

LTFU

Long-Term Follow-Up Study

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Surviving childhood cancer is a major life accomplishment. It took courage and determination to survive, and it takes courage and determination to live as a survivor. Congratulations, participants! Accomplishments can come with costs, however, and for some survivors those costs involve limitations on their ability to live independently in adulthood. In this issue, we present information about a recently published study of independent living status among LTFU Study participants.

Independence has a personal meaning for each individual. For some people, independence may mean living on one's own. For others it may mean having a voice in decisions that are made about one's living situation. However, everyone needs to feel that they can control aspects of their lives and participate in community life. On page 2 we offer information on some resources to help individuals realize their personal goals relating to independent living.

Courage of a survivor. Katie Sonnichsen has faced limitations brought on by side effects of cancer treatment with courage and humor. Read her story on page 4.



Thank you. As always, we want to thank you, our participants, for being our partners in research. We hope you are enjoying your Summer!

New Study of Women's Health

The EMPOWER Study is an exciting new LTFU study focused on women's health. If you are a woman between the ages of 25 and 49 who was treated with chest radiation for a childhood cancer, you may be contacted for this study.



If you'd like additional information about the EMPOWER study, please call the LTFU Study toll-free telephone line: 1-800-775-2167.

Would you like to receive the LTFU Study newsletter by email?

Let us know where to send it!

1. Go to <http://ltfu.stjude.org>
2. Click on "Update Your Info" in the menu bar at the top of the screen.
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Study Update

Independent Living Status of Adult Survivors of Childhood Cancer

Living independently, and caring for and being responsible for oneself are important goals for most adults, and most adult survivors of childhood cancer are successful in achieving these goals. Some survivors face challenges in this area, though, and we wanted to learn more about which groups might be most at risk.

What we learned. Most survivors in this study—more than 82 percent!—reported that they are living independently. However, survivors were more than twice as likely as the siblings in the comparison group to be living with parents or other relatives or to rely on nursing or caregiver support.

Survivors were most likely to be in a dependent living situation if they:

- Had received whole brain (cranial) radiation to treat their childhood illness
- Had a diagnosis of leukemia, non-Hodgkin's lymphoma or brain tumor (compared to solid tumor or bone cancer)
- Were younger at diagnosis: People who were diagnosed and treated before age 6 were only half as likely to report that they are living on their own as those who were at least 12 years old at diagnosis.
- Were depressed.

Dr. Alicia Kunin-Batson, the author of this study, says, “While some of these things can't be changed, others can be managed and assistance is available. If you are experiencing depression or you have difficulties in thinking,



Dr. Alicia Kunin-Batson

attention, learning, or remembering it is important to talk to your doctor about these potential barriers to independence.”

Why results are important.

The results of this study tell us about which groups of survivors might need help in achieving their goals in the area of independent living. They also provide information that can be used to plan interventions to reduce the impact of barriers to independence.

About the study. More than 6000 adult survivors and more than 2000 siblings who were at least 25 years old provided the answers to the surveys that were analyzed 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.

Alicia Kunin-Batson, PhD, is an assistant professor in the Department of Pediatrics at the University of Minnesota. Details of this study were published earlier this year in the journal *Pediatric Blood & Cancer*.



LIFT-OFF!

Resources to Reach Your Goals

Resources are available for survivors who are living with one or more disabilities who want help achieving their independent living goals:

Centers for Independent Living are private non-profit agencies that operate within a local community and provide many independent living services. Independent living centers (ILCs) exist in each state. They are funded by grants from the US Rehabilitation Services Administration. The idea behind ILCs is that people with disabilities are the best experts on their own needs. At least 51 percent of staff of ILCs are individuals with disabilities. ILCs are not places where people live. Rather, they provide the following types of services to people with disabilities:

- Information and referral
- Independent living skills training
- Individual and systems advocacy
- Peer counseling

Specific services provided by ILCs vary but can include such things as support groups, social and recreational activities, financial and budget counseling, assistive technology exchange and recycle programs, installation of wheelchair ramps and other home modifications, and many others.

Supported employment means work in a setting where both disabled and non-disabled people work together and where people with disabilities receive comparable wages to people who are not disabled. Often, even people with severe disabilities are able to work in supported jobs. In supported employment, a person has a job coach who stays involved long-term or permanently. Other help that may be provided includes transportation, assistive technology and individually tailored supervision. State Vocational Rehabilitation offices can help to arrange supported employment opportunities.

Please see the Web Links on page 4 for additional information.

Employment and Young Adult Survivors

Long-Term Follow-Up Study researchers often partner with colleagues from other centers to study issues that are important to survivors of childhood cancer and similar illnesses. One such partner, Dr. David R. Strauser, is a psychologist at the University of Illinois at Urbana-Champaign, where he is on the faculty of the Department of

“Very few young adult cancer survivors take advantage of the services offered by state Vocational Rehabilitation offices The majority of survivors in our study who received vocational rehabilitation services became successfully employed.”

—Dr. David Strauser

Kinesiology and Community Health. Dr. Strauser works in the area of occupational development and employment of young adults with disabilities. In the last few years, he has focused more and more of his attention on cancer survivors.

In a recent study he conducted, Dr. Strauser found that very few young adult cancer survivors take advantage of the services offered by state Vocational Rehabilitation offices. These offices offer a wide range of services to individuals who qualify for help. Services may include career counseling, job placement, assistance with job accommodations and adaptive technologies, even help with buying clothes that are appropriate for the work place.

