

VOICES OF OUR AYA COMMUNITY

CREATED BY AND FOR STANFORD'S AYA CANCER COMMUNITY | FALL 2023



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MEDICINE



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Our librarians are here to connect you to information, fitness classes, support, and anything else you might be looking for at Stanford or in your community. Our services are free and open to everyone.

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- **Share your story.** Stories remind us that we are not alone. We are here to help you share your story in whatever way works best for you.

Not sure what you are looking for?
We can help with that too.



Navigating Survivorship



PAM SIMON, NP



DEANNA BEYERS



GILLIAN KUMAGAI



Welcome to the third issue of Voices of Our AYA Community. This issue features stories from adolescents and young adults (AYA) with cancer about survivorship and what “survivor” means to them. Survivor isn’t a one-size-fits-all term and AYAs may identify with being a survivor at various stages, whether it be at diagnosis, during or after treatment, or at any other point in their experience. Others may choose not to identify as a survivor at all.

There is a community of AYAs who are at various stages in life and have had similar experiences and different perspectives along the way. Our purpose is to bring the AYA community together to find connection and belonging at a time that can feel so lonely.

We hope that as you read through this issue you find what resonates with you and learn through stories and shared experiences. Thank you to our contributors for being vulnerable and sharing their stories with our community.

We offer storytelling workshops for AYAs to come together to discuss various topics about their cancer experiences. We welcome you to attend a workshop and share your story through writing and other forms of artistic expression. We encourage you to share your story in a future issue. ●

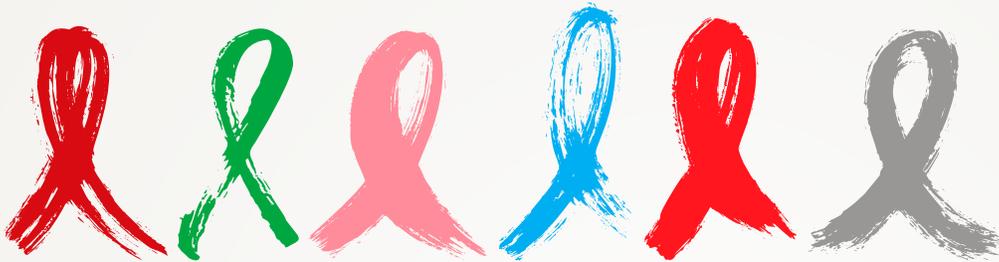
PAM SIMON, NURSE PRACTITIONER AND PROGRAM MANAGER
STANFORD ADOLESCENT AND YOUNG ADULT CANCER PROGRAM

We are here to help you tell your story.



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NAVIGATING SURVIVORSHIP



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Neon Jane

BY MAIA EVRIGENIS

My mom never told me to be strong during cancer. Not once. Not one time.

“Maybe you’ll write a book about what you went through someday,” she’d tell me instead.

“They won’t understand.”

“But what if they did?”

— *Neon Jane*, page 26

Following my treatment for acute myeloid leukemia (AML) at age 13, I decided to write a book about my childhood cancer experience. As I got older and moved further into the “after cancer” chunk of my life, I found the confidence to write a different story: the story of my healthy life now, and the way my sick past still shapes it. In my novel, *Neon Jane*, my 24-year-old self (Maia) struggles to move forward from her childhood cancer experience as she is haunted by a spunky, ghostlike, 13-year-old cancer patient named Jane (who represents me as a child). Jane wears a neon pink wig over her bald head, which is the same wig I wore during my cancer treatment at Lucile Packard Children's Hospital (LPCH). Sometimes I even wore neon orange as well!



