

A NOTE FROM US

Three recent “first of their kind” investigations from the LTFU Study have significantly advanced what is known about how exercise affects adult survivors of childhood cancer. These findings demonstrate the positive effects of exercise on survivors’ physical and mental health.

We are excited to share them with you, and in this issue the researchers themselves discuss what they discovered and its implications for survivor health. We have also compiled some useful tips for increasing or maintaining your level of physical activity.

Reminder to complete your survey

We finished mailing follow-up surveys in August 2018 and are now following up with participants who have not yet responded. Every survey is important! If you didn’t receive yours or need another copy, please let us know:

- Visit ltfu.stjude.org and click on “Update Your Info”
- Call us toll-free at 800-775-2167
- Email us at LTFU@stjude.org

Visit ltfu.stjude.com to keep up with new study results as they are published, or to browse a complete list of more than 300 papers we’ve published since the study began.

None of these advances could take place without your dedication to providing detailed data in survey after survey.

Thank you from all of us on the LTFU Study research team.

Greg Armstrong, MD
Principal Investigator



Exercise and survivorship: How it helps your health

This issue highlights results from three recent studies focusing on the role of exercise in survivor health.

We also provide some tips on how to incorporate exercise into your daily routine. We are pleased to be able to “give back” to you this important new information. We hope you find it useful and encourage you to share it with your health care team. You should always check with your physician before beginning or increasing your activity program.

Exercise helps survivors live longer

By Jessica Scott, PhD

This study provides important evidence that a relatively small increase in weekly exercise can make a big difference in survivors’ lives.

Analyzing data reported by more than 15,000 LTFU participants, we found a 42% reduction in mortality among survivors who were getting about 40 minutes of vigorous exercise each week compared to those who rarely or never exercised. “Vigorous” exercise is activity that makes you breathe hard, like brisk walking, dancing, or playing basketball or tennis.

From outer space to survivorship

My previous research took place at the NASA Johnson Space Center. Astronauts are like cancer patients—they develop side effects from being in space for long periods of time. We found that exercise was important in preventing and reversing a lot of the side (continued on pg 2)



Jessica Scott, PhD (Memorial Sloan Kettering Cancer Center), is the lead author of “Association of exercise with late mortality in adult survivors of childhood cancer” (JAMA Oncology)

Exercise helps survivors (continued from pg 1)

effects related to spaceflight. I wanted to apply what we learned from astronauts to cancer patients.

Next: Determining the dose

Exercise can be powerful medicine. This study focused on vigorous exercise, but we know from studies of the general population that even moderate levels of exercise have substantial benefits. Moving forward, we hope to identify the specific “dose” of lower levels of exercise required to provide benefits.



Emily Tonorezos, MD (Memorial Sloan Kettering Cancer Center) is the lead author of “Impact of exercise on psychological burden in adult survivors of childhood cancer” (Journal of Clinical Oncology)

Exercise improves long-term mental functioning

By Emily Tonorezos, MD

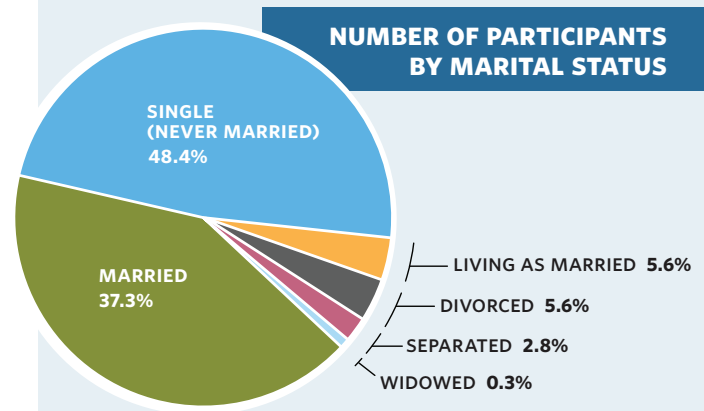
This is the first study to look at the long-term effects of exercise on survivors’ depression, anxiety, memory, and concentration. When we compared data from LTFU participants’ baseline surveys with what they reported seven or eight years later, we saw that the benefits of exercise on participants’ mental health continued for years. If you work out at age 33, you’ll feel brighter at age 40.

Around 10% of survivors whose data we examined were experiencing issues like depression and anxiety, and this was more common among people who weren’t exercising. Mood and mental processes like concentration, memory, and being organized were all improved among people who exercised vigorously (for example, walking briskly) for an hour a week.

Getting and staying healthy

I have the privilege of taking care of adults who had childhood cancer. Most of them are looking for ways to stay out of doctors’ offices and would prefer not to be taking medicines. I want to find better ways to help them get healthy and stay healthy. Exercise is a very appealing approach.

The LTFU Study community



The nearly 25,000 people from the US and Canada who participate in the LTFU Study have one important thing in common—each person was treated, as a child, for cancer. But within this community, each participant represents a unique combination of characteristics—age, sex, location, original diagnosis and treatment method, and hundreds of other factors. Each participant is uniquely important. Here is the most recent participant-reported data on marital status. Thank you to all of you for your dedication and ongoing contributions.

