA*. Information about this federal law, which helps people with pre-existing health conditions get and keep health insurance, is available at:
www.cms.hhs.gov
[Type "HIPAA" in the search box, then click Search for a list of topics you can select.]
- *Help with Insurance and Cancer-related legal issues*.
www.curesearch.org/resources
Scroll down to the section labeled "National and International Resources." Select the topic:
[Insurance Assistance](#)

Staying Healthy in Mind and Spirit

Quick Facts

What are the study's current findings?

- Most study participants reported few, if any, symptoms of psychological conditions such as depression or anxiety.
- Survivors were more likely than were members of the sibling group to report such symptoms.
- As in the general population, those reporting psychological conditions were more likely to be female and unemployed.

They were more likely to have:

- Income lower than \$20,000
- Not graduated high school
- Received intensive chemotherapy

In the brain tumor study, they were also more likely to be:

- Unmarried
- Less healthy

What is the study's future goal?

Future survey questions will allow us to look at ways in which the risk factors are related to the psychological conditions being studied.

For example, is depression due to lower education, lower income, and unemployment? Or, are failure to graduate and unemployment due to depression?

Why is this important?

- Being able to pinpoint the causes of emotional problems will help us focus our efforts on ways to address them.

We wanted to find out how well adults and family members are coping with the emotional effects of cancer and other serious childhood illnesses.

Serious childhood illnesses such as cancer take their toll on everyone in the family, not just the patient. Also, the emotional fallout can continue for decades after treatment. For these reasons, recent findings of good psychological health among participants of two LTFU studies are welcome news. The table shows the low percentages who reported symptoms of depression years after their treatment.

Results are important because they show us that rates of psychological conditions among survivors and their families reflect those of the general population (those adults who have not been affected by serious illness).

	Symptoms of Depression	
	Leukemia-Lymphoma Study	Brain Tumor Study
Survivors	5%	11%
Siblings	3%	5%
General Population	3%-10%	3%-10%

We measured psychological health by using a standard self-report survey designed to screen for depression, anxiety, and other psychological conditions. In the first study, we looked at the data of 2,565 siblings and 5,736 adult survivors of three childhood diseases: leukemia, Hodgkin's disease, and non-Hodgkin's lymphoma. In the second study, we looked at data of 2,817 siblings and 1,101 survivors of a brain tumor.

Research tells us that some survivors manage to grow in positive ways, and most are healthy emotionally and psychologically. Even those doing well may have concerns about the physical, psychological and social quality of their current and future life. Full study results were published in *Pediatrics*, 42-52, July 2002, and in the *Journal of Clinical Oncology*, 999-1,066, March 2004.



ONCOLOGY
On Canvas
Expressions of a Cancer Journey

Paintings courtesy of the Lilly Oncology on Canvas Competition

Contemplation The survivor in this self-portrait contemplates the future.

Learn to Let Go; Be Willing to Ask for Help

Melinda's story shows how she has moved through the wide range of emotions typical of those who live through a serious childhood illness such as cancer.

Like most long-term survivors, Melinda has gone through a wide range of emotions since she first received her disease diagnosis. She learned that she had non-Hodgkin's lymphoma in her first year of college. At the time, she was just beginning to enjoy her first taste of real freedom living away from home.

During treatment, her hospital had no support program for teens. But, the medical team seemed to understand her need to assert some control over her life. "So they let me have some say in how they carried out my treatment."

One of the next milestones in her cancer journey came after treatment, when a friend died of cancer.

"I spent months puzzling over why some patients died, and I didn't," she says. Since then, she has had to face feelings of survivor guilt in her role as a nurse, dealing with the death of patients with conditions similar to her own.

Finally, and with much practice, Melinda has learned to quit questioning whether she could have done anything to keep from getting cancer. "I will never get an answer to all the 'what-if' questions, so I have had to learn to let it all go," she says.

It was not until 10 years after treatment, when she was going through a divorce, that Melinda faced a bout of clinical depression. At that time, she sought out counseling and ongoing medical treatment for her condition.

Throughout it all, Melinda has been supported by a strong network of family and friends and a group of young adult survivors in her area.

"To deal with the feelings I was going through, I worked with a psychologist, who taught me meditation and relaxation techniques."

"I will never get an answer to all the what-if questions, so I have had to learn how to let it all go."