This book is my whole heart. While it’s a fiction book, it’s based on real experiences and feelings I had both during and after treatment. It’s largely about the challenges I faced due to the pressure I put on myself to live an incredible, “successful” life as a cancer survivor, and the way the cancer experience impacted my family,

friends, romantic relationships, and most of all, my relationship with myself and how I viewed my body as I got older. While the memories of my treatment will always stay with me, I had to find a way to let go of thinking of my body as “sick,” in order to move positively through my adult life. I had to stop living my life in fear of getting cancer again. Writing the book helped me do that, though I was so, so worried people wouldn’t understand what I was trying to say...

But readers have totally understood! And they say they feel the same ways that I do in the book! Through the adolescent young adult (AYA) program at Stanford, I’ve now been able to connect with so many people in this community who have told me that the book has made an impact on them. There is a huge gap in today’s movies and books about the realities, challenges, and dare I say, beauty of the AYA cancer experience. I see now that it was my calling from God to share my experience to help myself and others talk about the after-cancer experience and its impact on mental health. The response



from the book has been overwhelming. I had a wonderful book launch in May at my childhood home in Sacramento, California. My doctor during treatment (Kara Davis) even came, along with three of my hospital school teachers: Kathy, Kevin, and Dave! When I get messages from other survivors and their family members or medical professionals who say the book has helped them feel seen, that is the best feeling in the world.

People always ask me why I named the childhood version of myself Jane instead of just calling her Maia in the book. It’s tough to answer without spoiling some of the magic in *Neon Jane*. I guess you’ll have to check it out to see why I made that stylistic choice. If you’re thinking of reading it, I sincerely hope you like the book. I wrote it for all of you! ●



Navigating Survivorship

BY HANNA GREGORIO

For me, survivorship and processing my cancer journey began a few years after I officially ended treatment. Despite how hard I tried to repress the feelings, memories, and trauma that cancer brought, I found they slipped through the cracks. I naively believed that after chemo finished, my problems and body would forget. My two greatest tools—sarcasm and keeping busy—began to work less and less in my twenties, and while my journey continues, following is one of many stories of survivorship.

I was diagnosed with acute lymphoblastic leukemia at 15 years old in 2011, a disease I'd only heard about from reading *A Walk to Remember* and *My Sister's Keeper*. I was playing basketball, a sport I couldn't get enough of when a fall and injury during a game put me in the emergency room. Right before I was to be discharged from the ER, a physician changed his mind and decided to run a few more tests, finding my leukemia and ultimately saving my life. I went from playing basketball with my friends that weekend to discussing chemotherapy treatments and surgery. A time where

Navigating Survivorship

high school, friends, and sports were the most important things to me, I instead started to spend days and weeks in a hospital bed, too sick to play sports and watching life pass by on Facebook. That time was indescribably hard, mentally and physically, but through it all I had an incredible family, community, and an outpouring of support from many people that I'm still close with today.

Fast forward two and a half years, I was officially finished with treatment and cancer free. I had just turned 18, was 50 pounds heavier from steroid treatments, physically deconditioned, and heading to college ready to start my life. I was ready! I could erase all those bad memories and start feeling great again like I did when I was 15. However, as many of us know, that wasn't the case. I went from seeing doctors' multiple times a week to every few months, and then every few years. With this transition, no one told me that it would be scarier to not be around hospitals than in them. I started to think, what if something goes wrong or the cancer comes back? How do I accept these physical and mental scars my body inherited? What happens now that I'm done with treatment, and how do I tell new people I meet about my experience?

Instead of processing those three years of cancer, I got busy and jumped into nursing school, obtaining a nursing degree, and then began a career working in high-paced nursing environments. I rarely shared my cancer history with people I met that hadn't known me previously, and if I did share, I'd find myself anxious and crying trying to tell my story. I survived. I survived the chemo, the strain of illness on my family and friends, and so many missed experiences; that means it's over, right? Life can go on?

