

Childhood Cancer Survivors Face Workplace Challenges With Determination *Lingering Medical Issues Require Attention and Support*

Ashley Dobbs Vantrease overcame seemingly insurmountable obstacles to graduate from nursing school and land her dream job as a pediatric oncology nurse at Vanderbilt Children's Hospital in Nashville.

She had made the ideal of helping children with cancer her life mission. But on her very first night shift on the unit, she knew she would have trouble. The lights on the floor were dim. Struggling with cataracts and retinal scarring, Ashley had so much trouble seeing that she tripped over a patient's shoes and landed on the bed.

She also knew she'd probably get sick more often than the other nurses, and that her joints and feet would be in excruciating pain after every 12-hour shift due.

Ashley feared she might have attained what once seemed her impossible dream, only to be forced to let it go.

But Ashley is a fighter. Her refusal to give up is what got her through a leukemia diagnosis the end of her junior year in high school, three years of chemotherapy that left her with long-term physical, neuropathic and cognitive problems, and a grueling college program without taking advantage of any help offered by her university's office of disability services.

Determined to perform – and be treated – like any other nurse on the unit, Ashley figured out ways to compensate for the challenges at work. She carries a penlight to light her way as she moves through hallways and into patient's rooms. She utilizes dimmer switches and the glow from the in-room computers, turning them away from the patients enough to protect them but still allow her to move easily about the room. She arranged her schedule so she doesn't work two nights in a row, allowing her body time to recover from the physical demands of her shift.

Ashley is just one of an estimated 400,000 childhood cancer survivors in the U.S., many whom are now adults wanting to work – and needing to work to pay for their long-term health care needs. The number of childhood cancer survivors is expected to continue growing in the coming decade as the survival rate continues to improve, according to the National Cancer Institute.

As the number of survivors continues to increase, the need for support around survivorship issues, such as working during and after treatment, is becoming more and more important and demanding of attention.

What is the outlook for children with cancer?

- The cancer mortality rate among children 0-19 declined by more than 50% from 1975-1977 to 2007-2010
- Health problems that develop months or years after treatment are known as late effects
- The specific late effects a childhood cancer survivor might experience depend on the type and location of the cancer, type of treatment received and patient-specific factors such as age at diagnosis
- Two-thirds of childhood cancer survivors will experience at least one late effect and 30% of those will experience a serious late effect such as a secondary cancer

Source: The National Children's Cancer Society

Survivors of childhood cancer often have late effects that limit their initial entry into the workforce or restrict their employment options, according to the [National Center for Biotechnology Information at the National Institutes of Health](#).

When employed, cancer survivors have often reported problems in the workplace, including dismissal, failure to hire, demotion, denial of promotion, undesirable transfer, denial of benefits, and hostility. Studies conducted prior to the passage of employment discrimination laws suggest that survivors of childhood cancer encountered substantial employment obstacles. For example:

- 43 of 403 (11 percent) Hodgkin's disease survivors treated at Stanford University experienced difficulties at work that they attributed to their cancer history (Fobair et al., 1986),
- Approximately 11 percent of adult survivors of childhood cancer reported some form of employment-related discrimination according to a study of 227 former pediatric cancer patients (Green et al., 1991),
- 15 of 60 (25 percent) survivors of childhood cancer in another study reported job discrimination (10 persons were refused a job at least once, 3 were denied benefits, 3 experienced illness-related conflict with a supervisor, 4 reported job task problems, and 11 were rejected by the military) (Koocher and O'Malley, 1982)
- Younger cancer survivors who were either employed or active in the labor market were more concerned than older survivors about revealing their cancer history in searching for another job (Koocher and O'Malley, 1982).

The [Childhood Cancer Survivor Study](#), a collaborative, multi-institutional research study of individuals who survived five or more years after diagnosis of childhood cancer, examined 10,399 pediatric cancer survivors and 3,083 siblings. It found that compared to siblings, adult childhood cancer survivors are at increased risk for unemployment with highest risk defined by diagnosis, treatment and demographic factors.

Treatment repercussions, or late effects such as those experienced by Ashley Vantrese, are key contributors to employment problems. "Late effects" is a term used to identify any medical, cognitive and emotional problems that can be a result of cancer treatments such as surgeries and chemotherapy drugs.

