



ISABELLA SANTOS
FOUNDATION

Beat Cancer. Grow Hair. Live My Dreams.



THE CANCER SURVIVOR'S GUIDE

FOR ADOLESCENTS AND YOUNG ADULTS



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ACKNOWLEDGEMENTS

This guide is written by a cancer survivor for other cancer survivors and is intended to provide a candid, relatable look at what life for survivors is like. I had wished there was something like this that existed when I was going through treatment back in 2011. My hope is that this guide is a method of support and inspiration to others, and if it helps just one person, I will feel that I've made a difference. You are not alone in your experience, thoughts, and emotions. Through this guide and the shared narratives included, I hope that you feel a little bit better about what you are going through. The last few pages include notebook sheets, so that if you choose you can begin documenting your journey or writing down things that you like in this guide.



I would like to thank the team at ISF for allowing me to work with them to create this for my graduate research project, and a special shoutout to Rachel Wood for her continued support and mentorship.

I would also like to thank all the project participants for sharing their stories with me and being vulnerable for the sake of helping others.

- Brendi Bluitt



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GLOSSARY

- **Arts for Life:** Hospital program that has different crafts and projects
- **ALL:** Acute lymphoblastic leukemia, a type of blood cancer
- **AML:** Acute myeloid leukemia, a type of blood cancer
- **Beads of Courage:** Hospital program that uses beads to represent your cancer journey
- **homebound teacher:** teacher who comes to your house/hospital on a regular basis to administer exams, assist with schoolwork, etc.
- **music therapy:** Using music, lyrics, songs, and instruments to help you feel better
- **pet therapy:** Using dogs or other animals to help you feel better
- **survivor/survivorship:** Everything that happens in life after receiving your diagnosis

SUR-VI-VOR

noun (ser-vy-ver)



From the moment that you are diagnosed until the end of life, you are considered to be a cancer **survivor**. This means that your life has forever changed, and the next several months to several years will look a lot different than you are used to. You might be feeling anxious, scared, confused, or worried, and that is okay. I felt all of those emotions at one point too. 7 other cancer survivors and I are here to tell you that it does eventually get better. You are not alone.

Survivorship encompasses everything from treatment to adjusting to a new normal to late side effects, and everything in between. Dealing with something as life-changing as cancer at a young age can be scary, which is why it is important to have various methods of **support**. Support looks different for everyone and can be something simple like having a friend provide a meal or something more complex like a family member creating a fundraiser to offset medical bills. Having positive support methods can help to alleviate stress, improve your quality of life, and help you to better manage treatment.



What really makes a difference is having lasting support, because people say that they're there for you in the beginning, but they don't realize treatment can be for months or years. That support does start to diminish, and you truly can see who is there for you.*

- Samantha, Wilms Tumor Survivor**

Don't be afraid to be transparent and ask your family, friends, or other support members for assistance. You are probably used to being independent, but it is always okay to ask for help. It can be frustrating when people assume and offer support that is unwanted, which is another reason to be honest about what you need.

**Names have been changed to protect privacy*

***Quotes have been paraphrased*



SCHOOL

.....

School as a cancer survivor looks different for everyone. With a compromised immune system, going to school in-person or more traditionally may not be the safest option.

Many survivors switch to homeschooling or have a **homebound** teacher come and assist with schoolwork. Your parents and your care team will come up with a plan to ensure you can get your treatments safely without falling behind in school.

It can be isolating and frustrating if you are unable to attend school, but it is important to remember these changes are temporary. It is understandable if you feel angry or upset about missing out on experiences such as starting school, sporting events, or other activities that we all want to have. All of your thoughts and feelings are valid, and it's unfair that you have to go through this.

If you are looking to pursue higher education, one benefit is that there are several scholarships that exist solely for cancer survivors. These scholarships can help ease any financial burden that comes with wanting to attend college, and there are several listed on the next page.



Not being able to go to school was pretty difficult for me. I wasn't able to attend school for a long time so I didn't see my friends, and as more people are beginning to understand [due to the COVID-19 pandemic], when you can't go to school for an extended period of time, it can be very sad.