I wished it was that simple, but I started to learn that the emotional impact of having leukemia as a teenager started to catch up to me in my twenties. Things like body image issues, sexuality, and anxiety about my health started to appear in ways I wasn't prepared for. As a



With me and other young adult survivors I've met, this feeling of guilt or pressure comes up. We survived, shouldn't we do something impactful with this chance or live every day to its absolute fullest?

cancer patient, you have a goal: surviving, or wishing and hoping these treatments are temporary. But once the doctors determine you're done and you're labeled a "survivor," what do you do?

With me and other young adult survivors I've met, this feeling of guilt or pressure comes up. We survived, shouldn't we do something impactful with this chance or live every day to its absolute fullest? We lose so many lives to cancer, why did I get a second chance? The pressure to make something of myself felt overwhelming at the beginning, and while it helped push my education and career goals, I found that the emotional aspect of cancer treatment continued to affect me.

To understand those emotions, I've spent and continue to spend time with a therapist that can help me unpack and understand those years. It's allowed me to start to heal and be able to help others in vulnerable positions. As a practicing nurse, I'm able to pull from my own experiences to understand how it feels physically and emotionally to be a patient. Giving back through healthcare has been extremely rewarding for me. I've also continued to have extremely supportive family, friends, and a partner that understands my fears and anxieties

about cancer. I've come to accept myself and the changes cancer has made to my body and mind along with being comfortable sharing my story with others to offer hope.

Through all my experiences and looking back, I'm extremely grateful for the path my life has taken. I find it a privilege to be a cancer survivor. It's a community of people that had no control over the diagnosis they were given or the treatments and pain they had to endure, but they continue to show up every day. The shared suffering and understanding makes survivors incredibly resilient and I have the privilege of seeing this both inside and outside the hospital.

In this journey, transitioning from not only surviving, but thriving, is what I hope for all cancer survivors, but we can't do it alone. The scars cancer leaves on the person, their families, and the people around them cannot be understated, and the journey doesn't end when treatment ends. Our experiences and cancer can stay with us through life. So, continue to fight for us and be there, because I hope one day cancer survivors aren't a community anyone needs to be a part of. Until then, squeeze the people around you extra tight and remember we're all survivors in our own right. ●



Chemo at 5 and a Music Festival at 6

BY CARLY FOSS

My three-week rotation of health and illness is like clockwork. Two weeks off and one week of infusion and recovery. It's become my mindset to live by each week as a 24-year-old battling breast cancer. This is just a part of my story—after my first teenage cancer diagnosis and treatment, it was easier to move on, get better, and feel done with cancer.

But three years later, right after I moved to a brand-new city with my best friends and started at a new university, I felt another lump. I instantly knew something was off and within a few days, I had ultrasounds, mammograms, two biopsies, and a new diagnosis. Surgeries, IVF, and chemo started from there, and I moved back in with my family for treatment. I was devastated to say the least and couldn't imagine losing the joyous life I had worked so hard to build. It sounds crazy but I ended up feeling strong enough to fly back and forth between my college town and my hometown on that three-week rotation. On my bad weeks, I'd get chemo and recover at home with my mom, barely eating or getting out of bed. Like clockwork, on that fifth day I somehow felt better and would board a plane to San Diego for two weeks until I came home and did it all again. This is how I kept my friendships, hobbies, and self-care going.

Friends, acquaintances, friends of friends, and even doctors, would voice their concerns about my lifestyle, wondering how I managed to remain so full of life and not sick in bed like their Hollywood idea of what a cancer patient looks like. I realize it's not the norm but I am so happy with my decision to keep going; to keep doing what felt good for me, it's what gave me hope. And now in my "survivorship" I continue to do the same thing. Good weeks are good weeks, and bad ones are often hard. And sometimes, you get caught in the middle—that's where the chemo cowgirl mindset comes in and we must choose

our normal life even when we're caught up in cancer world, getting infusions. We push on after the infusion and go see Stevie Nicks with our best friend, wearing red boots and making the best memories.