Also helpful was a counselor, who taught her how to set healthy boundaries with patients and families at work. "I've learned how to give to others without losing myself."

Finally, she tells about an experience that answered some of her earlier questions. "When my disease relapsed, a friend sent me a card, letting me know that someone was praying for me 24 hours a day. It hit me that 'Something' was getting me through this. That's when I began a faith journey. As I continue my journey, faith is my source of strength."



Paintings courtesy of the Lilly Oncology on Canvas Competition

Embrace Life This painting expresses another woman's response to her cancer experience, years after diagnosis and treatment.

Counseling Resources

Most survivors and families cope well with the long-term effects of childhood illness and treatment.

But, it's normal for all of us to struggle with serious emotional issues from time to time. When you do, don't be afraid to ask for help. Check with your insurance company about coverage for counseling and a list of providers. Contact your doctor or one of the following for referrals.

Cancer Care [1.800.813.4673](tel:1.800.813.4673)

American Cancer Society [1.800.ACS.2345](tel:1.800.ACS.2345)

Leukemia & Lymphoma Society [1.800.955.4572](tel:1.800.955.4572)

Teen support group www.grouploop.org

Patient/family support www.wellnesscommunity.org

Support and humor www.planetcancer.org

Reaching Educational Goals after Childhood Illness

Quick Facts

What are the study's current findings?

- Rates of high school graduation were just about the same for the siblings and survivors who used special education services.
- In the survivor group, both boys and girls used special education services more often than did those in the sibling group.
- Girls in the survivor group were more likely to use special education services than were boys in the group.
- Survivors whose disease was diagnosed before they were 6 years old used special education services more often than did other age groups.

What is the study's future goal?

We need to increase awareness among doctors and teachers about the long-term effects of serious childhood illness on school progress.

Why is this important?

Future patients: If the medical team and school staff are more aware of these issues, they can start working together earlier on to help students.

Adult survivors: Adults who received certain treatments as children may struggle with some of the same issues that keep children from doing well in school.

Some of the same steps we take to help students can help adults keep their jobs and get along better with friends and family.

We compared survivors' rates of graduation and use of special education services with those of the sibling comparison group.

We've known for a while that children who receive treatment for cancer or other serious illness tend to fall behind in school. In one LTFU study, we wanted to find out whether they are less likely to graduate than members of a sibling group. We also wanted to identify which groups are more likely to use special education services.

Results are important because they helped us identify the groups of children that need help keeping up in school after treatment for a serious illness like cancer. Knowing which groups need help alerts us to be on the lookout for early signs of problems and to give these children the help they need early on.

Graduation Rates

In our overall group, we found that study participants who had serious illnesses such as cancer graduated from high school at lower rates than did the sibling group. But we also found good news when we dug a little deeper. When we looked at those who received special education, differences in high-school graduation rates disappeared in all but a few groups: those who had brain tumors or kidney cancer.

The lowest rates of graduation were among patients who had leukemia, brain tumors, non-Hodgkin's lymphoma, or neuroblastoma.



Use of Special Education Services

All groups of survivors used special education services more than did the sibling group. The ones most likely to use special education had diagnoses of leukemia, brain tumor, and Hodgkin's disease.

As with previous studies, we found that earlier age at diagnosis and being a female survivor of a serious illness were risk factors for needing special education. We also found a relation between the need for special education and two types of treatment: radiation therapy and the drug methotrexate, when it is given in the spinal fluid. Greater doses of either type of therapy increased the need for special education services.

We based our findings on data for 12,430 survivors and 3,410 siblings.

Full results were published in the journal *Cancer*, 1115-26, February 15, 2003.

Use of Special Education Services

	Overall
Survivors	23%
Siblings	8%

Keep Life Simple; Know Your Limits

Blair's story shows how she overcame the effects of a serious childhood illness such as cancer to achieve her educational and personal goals.

Blair never experienced a relapse of her childhood cancer, and her hair had grown back by the time she entered kindergarten. But the effects of the disease and treatment dogged her steps from the first day of elementary school through college. "I always had trouble with memory and concentrating," she says. "Even though I understood what I was being taught, I just couldn't get it down on paper."

To help remember what she read Blair made up little songs and other short rhymes and phrases. Even so, she recalls that school was very hard, especially when she had to remember a lot of facts.