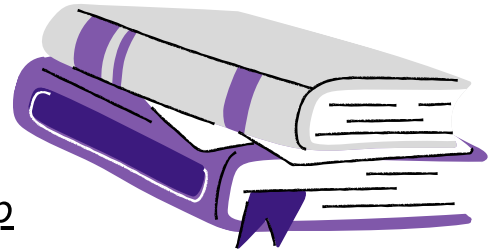
- Anna, ALL Survivor



SCHOLARSHIPS



- *Beyond the Cure Ambassador Scholarship*
- *Cancer for College*
- *Children's Cancer Cause*
- *Jackie Spellman Scholarship Foundation*
- *Kids 4 Kids with Cancer*
- *Luis E. Torres Scholarship Fund*
- *Michael A. Hunter Memorial Scholarship*
- *Mesothelioma Cancer Alliance Scholarship*
- *National Collegiate Cancer Foundation*
- *Patient Advocate Foundation*



This is not an exhaustive list, and there are many other cancer scholarships that exist, check with your Child Life Specialist or Social Worker to see if they have any other resources.

CONNECTING WITH SURVIVORS



One way to help make sense of what you are going through is to talk with other cancer survivors. There are support groups, camps, social media platforms, and many other ways to meet and talk to people who also have cancer. Going to camp is another way to show that you are not alone in your experience, and there are other people out there who can relate to you.



I went to camp when I was a teenager because my mom made me go. The first couple of days, I didn't really talk to anyone. I didn't want to be there or think about what I had gone through. After a few days, seeing people who had went through similar things or worse, and we were still all able to hang out like regular kids, I thought maybe I could deal with being a cancer survivor in a healthier way. Going to camp was really helpful and meaningful that after just one week, I immediately wanted to go back and I've been back nearly every year since.

- Jeremy, B-Cell Lymphoma Survivor



Growing up, going to camp was one of the best experiences of my life. I can talk about it forever and I'm super passionate about it. I've been able to go back as a counselor, and I think it's important for campers to see someone like me who had cancer and is still okay today.

- Fiona, Osteosarcoma Survivor

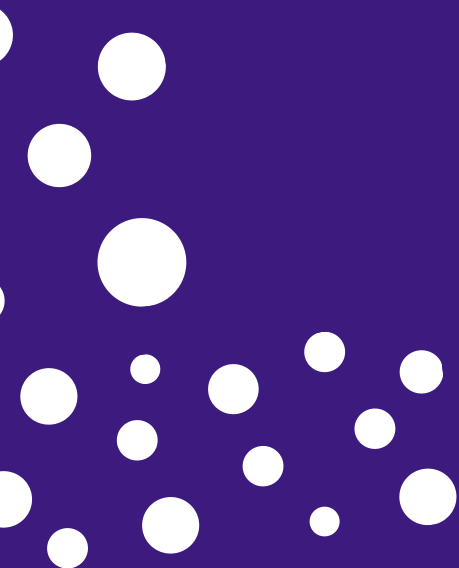
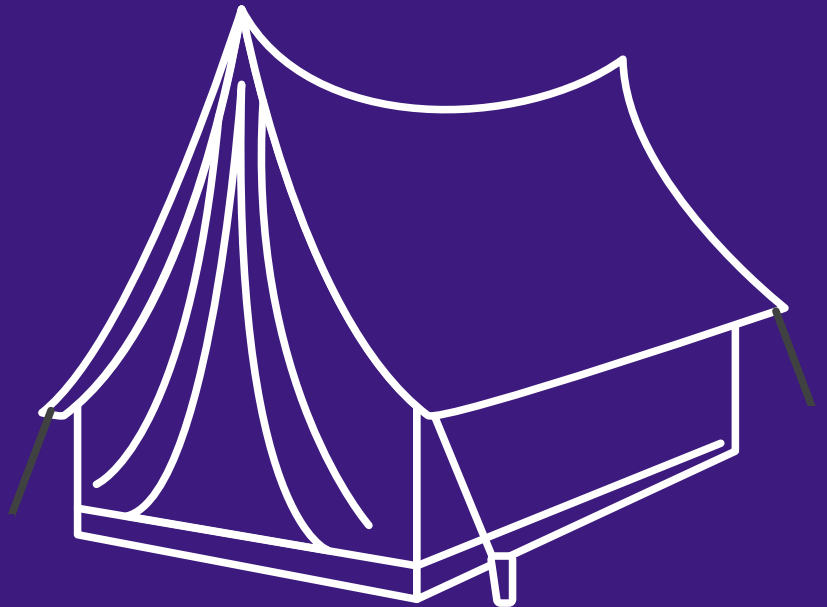
Each camp varies, but there are typically fun activities like art, swimming, archery, sports, nature walks, and more. It allows a space for you to just be a kid, without worrying about your cancer. You can ask your hospital Child Life Specialist or Social Worker for a list of camps that they may know of, and a few popular ones are included on the next page.