The majority of survivors in the study who received vocational rehabilitation services became successfully employed. In fact, the study showed that those who received job search assistance and on-the-job support were four times more likely to be employed after receiving such services.

“Applying for vocational services through state offices

is an important step survivors can take if they’re seeking employment,” says Dr. Strauser. “State Vocational Rehabilitation offices are sometimes unfamiliar with the specific needs of cancer survivors. Still, it is definitely worth applying. Your pediatric oncologist or other health care provider can provide information to help with the application process,” he says.

Dr. Strauser is also starting work on a project to learn if individualized support can help young adult brain tumor survivors develop job-related skills and achieve successful employment.

The preliminary results from a small group of individuals suggest that brain tumor survivors who were diagnosed before age six and those who were diagnosed at age 12 or older are able to develop the personal skills needed to hold down a job better than those who were diagnosed when they were between the ages of 6 and 12. These skills include understanding how to fit in to the work place environment and work well with others, being on time for work, staying focused on the task at hand, and similar capabilities.



Dr. David Strauser

“These are preliminary results from a small group,” say Dr. Strauser, “but, they show the importance of research in designing programs that can target the needs of individuals who most need help.”

Comments by Dr. David R. Strauser: “There are many levels of independence.”

Editor’s note: We asked Dr. Strauser to comment on the research highlighted in the Study Update on page 2. Below are his remarks.

By the time they are in their late teens or early 20s, most people make the transition from living in an environment where they are dependent on others to living independently and being responsible for their own care. For young adult survivors of childhood cancer this transition may present unique challenges. This research from the LTFU Study presents valuable insights about specific risk factors that may make it challenging for survivors to live independently in adulthood.

In seeking to help survivors achieve an optimal degree of independence, healthcare providers must assess how a person’s social environment, personal relationships, employment status and potential, access to medical care, and ability to manage late effects may affect their ability to live independently. Independent living is not an all or nothing affair; however. There are many levels of independence and each represents a significant achievement. Helping individuals attain their desired level of independence should be a primary goal of psychosocial treatment.

Notes from Participants

Katie's Story: Coping with Late Effects of Treatment

To a 4-year old, childhood cancer might not look so bad. But today, 31-year-old Katie Sonnichsen, of Sioux Falls, South Dakota, is still dealing with delayed effects of treatment. Even so, she believes that looking back on 27 years as a cancer survivor is cause for celebration. “As a result of my treatments and the love and support of my family and friends, I am here 27 years later to share my story,” she says.



Katie and her mom during treatment

Katie was diagnosed with Acute Lymphocytic Leukemia (ALL) in June, 1984. Her parents signed her up for a clinical trial which determined her treatment protocol. She received an aggressive treatment of various chemotherapy drugs, as well as whole brain (cranial) radiation. The radiation was given to Katie as part of the clinical trial research. “We were concerned about that because we knew there might be residual side effects,” recalls her mom, Pam, “but Katie never had a relapse after treatment. The cranial radiation may have helped.”

As a young adult, Katie has had to deal with many challenges caused by treatment side effects. “I have a learning disability that makes reading comprehension difficult,” she explains, “but I was able to persevere through high school and college.” Katie received accommodations in college to help her deal with her learning disability. “I was allowed extra time to finish tests,” she says, “and I had assistance with note-taking so that I might be able to focus on the professor’s lecture for the day.” Treatment also left Katie with cataracts in both eyes and affected her growth—at 31 years old, she stands 4 feet 10 inches tall.

Social relationships have also been difficult for Katie. “I have had some of the most meaningful friendships a person could ask for, yet sometimes I have not felt as though I fit in,” she says.

“I can be a persistent person . . . I will do what I can to finish a job or task no matter how long it might take me.”

“It takes me a while to feel comfortable enough to enter into a conversation or situation. I guess it’s that fear that I might say or do something wrong or even be rejected. It seems kind of silly when I consider the chances and risks my parents took when it came to my treatments.”

Despite all these challenges, Katie graduated from Augustana College with a bachelor’s degree in social work. She also holds a diploma in culinary arts from Mitchell Technical Institute. “Over the last few years I have become more assertive,” Katie says. “I am willing to stand up for what I believe in—I can be a persistent person in that I will do what I can to finish a job or task no matter how long it might take me.”

Today, Katie is successfully supporting herself and living independently. She is working at a restaurant in Sioux Falls and at a local grocery store. “I’m still in pursuit of the perfect job,” she admits, “and have no idea what I want to be ‘when I grow up.’”

Surrounded by two loving parents, four siblings, and friends, Katie celebrates her cancer-free life by advocating for research. “Do not be afraid of the word ‘research,’” she says to others. “Through being part of a study, you are doing your part to help someone else. The treatments that I’ve undergone will aid the doctors, nurses and scientists in finding answers to what may cause these cancers, how we can prevent them and, most importantly, how we can cure them.”

Editor’s note: Katie’s story originally appeared in the Children’s Cancer Research Fund’s Butterfly newsletter. It is reproduced here with permission in a modified form.



Katie Sonnichsen

Web Links

For more information about supported employment, see this page from the U.S. Department of Labor:

<http://www.dol.gov/odep/archives/fact/supportd.htm>

The Social Security website lists contact information for the Office of Vocational Rehabilitation of each state. It also includes information about Centers for Independent Living, listed by state:

<https://secure.ssa.gov/apps10/oesp/providers.nsf/bystate>