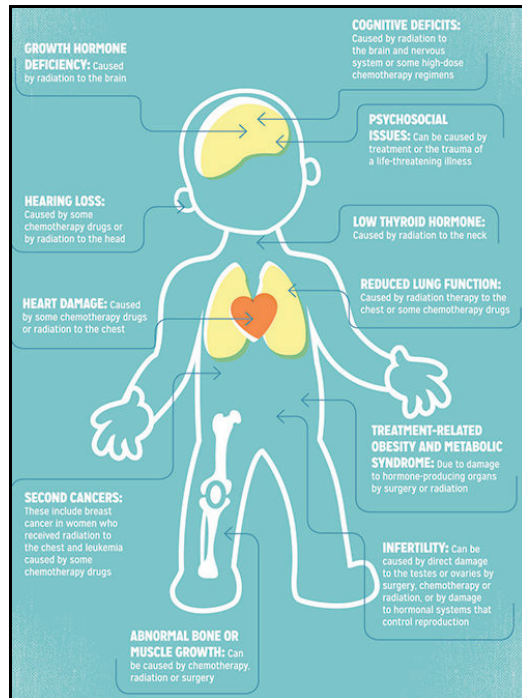


Source: St. Jude's Children's Research Hospital

[The National Children's Cancer Society](#) helps survivors learn about late effects from their cancer treatment and find resources to help with college and vocational issues. It has begun working with The Washington University School of Medicine and the Late Effects Team at St. Louis Children's Hospital on ways to help survivors identify vocational and workplace challenges and empower them to find solutions.

"Many survivors don't realize the impact that their late effects might have on them once they're in the workplace," said Pam Gabris, coordinator of the NCCS Beyond the Cure Program, which provides educational assistance and other resources to meet the long-term needs of pediatric cancer survivors. Medical centers around the country also are addressing these issues with a [Late Effects Program](#) like the one at St. Louis Children's Hospital, where survivors are provided a broad array of screenings to identify all the issues that are impeding their progress in normal life activities. A cadre of specialists, including pediatric oncologists and nurses, a neuropsychologist, school liaison, registered dietician, occupational and physical therapists and social workers provide a team approach to helping each survivor find and implement strategies to manage their challenges.

"Perhaps they have physical limitations like neuropathy that make it difficult to stand for long periods of time, or slower processing speeds that make it harder for them to complete tasks," said Gabris. "Many survivors discover these issues when they get into college, and the office of disabilities will provide them compensations such as extended time for tests. But if survivors haven't gone to college, they will discover these issues on the job and that can lead to great frustration."



Source: American Association for Cancer Research

Cancer survivors with physical or cognitive disabilities caused by late effects may find protection from job discrimination under the Americans With Disabilities Act, which covers all private employers with 15 or more employees, state and local governments and the legislative branch of the federal government. A [“qualified individual with a disability”](#) is protected by the ADA if he or she can perform the “essential functions” of the job. A “disability” is a major health “impairment” and cancer is an “impairment” as defined by the law. The ADA requires employers to provide them with reasonable accommodations for problems related to late effects. Common accommodations for survivors include changes in work hours or duties to accommodate medical appointments and treatment side effects.

Many survivors aren’t aware of the ADA accommodations, said Gabris, and are apprehensive about sharing their story with employers or asking for help once they start working.

The NCCS has worked extensively to teach survivors to learn about and understand late effects that might have long-term health repercussions and impact their function in the workplace. The organization even offers an online [Late Effects After Treatment Tool \(LEATT\)](#) to help them assess their risk of late effects. The tool is easy to complete and can be accessed on a tablet or mobile phone as well as a personal computer. Users can save their report if they choose, and have the option to email it to any desired recipient, such as a physician or therapist.

Once their late effects are known, survivors then need tools to identify how they will impact their performance on a job. Courtney Metzinger, MFA, OTD, OTR/L, is an occupational therapist at St. Louis Children's Hospital serving the Late Effects Program in conjunction with the Washington University School of Medicine.

"If you have a childhood health trajectory where you're in and out of hospitals and miss a lot of school, and perhaps didn't build typical vocational skills – even like starting and finishing chores at home – then you're not building a readiness or what we call a 'vocational identity,'" said Metzinger. "Then, as survivors begin to age, it can be challenging to just complete high school, and eventually the educational challenges bleed into the vocational."

Metzinger has noticed that many survivors who come to the Late Effects Clinic lack exposure to careers in general, so they tend to seek only jobs they've been exposed to as a cancer patient, such as a hospital employee or chef. Often, a survivor will get a typical first job, perhaps at a restaurant, and suddenly discover their late effects impact their ability to perform. Most don't know how to ask for something as simple as ADA-mandated work shift breaks that might help them succeed.