No one linked her problems with her prior treatment, which had included radiation to the brain. "And, I was too embarrassed to ask for help," she says. Things began to turn around for her in high school, when a teacher noticed some low test scores on material that she knew Blair had understood. "When she gave me the quiz orally, I made an A," Blair says.

Her next big break came when applied to college during her senior year of high school. She was allowed to take her college entrance exam without a time limit. Even then, she made a lower score than some schools accepted. At this point, the president of a small private school in a nearby state stepped in.

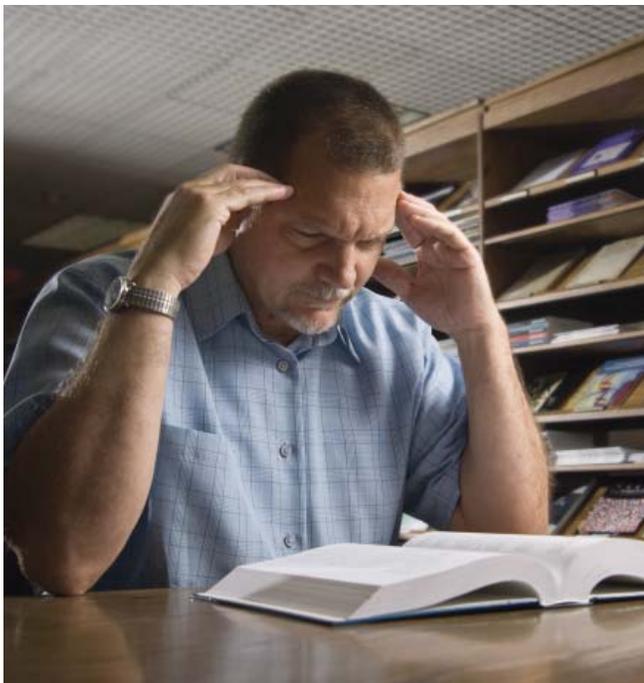
After talking with Blair, he believed she could do the work and admitted her to her freshman year of college.

Blair continued to work hard and try to make good grades. Even so, she had to struggle just to keep up. She felt frustrated and confused about the problem. Then one day, she had a chance to talk to one of the doctors at her old hospital during a special Survivors Day.

"I explained the problems I was having, and he didn't seem surprised at all," she says. He took her chart out, and showed her the part of the brain that controls short-term memory. "He explained that my short-term memory had been affected by the treatment."

After college, Blair chose a career in the home, first as a nanny and then as a full-time mother of her own children. She also finds time to run to keep fit and to help raise money for research into childhood illnesses such as cancer.

Today, Blair manages to stay on top of an active home life by using some of the same time- and organizational management strategies she learned during college. See her list of tips in the box labeled "Resources" below.



Seth Dixon, BMC, St. Jude

Resources

As the mother of two, Blair often finds herself at the epicenter of a very busy and happy home life. Here she shares some of her tips for keeping things all quiet on the home front.

- *First, I keep my life simple.* I know my limits and I don't take on too much.
- *Second, I don't compare myself to others.* I know that we each have different skills and talents. It doesn't matter whether I can't do some things well, because I have great skills in other areas.
- *Third, I write it all down.* Having things written down is the only way I can remember what I need to do each day.
- *Finally, I have joined an organizational club.* I get organizational tips and tricks via e-mail.

Study participants who received certain treatments during childhood may continue to struggle with tasks that require concentration, attention to detail, and organizational ability. Such skills can be improved, even in adulthood.

LTFU

Long-Term Follow-Up Study

www.stjude.org/ltfu

1.800.775.2167

E-mail: 1tfu@stjude.org

[St. Jude Children's Research Hospital](#)
[Children's Health Care-Minneapolis St. Paul](#)
[Children's Healthcare of Atlanta/Emory University](#)
[Children's Hospital at Stanford](#)
[Children's Hospital of Columbus](#)
[Children's Hospital of Los Angeles](#)
[Children's Hospital of Orange County](#)
[Children's Hospital of Philadelphia](#)
[Children's Hospital of Pittsburgh](#)
[Children's Medical Center of Dallas](#)
[Children's National Medical Center](#)
[City of Hope National Medical Center](#)
[Dana-Farber Cancer Institute/Children's Hospital Boston](#)
[Mattel Children's Hospital at UCLA](#)
[Mayo Clinic](#)
[Memorial Sloan-Kettering Cancer Center](#)
[Miller Children's Hospital](#)
[Riley Hospital for Children-Indiana University](#)
[Roswell Park Cancer Institute](#)
[Seattle Children's Hospital & Medical Center](#)
[St. Louis Children's Hospital](#)
[Texas Children's Hospital](#)
[The Denver Children's Hospital](#)
[Toronto Hospital for Sick Children](#)
[U.T. M.D. Anderson Cancer Center](#)
[UAB/The Children's Hospital of Alabama](#)
[University of California-San Francisco](#)
[University of Michigan-Mott Children's Hospital](#)
[University of Minnesota](#)