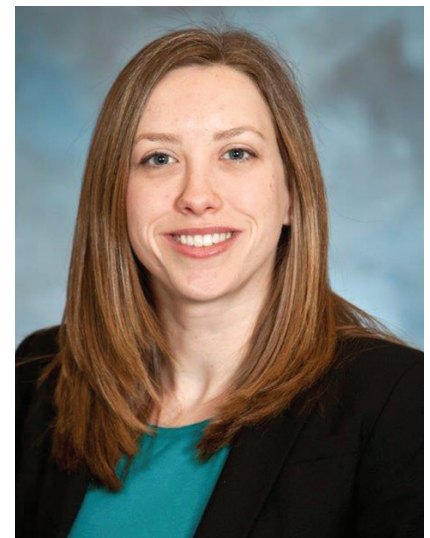
Addressing inactivity in survivors

By Katie Devine, PhD

Physical activity is important for young people in general, and even more important for those who are cancer survivors, because of its positive effects on long-term physical and mental health. However, when we looked at LTFU participant data, we saw that 46% of adolescents and 41% of young adults were not achieving a healthy level of activity.

My driving force

As a psychologist, I see how hard it can be for people to start exercising. Survivorship can (continued on pg 3)



Katie Devine, PhD (Rutgers Cancer Institute), is the lead author of “Factors associated with physical activity among adolescent and young adult survivors of early childhood cancer” (Psycho-Oncology)

Let's get moving!

By Kiri Ness, PT, PhD

Physical activity can improve survivors' physical and mental health. I encourage my patients to add activity to their daily routines in easy, realistic ways. You don't need to make big changes!

Tips to try

- Park a few spaces further away than you normally park.
- Instead of the elevator, take the stairs for one or more flights, then take the elevator the rest of the way.
- When you're sitting at home or at work, get up once in a while and walk around for 2-3 minutes. Set a timer to remind yourself it's time to move!
- Make an appointment with a friend or family member to go for an easy walk.
- Walk down the hall or march in place whenever a commercial comes on tv.

Turn your screen into an exercise machine

Videos can provide "virtual exercise" right at home.

Explore what's available on YouTube, or search for some of my favorites:

- Five(ish) Minute Dance Lesson: African Dance (Kennedy Center Education Digital Learning)
- One-Mile Happy Walk (Walk at Home)
- The Best 15-Minute Beginner Workout—No Equipment Needed (POPSUGAR Fitness)
- 3-minute Daily Exercise—Easy Yoga (Tai Chi Health Products)
- Nature Walk videos



Kiri Ness, PT, PhD, is a physical therapist and researcher at St. Jude Children's Research Hospital and co-author of the three studies highlighted in this newsletter.

pose additional barriers. My sister is a long-term osteosarcoma survivor. I've witnessed how exercise has helped her; I've also seen her ups and downs and challenges.

I conducted this study because I wanted to understand how to help people who are struggling to thrive in their survivorship—how to help them make healthy changes. That's my driving force.

Predicting risk, providing support

Analyzing data from the LTFU Study, we learned that many inactive adolescents:

- Had been treated with cranial radiation
- Reported a lot of "screen time" (tv and videos)
- Had health issues limiting their ability to be active
- Were girls and/or had parents without a college degree (this is similar to the general population)

We also learned that adolescents who had poor self-esteem or diets that were not healthy were less likely to get enough exercise later as young adults.

How these findings help

Knowing this, we hope to address inactivity by being able to "predict" a young cancer survivor's risk for low activity, and help them choose and sustain healthier lifestyles.

Read a summary of the study in Latest Results at ltfu.stjude.org.

Beating barriers

Inactivity is a problem for a majority of people in the US, and survivors have even more reason to pay attention because it can benefit them greatly. But they also may have unique concerns.

Motivation When I prescribe exercise for a patient I say, "You are worth it. You need to love yourself and remind yourself you are worth it." Everyone around you will benefit, too, because you'll be healthier and more productive.

Fear If you fear movement or lack confidence, an exercise professional can prescribe exercise that starts you at the right level. Some physical therapists and exercise physiologists specialize in working with cancer survivors.

Limitations If physical impairment interferes with your ability to exercise, a rehabilitation professional can provide guidance on how to incorporate exercise into your daily activities.

Fatigue The treatment for fatigue is exercise. A little activity will help reduce your fatigue.

Tip: Sign up for a survivorship walk/run and train for it.



Photo credit: Seth Dixon, St. Jude BMC

AC Walton: Living life on his own terms

A rare diagnosis

AC Deonte Walton was seven years old when he was diagnosed with Hodgkin lymphoma, a cancer that starts in lymph cells in the body's immune system. It is most common in adolescents and young adults, but it is extremely rare in children as young as AC was. As AC recalls, "I kept falling down outside, and I was short of breath—I was diagnosed after my mom took me to the hospital because I couldn't breathe."

Growing up poor

AC grew up poor in Chicago, and his disease and treatment put a lot of strain on his family. "My mom and dad didn't have much," he says. "There were a lot of troubles in our life. It was a big family—my mom was pregnant with my third sister at the time I was sick. My brother was born when I was 10 years old and still on treatment. And both my parents had problems with drugs."