So Metzinger teaches survivors to identify their late effects, figure out how they might impact them on a job, and identify ways they could compensate – just like nurse Ashley Vantrease did for her job as a pediatric oncology nurse.

"It's all about positive uplifting and self-advocacy," Metzinger said. "We look at their goals, what they'll be challenged with, and then we problem solve. I can even set up a work environment where they can try different things, we can talk about what went well and what didn't, and help them figure out what they could do differently. Then we create a recipe for meeting goals."

An example would be a 21-year-old female survivor of a childhood brain tumor who had a much-desired new job as a church counselor but struggles with memory problems. She was worried she might not retain information gleaned during her initial interviews with clients, so Metzinger videotaped a session with herself in the client role. After the young woman had trouble remembering both her own questions and Metzinger's answers, the two developed an intake form that would help her ask and retain the correct information, and even created a personalized shorthand to improve her note-taking.

Another young man, an 18-year-old leukemia survivor with neuropathy and executive functioning challenges, was struggling in his job at a sandwich shop. He came to the program after his supervisor complained that he was too slow performing his duties. Through his work with Metzinger, the teen found different shoes that would supported his feet better, asked his manager for regular 15-minute breaks, and learned a "teach back method" of repeating his customers' orders out loud to help him integrate the information and work more efficiently.

The NCCS has joined the Washington University projects to assist survivors with workplace issues, including co-sponsoring pilot programs to help survivors determine their strengths and weaknesses and identify jobs their late effects would impact less.

“Once they have that information, we’re showing them ways they can go online to explore the requirements for jobs, which helps them narrow the field of careers they’re interested in to ones they can succeed at,” said Gabris.

The NCCS offers job and vocational information on its website at thenccs.org/employment, including tips for interviewing for a job and information on federal and state laws and state vocational rehabilitation services. There also are links to resources like the Job Accommodations Network and the U.S. Equal Opportunity Employment Commission (EEOC).

Gabris said the next step for the NCCS and others advocating for childhood cancer survivors is getting information about the long-term impacts of late effects earlier to their parents.

“Our goal is always to help survivors have a better quality of life with their late effects, and a big part of having a meaningful life is having a job. If we can get parents to think more about how they work with their child early on with both educational and vocational skills, and how their late effects might impact them later in life, we can better prepare survivors for solutions to those challenges when they reach working age.”

As she continues to navigate her job well despite her challenges, childhood cancer survivor and pediatric oncology nurse Ashley Vantrease offers these heartfelt tips for other survivors entering the workplace:

- *Your best advocate for yourself is yourself. For some, this can be an adjustment from how things were during treatment, when your health care team constantly guided you. Educate yourself on what options you have.*
- *Do your research, utilize your resources, and invest in your own success.*
- *It's okay to be stubborn sometimes. The people closest to me will be the first to tell you, I can be stubborn to a fault at times. However, I like to think my stubbornness (or determination, as I like to call it) led to my success. I refused to give up on my dreams, settle, or limit myself.*
- *Be gentle with yourself. You're doing the best you can. I am always my toughest critic. You have to accept your new normal, which may bring significant challenges. You may fall short of your goals, or not be able to do it all...all the time. But try to embrace the challenges that come with survivorship, as they represent your biggest accomplishment: you survived!*
- *Even though I get really frustrated when late effects of my treatment hold me back or make things seem impossibly difficult, I am reminded that my battle*

against cancer is so much of what makes me, me. If I didn't struggle, if I wasn't constantly faced with challenges, if things came easily to me, I wouldn't be the determined, driven and stubborn person I am today. My passion for helping patients and families, the way I can really relate and empathize with them, and my commitment to my field are all fueled by my personal trials. Sure, there will be times where it seems I have to work infinitely harder for it, but I never take my success for granted. So when you're faced with one of those times when giving it your all just wasn't enough, cut yourself some slack and take pride in your efforts.

About the NCCS

The mission of The National Children's Cancer Society is to provide emotional, financial and educational support to children with cancer, their families and survivors. To learn more about the NCCS and its support services, visit thenccs.org. To read all articles and white papers published by the NCCS, visit <https://thenccs.org/articles#>. The National Children's Cancer Society is a 501C(3) organization that has provided over \$62 million in direct financial assistance to more than 38,000 children with cancer. To contact the NCCS, call (314) 241-1600. You can also visit the NCCS on Facebook at <https://www.facebook.com/thenccs>.