CAMPS



- Camp Care
- Camp Carefree
- Camp Mak-A-Dream
- Camp Oziku
- Camp Rainbow
- Nighthawk Ranch
- Victory Junction



PROGRAMS



There are several programs and events that hospitals create to try to make your stay a bit better. Additionally, there are trips, events, and other activities you may qualify for as a cancer survivor. Your Child Life Specialist, Social Worker, or other nonprofits that work with your hospital can give you information about what is available to you.

Arts for Life is a nonprofit that provides educational art programs at several area hospitals. There is also an online hub for virtual lessons, videos, and downloads, through the [Arts for Life Anywhere page](#).

Beads of Courage is a nonprofit that helps to improve quality of life for children and teens through the use of beads to express and represent one's cancer journey.

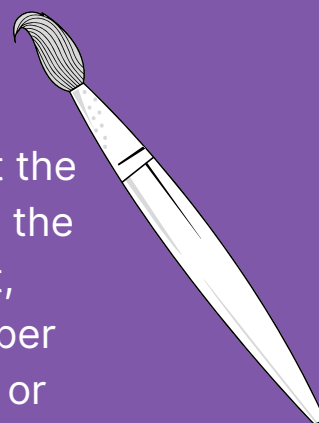
Make-A-Wish is an organization that grants wishes to children with critical illnesses. You can be referred to receive a wish by a medical professional like your doctor, nurse, or child life specialist. Wishes can include things like a vacation, a bedroom makeover, meeting a celebrity, and even more.

There are also fun activities like **pet therapy** and **music therapy** that your hospital may offer. Through all of these different events and programs, you can have several ways to help pass time when staying in the hospital or simply have something to get your mind off of treatment.



I truly enjoyed the Arts for Life program. My favorite thing at the hospital was when the art table was open. If I was staying in the hospital for the night or even waiting for my appointment, getting to do a craft was always exciting. They also had super creative projects, it wasn't something simple like just paint or draw, it would be a very interesting and detailed project.

- Amanda, ALL Survivor



RESOURCES

Podcasts



Cure Talks Cancer



**AYA Cancer Chat:
Life Interrupted**



**Your Stories:
Conquering Cancer**



Cancer Survivor Guide

These podcasts are a great resource to hear from doctors, nurses, and survivors about the cancer experience, wellness, survivorship, and other important topics.

WHAT ADVICE WOULD YOU GIVE TO A CLOSE FRIEND THAT HAS RECENTLY BEEN DIAGNOSED WITH CANCER?

Keep your faith, that's what helped me. Having cancer is challenging, it's terrible, and it makes you so upset that you want to scream. But really, you can't do anything except have faith that everything will work out in the end. It may not be quite how you want it to be, but everything will happen how it's meant to.

- Eliza, ALL Survivor

You are more than your cancer diagnosis. While cancer will be a major thing in your life, it's still crucial to dedicate time to the things you enjoyed before your diagnosis. Whatever those things are, they'll help you get through it and no matter what happens in the end, those things will still be there for you. Going through cancer and treatment is intense, so you need to have things to take your mind off of it.

- Jeremy, B-Cell Lymphoma Survivor

Create a circle of others who are dealing with something similar, so talk with people at the clinic or seek out a support group. Also, have a bag of some items you like and have them ready to take to the hospital. Small things that make it feel a bit cozier, like good tissues and other things to make your stay more comfortable."

