

AYA Survivor Perspective

By Allie Stevens, as told to Tricia Hernandez

Allie Stevens was 15 years old when she was diagnosed with acute myelogenous leukemia (AML). While friends were navigating social relationships amid a pandemic, Allie was trying to manage her treatment. Her experience was made more challenging by extremely low blood levels due to an initial misdiagnosis, fluid in her lungs, leaking spinal fluid that left her in excruciating pain and immobile, all in addition to the side effects of chemotherapy. Now, at 20 years old and four years in remission, she reminds herself how humor helped her throughout her cancer experience and how it has forever changed her focus and identity. She describes herself as “really healthy now.” Allie is studying journalism in college and has volunteered and interned with The Leukemia & Lymphoma Society (LLS) in various roles; she proudly advocates on behalf of other AYA cancer patients.

Allie describes her cancer care as responsive to her needs when she was involved in discussions about her care. “It’s interesting to reflect on, I have anxiety now, but at the time, I couldn’t think about it. As soon as I was diagnosed, they were hopeful about my prognosis, which left me relieved and ready to finish treatment. I wanted to know what was being done and why. What made me nervous were the unknowns. The oncology team was very engaging and willing to discuss treatment and interventions, and I was treated as part of the team and provided with the information I wanted,” says Allie.

What Allie Says About Language

Combat Metaphors

“It can feel like a war to those outside of the patient, but that is not necessarily how the cancer patient feels. Others expressed how sorry they were that I was dealing with cancer, but that didn’t make sense to me; it felt negative. For me, I use humor, so my response would be, ‘I’m alive, so I am not sure why you are sorry.’”

“I reclaimed warrior language; I did have to battle cancer and get through it. It resonated with me and helped me as a teen with cancer because I was disconnected from so much, and this language empowered me.”

Journey Language

“Treating cancer like a journey goes hand in hand with people saying you are brave. I didn’t have a choice about getting cancer. I did not notice much of this when going through treatment and appreciated any kind of support at the time. Since I started advocating and reflecting on my own experience, I realize how this language might make some patients feel uncomfortable, as we don’t have autonomy or control over having cancer.”

Loaded Medical Terms Like Remission and Prognosis

“Today, after treatment, I think more about the word *remission*. When diagnosed, my prognosis was comforting. Technically, they say after five years of remission, I am cured; but there are different issues I face. There is a risk of different cancers and effects. Remission may signal the end of treatment for a current diagnosis, but it does not capture future concerns and risks.”

Cancer and Identity

“When I first left the hospital, I struggled with the loss of my old life and dealing with my new normal. I was 16, from a small town, and lost all the friends I had before I was sick. I had a lot of issues coming to terms with people not understanding that I felt different after being sick. I don’t think you are your cancer, and it doesn’t have to define who you are, but for me, it did help me become who I am today. Although I would have appreciated developing character growth differently, I gained some good experiences from this and enjoy my work—I can be a writer and advocate for blood cancer. It’s very personal. You can decide how closely cancer is tied to your identity. The extent to which the risk of death shapes your experience can vary. I am proud of the way I was able to make the best out of having cancer. If you can make it through, it should be talked about and something you can be proud of. This is only my perspective, and I wouldn’t want to be insensitive to those who feel differently.”

Generic Cliches

“All offers of help are appreciated as well as kind words, but it can be overwhelming, especially when we may need specific help and others don’t know how to provide that. The intention is good, and people are trying to be helpful; my parents and I tried to remind ourselves of that. If I were to give advice, I would ask those offering help to imagine themselves in a situation where they couldn’t tell you exactly what was needed. What would you bring them in their most difficult time?”

Suspicious Causes and Treatments

“I did hear some of this. The truth is that many things can cause cancer, but I heavily trusted my medical team and didn’t have a clear cause. I have learned that there are some environmental causes of leukemia, but I know I didn’t get it from the various reasons people assume. I always knew those comments came from a misunderstanding of what causes cancer. I know how to take care of my body and lead a healthy lifestyle.”

Questionable Justifications: Where Do You Get This Stuff?

“Everything happens for a reason.”