This drawing represents the endurance we have to put up in order to not sacrifice normal life. I have forced myself to have the strength and commitment to living the life I want to live despite the "forks" cancer puts in my road. I don't want to look back and wish I had gone to the festivals, graduations, or classes, or know that cancer stopped me from doing so. Cancer has actually opened so many doors, connections, and relationships for me, and with this mindset I get to say I did it all. I am still fighting for my life—literally—and for my outside cancer life, and I am doing it with gracefulness and strength. I have six more infusions left as I write this, and then four years left of other medicines, so the three-week schedule will come to an end soon but for now, this is my definition of survivorship: balancing treatment and taking on the good with the bad. ●

We must choose our normal life even when we're caught up in cancer world. We push on after the infusion and go see Stevie Nicks with our best friend, wearing red boots and making the best memories.

For You

BY VIVEK CHOTAI

I was told that most stem cell transplant patients take a year or two to recover, before transitioning back into society. My entire life, all I wanted to do was go to college, to learn, and to feel limitless. I was miserable at home, recovering from taking a year off for treatment after being diagnosed two days after my high school graduation, thinking I was behind all my friends and watching them live the dream I fought so hard for. I didn't want to survive, I wanted to live. What was supposed to be a sanctuary, the walls of my home, shackled me to isolation; I was restrained by the chains of being labeled "immunocompromised." I started pondering the point of survival, to really question if this quality of life was even worth fighting for. I remember the day I brought this up in clinic. Dr. Bertaina had heard this story before but gave me a different response this time. She questioned, "Are you happy?" I answered so quickly that I surprised myself: "No."

I'm two years out now, in remission. I also happen to be finishing my second year in college. It's not how I imagined it would be. I was sent off after being given orders to "take it easy," and "not think about the hospital for a long time," by the same people who ask me when I'd like to schedule my next appointment. I was instructed to enjoy college and not think about cancer by the same people who prescribed me pills to remind me of it. I was taught to live in fear by the same people who drilled belief into my mindset, hoping for a second chance.

My major is in molecular biology. I actually chose it before I was diagnosed,

but I'm more confident about it after going through leukemia. The way I coped with my treatment was by understanding the science behind it. Feeling like I knew what was happening made me feel more in control of my life, as if understanding how the molecules of the chemotherapy were binding to my DNA would actually make it more effective. And honestly, I thought it was really interesting; I just wish it wasn't real. Now in college, I listen to professors and students lecture me about how tumor cells work, with no idea that I've already learned it—the hard way.

I miss the days when I used to be friends with everyone in my classes. These days

I seem to be surrounded by premed students who I don't relate to as much. I sit in 350-person lecture halls, listening to my peers discuss their biggest problems which consist of choosing which country to visit on vacation for break, pushing unethical boundaries to ensure that coveted "A" is secured on their transcript, and other things that seem too superficial to remember now. One day, these same students will become our doctors.

I won't pretend I don't want to go into medicine too because I do. And I've really questioned whether this ambition is mine, or shared by all pediatric cancer survivors, stemming from a need to give back. I recognize there is a sense of pressure I feel to take advantage of this life, after being given a chance to continue—something not everyone is given. But I affirm there are ways outside of medicine in which I do give back. A career in medicine is my choice, not because I feel the need to, but because I want to.

College is fun, too. A good part about being surrounded by so many driven students is that there are so many amazing projects to join. I'm involved in a couple, but by far, my favorite activity has been delivering cards to the hematology/oncology floor at Reagan Hospital. We make these well wishes cards to give to the adult patients going through treatment, but really, they're just a way for us to start a conversation. I love talking to the patients and learning about their stories. Usually, our interactions start with them being uninterested and exhausted, annoyed at someone coming into their room. And that's totally understandable—I've been there before, too. But after I introduce myself as a survivor, they raise their eyebrows and become interested. I give my routine "one day at a time" speech, to pass on the advice that worked for me, and they start sitting up, listening intently. I tell them all of UCLA is rooting for them, that we all believe in them, and that they have the best doctors and nurses in the world to help them get through this, because they will. My goal is to instill hope in them, like my nurses did for me. Then they start asking questions like, "Does it really get