A little boy's fight

AC's doctors found that the lymphoma had spread from his neck, where it was originally found, into his abdomen. He received intense chemotherapy and had to have his spleen removed, but he was fortunate not to be treated with radiation. Sadly, he does recall one positive thing about treatment: "At home it was a fight to know when we were going to eat. When I was



AC Walton and his wife, Shani

in the hospital, I sometimes ate better than at home. The treatments were hard on me, but I came out of it a stronger person. When you have to fight, it makes you stronger."

Cancer-free

Things got easier for AC when he finally achieved remission at age 11. He's now 33 years old, and the lymphoma has not returned. "It took my body a while to recover, but now I feel good, I feel fine," he says. Hodgkin lymphoma survivors may be at risk of developing chronic health problems later in life because of the treatment they received. [\(continued on back\)](#)

Sam Watson and The Samfund: #cancerisntfree

The Samfund is one of the largest nonprofit organizations in the U.S. dedicated to offering financial assistance to young adult cancer survivors (ages 21-39) who are struggling financially because of cancer. The organization provides small grants to bridge income gaps and cover survivors' immediate financial needs. It also provides online tools to help survivors develop the skills to advocate for themselves and take control of their financial lives after cancer.

Two-time survivor finds "her people"

Samantha Eisenstein Watson is the founder of The Samfund. Sam is a two-time young adult cancer survivor. She was diagnosed with Ewing sarcoma in 1999, in the

middle of her senior year at Brandeis University. In 2001, she was diagnosed with secondary myelodysplastic syndrome and received a bone marrow transplant. Sam, who is originally from New York, was treated at Memorial Sloan Kettering Cancer Center in New York City.

Sam says, "The Samfund got started almost by accident. After my bone marrow transplant, I was looking for a way to make a contribution. In 2003, I attended a conference in Boston for adolescent and young adult (AYA) cancer survivors. At that conference I felt that I had found 'my people,' and I realized I wanted to do something meaningful to support young adult survivors after treatment. I couldn't find any resources that offered financial help to survivors, [\(continued on back\)](#)

Life on his own terms (continued from front)

But, AC says, “I haven’t had any permanent side effects—except that I found out I couldn’t have kids.”

Living on his own terms

Today, AC and his wife, Shani, live just outside Chicago in Riverside, Illinois. They recently found out that, with the help of assisted reproduction techniques, Shani is pregnant with their first child. AC, who has worked in fire and flood restoration since he was 20 years old, currently does carpet cleaning, a job he loves.

In spite of the hardships his family faced, AC has strong family relationships today. “I had to go through a lot basically by myself. Being so poor broke up the family, but we survived, and now Shani and I see my parents all the time. We live just 20 minutes away, and everyone gets along just fine.”

To stay on top of his health, AC is seen once a year at the childhood cancer survivors’ clinic at Advocate Children’s Hospital in Chicago. He’s lucky to have a dedicated survivorship clinic nearby and smart to take advantage of it. AC realizes that participating in survivorship care can help him accomplish his simple goal for the future: “My goal is just to live a life with my family the way I want to live it,” he says, “and not worry about cancer.”

Sam Watson and The Samfund (continued from front)

so I decided to start my own! At 25 years old, I had no idea what I was getting into, but I knew I had great people around me to help.”

From groceries and rent to starting a family

The grants currently provided by The Samfund average between \$1,500 and \$2,000. They are most often used for everyday living expenses such as rent or mortgage payments, groceries, health insurance, or car insurance. The fund also offers slightly larger grants to survivors who want to start families, to help cover the costs of adoption or assisted reproduction. Cancer survivors who are between the ages of 21 and 39 at the time of application are eligible to apply for a Samfund grant. (Full eligibility requirements are available on the group’s website at: www.thesamfund.org/get-help/grants/)

Sam notes that, “In addition to helping with finances, a big part of our mission is to validate the struggles that young adults face and help them feel more empowered to advocate for themselves. One of the most important things you can do as a survivor is to speak up and ask for help when you need it. I was lucky to learn this from my mom, who was an oncology nurse at Sloan Kettering.”

But asking for help can be especially hard when it comes to finances. “There is a lot of shame around financial stress,” Sam observes. “But if you’re struggling financially because of cancer, it doesn’t mean you did anything wrong. We hear from so many survivors that the validation they feel from receiving a Samfund grant goes even further than the money.”

Celebrating 15 years

The Samfund recently celebrated its fifteenth anniversary. Since 2005, the fund has distributed over \$1.9 million in grant funding to young adult cancer survivors. Individual small donors provide 80-90 percent of the grant funds. And, remarkably, almost a quarter of the grant recipients go on to become

donors themselves—“paying it forward” in the spirit of Sam herself.

To learn more about The Samfund, to donate, or to apply for a grant, visit their website:

www.thesamfund.org.

The website offers an informative online video as well as slides to walk survivors (and their family members or social workers) through the application process.



Samantha Eisenstein Watson, founder of The Samfund