“I did hear this. When people don’t know what to say, they say this. I was really connected with my faith when I was sick so it resonated

with me that I could manage cancer with the help of my faith. Now I am agnostic, but I do feel things happen for a reason. Who I am now is related to having had cancer. I understand this may be based on some ignorance, but it may be related to someone not being able to handle how serious cancer is. We assign a meaning to things, especially life-threatening things. People need to feel there is a reason rather than it being random, especially when dealing with death."

Outright Denials

"I had denial after the fact, not during treatment. It was obvious that I was sick when I was going through treatment. I was out of school and activities a lot. Once I got out of the hospital, people didn't recognize how much I was emotionally struggling, especially after treatment. I didn't have a big falling out with friends, but I struggled to connect because they could no longer relate to me. I couldn't keep up with social demands, and people didn't understand that I couldn't just jump back in. I dealt with anger about being in a classroom and couldn't relate to other students. I was told I would likely have to deal with mental health issues and had therapy and psychiatry appointments set up for when I left the hospital. Although I maintained it, I didn't feel like I had AYA support. That's why I created the outreach website and connected with LLS to become an advocate and volunteer; AYAs need these connections."

Dubious Comparison

"I had these thoughts about myself, not from others. I am not sure what my response would have been had someone said something like, "You are lucky." I struggled with this from the beginning. I did have cancer, but it was treatable. I still struggle with my treatment not lasting as long as someone with chronic cancer. Again, I think people who say these things lack understanding. Survivors guilt is something many cancer patients face."

Questionable Praise

"I heard a lot of people saying I was brave, and I understand they were trying to be more positive, but I struggled following treatment. I didn't choose cancer and I didn't have a say on whether I would be brave. They told me what they would do to save my life and I accepted that. I feel a bit of imposter syndrome, anyone else would have made the same decision. Now reflecting on it, a better way to phrase this would be to say, 'I respect what you went through and how hard that must have been.'"

Premature Closure

"Within the first couple of years, it can be invalidating to a survivor that cancer is not something we have to think about anymore. I won't be the same. Cancer completely altered the trajectory of my life and how I deal with things. People need to be educated about how cancer impacts people, and how life is different following cancer. Patients need support to navigate these feelings. I had to prioritize what is important. Going back to high school and being in classes with younger kids was hard for me. This comes with the territory of being a survivor, but others need to realize their expectations need to change."

Inattentive Listeners

"I had a couple of these instances where people shift the story to their own experience with cancer. I think people are trying to make sense of it. There was a time when someone came up to me where I worked and told me someone they knew died from leukemia; that was all they said. I laughed in response. I felt bad for laughing, but it seemed ridiculous. People are trying to relate to you and are well intentioned. Survivors are pretty good natured with this stuff. I suggest people mention their connection to cancer, but also bring it back to the patient. They could say they knew someone with cancer, but also that they respect what I am going through as a patient, rather than just redirecting the conversation to themselves."

Allie also had some tips for healthcare professionals, especially those working with teens in pediatric cancer care units.

"If you are working with teens, you don't necessarily need to treat me as an adult because I am in a peds unit, but don't underestimate my maturity as a teen dealing with cancer. Kids with serious illness grow up faster than others. I had already been through so much before cancer, I was more mature than I was given credit for. I suggest professionals recognize that I am a teen, and that I do not need to be babied. Rather than always trying to make light of the situation, be real. I struggle with this with my primary care provider who gives false praise and uses cookie cutter phrases to try to make me feel OK. I also felt like I was being put on a pedestal as an older person on my unit, being told how brave I was. I didn't feel brave or have a choice about what I was going through. I wanted to be empowered."

"Be personable, but realistic. Being upfront in the hospital will help with the realities survivors face when leaving the hospital and into survivorship." ●



Allie Stevens a junior at Ohio University, majoring in journalism news and information with a minor in African American studies and a certificate in women's, gender, and sexuality studies. She was diagnosed with acute myeloid leukemia in 2019 when she was 15 years old, and suffered an acute lung injury as well as a major spinal fluid leak while in the hospital. Since beating cancer, Stevens has dedicated herself to her studies and has performed as both a news intern in Washington, D.C., as well as an advocacy and communications intern with LLS nonprofit, hoping to provide necessary support to fellow AYA survivors.