Helping Others

better? Be honest.” or “Does the transplant hurt?” I keep my answers real, but still hopeful. Sometimes I get questions that I don’t know how to answer, like when a newly diagnosed mother asked me, “What about my kids?” That completely shattered my heart, and I still don’t know how to respond to that. But most times as our conversation continues, I see them start to sit up, relax their body posture, and even start to smile. Some days they even start laughing with me, and other days they cry with me. Either way, they finally have someone who can understand how they feel and what they’re going through—someone who’s done it before. They can see me as a survivor, out of treatment, who has come back to show them that it’s possible to get through this and live life afterwards. Sometimes I wish I was exaggerating when I say this, but I can feel what they feel. I was in their position, on a hospital bed with those same anxious, stressful, angry, unmotivated feelings, two years ago. And being able to talk to these people and ease their feelings, even if it means letting them forget about cancer for just one minute, is why I live my life.

When I was a patient in the hospital, what helped me was talking to survivors. Now I’m the survivor talking to other patients. And being able to connect with someone during one of their roughest days of life and seeing them feel better, open up, and smiling, really makes me feel proud of myself.

Last week, I met a young man in his twenties, who had been diagnosed four days prior to my visit. He hadn’t shown any emotion at all, as if the diagnosis didn’t affect him. A doctor had asked me to talk to him specifically. I walked into his room and introduced myself. I got to know him as a human, without even talking about the diagnosis at all. I noticed three jackets on his couch and mentioned that it seemed like he had a good support system. He paused and then told me those jackets belonged to some friends who were visiting. I asked him, “Have you told your family yet?” He broke down crying. I could tell that was his first time crying, the first time lowering his apathetic guard.

I knew he was opening up for the first time, letting his tears fall when his family or friends weren’t watching. I walked around the bed to sit right next to him and kept my hand on his upper back, like my papa did to me. My new friend let out his emotions, telling me he started chemo four days ago and didn’t know what to do. I said that was absolutely fine, and that he didn’t need to know what to do. I told him that we all believe in him and that every single person in the hospital was there to make sure he got better and was out of this place in no time, that it’s OK to cry and feel this way, that he does not need to fight alone because he has an entire family and care team to fight with him. He was nodding as I spoke, sobbing too hard to speak—like I had when I was classified as high risk two years prior. I told him that I know it felt like he was on a good track, which all was derailed for an unknown, unfair reason. But sharing how he was feeling was how he could find control—and stay in control—of his life. I told him that he could tell the doctors or the nurses or his family and friends how he was feeling, and how he has control

of today and always will. That there will be hard days like today, but that’s OK, because he will be able to get through them. That he has an entire team around him to help him do so.

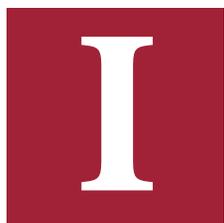
Once he had some time to recover and feel calm, he showed his gratitude to me, and I left his room. But after I closed his door, I needed some time to breathe. Because I had been in his place before. And I remember feeling how he felt, as a man who didn’t want to show any weakness in front of his loved ones. As someone who felt like he needed to take care of his parents first, before taking care of himself. And now, as someone who realized that they couldn’t do this alone.

I can’t go back and tell my past self what I know now. But I can help other young adults survive by telling my story. I relive the most traumatic memories of my life and face death again, for humans like him, and readers like you. And if showcasing the most vulnerable side of my identity means making another kid like me feel understood, then that’s worth it to me. I’d do it again for anyone—for him, for me, for you. ●



One Day at a Time

BY ANONYMOUS



I'm an angry dude. I'm angry about having had cancer. Angry about its effects on my body. Angry about its effects on my mind. Angry about having survivor guilt. Angry about being angry.