St. Jude Children's
Research Hospital

ALSAC • Danny Thomas, Founder
Finding cures. Saving children.

332 N. Lauderdale

Memphis, TN 38105-2794

To Learn More about Study Results

The following articles provide additional details about study results.

Nagarajan R, et al., Education, Employment, Insurance and Marital Status Among 694 Survivors of Pediatric Lower Extremity Bone Tumors: A Report from the Childhood Cancer Survivor Study. *Cancer* 2003; 97:2554-64.

Sklar C, et al., Abnormalities of the Thyroid in Survivors of Hodgkin's Disease: Data from the Childhood Cancer Survivor Study. *J Clin Endocrinol Metab* 2000; 85:3227-32.

Oeffinger KC, et al., Obesity in Adult Survivors of Childhood Acute Lymphoblastic Leukemia: A Report from the Childhood Cancer Survivor Study. *J Clin Oncol* 2003; 21:1359-65.

Meacham LR, et al., Body Mass Index in Long-Term Adult Survivors of Childhood Cancer: A Report of the Childhood Cancer Survivor Study (CCSS). *Cancer* 2005; 103:1730-9.

Gurney JG, et al., Final Height and Body Mass Index Among Adult Survivors of Childhood Brain Cancer: Childhood Cancer Survivor Study. *J Clin Endocrinol Metabol* 2003; 88:4731-9.

Kadan-Lottick et al., Childhood Cancer Survivors' Knowledge about Their Past Diagnosis and Treatment: Childhood Cancer Survivor Study. *JAMA* 2002; 287:1832-9.

Hudson MM, et al., Health Status of Adults Who Are Long-Term Survivors of Childhood Cancer: A Report from the Childhood Cancer Survivor Study. *JAMA* 2003; 290:1583-92.

Mertens AC, et al., Pulmonary Complications in Survivors of Childhood and Adolescent Cancer: A Report from the Childhood Cancer Survivor Study. *Cancer* 2002; 95:2431-41.

Gurney JG, et al., Endocrine and Cardiovascular Late Effects Among Adult Survivors of Childhood Brain Tumors: Childhood Cancer Survivor Study. *Cancer* 2003; 97:663-73.

Packer RJ, et al., Long-Term Neurologic and Neurosensory Sequelae in Adult Survivors of a Childhood Brain Tumor: Childhood Cancer Survivor Study. *J Clin Oncol* 2003; 21:3255-61.

Kenney LB, et al., Breast Cancer After Childhood Cancer: A Report from the Childhood Cancer Survivor Study. *Ann Intern Med* 2004; 141:590-7.

Nagarajan R, et al., Function and Quality of Life of Survivors of Pelvic and Lower Extremity Osteosarcoma and Ewing's Sarcoma: The Childhood Cancer Survivor Study. *Br J Cancer* 2004; 91:1858-65.

Bowers DC, et al., Stroke as a Late Treatment Effect of Hodgkin's Disease: A Report from the Childhood Cancer Survivor Study. *J Clin Oncol* 2005; 23:6508-15.

Castellino SM. Minority Adult Survivors of Childhood Cancer: A Comparison of Long-term Outcomes, Health Care Utilization and Health-Related Behaviors from the Childhood Cancer Survivor Study. *J Clin Oncol* 2005; 23:6499-507.

Punyko JA, et al., Long-term Medical Effects of Childhood and Adolescent Rhabdomyosarcoma: A Report from the Childhood Cancer Survivor Study. *Pediatr Blood Cancer* 2005; 44:643-53.

Nathan PC, et al., Health-related Quality of Life in Adult Survivors of Childhood Wilms Tumor or Neuroblastoma. A Report from the Childhood Cancer Survivor Study. *Pediatr Blood Cancer* 2007; 49:704-15.