- Amanda, ALL Survivor

*"Even though it might seem bad now, trust me, it'll eventually start to improve. Don't be afraid to tell your doctors and nurses everything that's happening with you. You need to tell them if you're feeling sick or hurting or anything, because they're there to help." **

- Hailey, AML Survivor

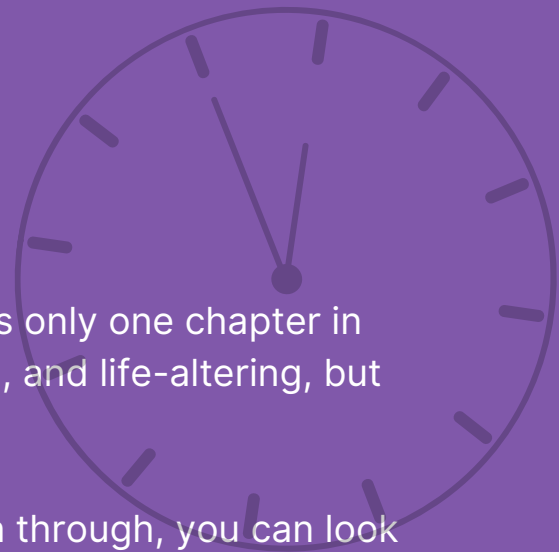
Try to keep your head up, it's a lot easier said than done, but just take it one day at a time. You'll have your good days and your bad days, but everything will be alright in the end.

- Isaac, Osteosarcoma Survivor

PERSPECTIVE



Overall, it may take time to realize this, but cancer is only one chapter in the entire book of your life. It's difficult, it's isolating, and life-altering, but it is something that you can get through.

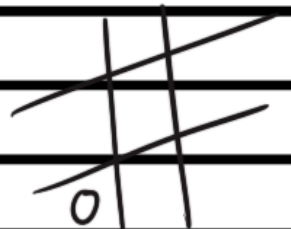


Any time you need a reminder or motivation to push through, you can look back to this guide and to the advice that other cancer survivors have left you with. Whether going through treatment now or reflecting back on their experiences from 10 years ago, all of us want you to know that you can overcome this challenge and maybe even grow as a person along the way. Instead of worrying about how you will get through this, just focus on taking one day at a time.

For many survivors, myself included, their experience with cancer has changed the way they view the world. At the time of going through treatment, it can feel unfair and that there is no end in sight. In retrospect, make sure you take time to celebrate the small wins, like moving to the next phase of treatment or having good blood counts. We all know and can relate to how it feels going through treatment, but in the end when you finish and look back, the most important part will just be that you survived.

The next few pages of this guide include notebook pages and information about the author. I highly encourage you to journal or write down what you experience each day. Then, as you become further and further removed from your treatment, you can look back and reflect on all that you have overcome. I am so thankful that I can look back on my experience, and my only regret is that I wish I would have written more.

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about me

Hi, I'm Brendi! Thank you for downloading this resource guide. I put this guide together because it is something that I wish I had when I was first diagnosed. Here is my story:

In September 2011, after months of pain and a few doctor's appointments, I was diagnosed with Non-Hodgkin's lymphoma, a blood cancer. I had an amazing team of doctors, nurses, nurse practitioners, and more that helped care for me and since January 2014 I have been cancer-free.



After graduating high school in 2015, I began pursuing higher education at Campbell University (Go Camels!) where I obtained my degrees in Health Communication and Public Relations. It was here that I discovered my passion for finding ways to connect with people through shared experiences and qualitative research. In August 2019, I began my degree at UNC Charlotte for a Master's in Communication Studies and graduated in May 2021. During the summer of 2020, I had the opportunity to intern with the Isabella Santos Foundation (ISF) as a Lead Intern and had such a blast! The work that ISF is doing for the pediatric cancer community is so meaningful and I'm thankful to have been a small part of their work.

Sharing stories of cancer survivors is so important to me and why I wanted to create this project. In the future, I would love to work in elected office and advocate for funding and research for pediatric cancer and other health issues that impact children. Remember, cancer is only part of your story, it does not define you or your future.