My most recent treatment was in 1997, so it's been all rainbows and unicorns since then, right? Nah. Even after treatment, cancer has never left me, buzzing around like an annoying mosquito. It has caused physical side effects, surgeries, and other procedures. It has contributed to mental health issues—depression, anxiety, anger, and fear of recurrence. I always tried to keep my scars covered up. No way would I ever want to give a stranger an opening to talk about my cancer experience. I expended an incredible amount of time and energy not talking about or even thinking about cancer. Pushing those feelings down further and further was like trying to stuff too many T-shirts into a small suitcase. I was deeply depressed for close to 20 years. Eventually, I realized I needed support and found a therapist to help me figure out the mess that is my mind. In a very roundabout way, that helped me become involved in the cancer world as an advocate.

I know so many people from the adolescent young adult (AYA) cancer community that have passed away. So many I can't even keep track. Why are they gone and I'm still here? There's my survivor guilt. Every time we lose another person, it fires me up to try and do more so that additional people aren't lost. My buddy Tony died in 2019. He was the best guy—thoughtful, funny, and over the moon in love with his wife, who was connected to his hip. We

bonded over sports, music, cancer, and anger. He had a really rare cancer and went from clinical trial to clinical trial and treatment after treatment to extend the amount of time he would be able to spend with his wife. We had a text exchange about a month before he passed away. He was in immense pain but his focus was on me: "You should work on your anger issues, they're never good." And this caring, compassionate dude is gone but I'm still here, angry and trying to fight the world?

More survivor's guilt—what have I done to my parents?! They tried for several years to have a baby and then ended up with one who got sick at six months old, immediately pushing them into the raging whitewater river of hospitals, treatment decisions, insurance companies, and financial instability. Neither one of them had ever had any serious illnesses and no one on either side of their families had ever had cancer. They went through a trial by fire in learning how to make what the care team said were life-or-death decisions for me. And now they're still worried about my health, decades later. I'm grateful for them making sure that I'm still alive and kicking and (mostly) healthy. They gave me the tools to be able to advocate for myself and other survivors, so they've had an incredible impact. But I wish they didn't have to go through all that long-term stress.

I hate when I have to see a new doctor. Explaining my medical history takes a long time, but it also brings up all of those feelings about having been sick. I especially hate when the provider looks at me with awe as if they're surprised that I'm still here. The absolute worst is when I see a new doctor who doesn't read my chart and just assumes that because I look healthy that I've never had any medical issues. It's also really tough for me to work with someone who doesn't respect that I'm the expert on my own body. I have decades of de facto medical experience, much more experience than most of the doctors I've ever seen, so I really wish they would trust me when I tell them what works and what doesn't.

Fear of recurrence has taken up permanent residence in the back of my mind like an unwanted family of possums in a farmhouse. When I have a weird pain or have an annual checkup, it's there. My mind goes to the most catastrophic outcome possible instead of something normal, because I've never felt normal. I know it's not productive, but I've always tried to prepare for the worst while hoping for the best.

This is a cautionary tale. It's OK to be angry and stressed and depressed and anxious and scared during and after treatment. But don't let it take over your life. Find help in a way that works best for you—a therapist, a peer or support group, exercise, meditation, an emotional support animal, whatever. I'm way out of treatment and am still working on my mental and physical health. I'm in a love-hate relationship with my body—it's bounced back every time it's been endangered, but I'm still waiting for it to try to kill me again. But I'm still here. One day at a time, one breath at a time. ●

19 for Life

BY TRACIE FRANSDEN

19 For Life is a foundation created to celebrate the gift that DJ Frandsen was to his family, friends, and community. He lived his life with a strong will, optimism, and compassion. The 19 For Life Foundation is a lasting legacy to DJ's beliefs in giving back, making a difference, being a man for others, and never giving up. It was started by Kevin Frandsen, DJ's brother, who wanted to ensure DJ's spirit lives on forever.

19 For Life helps fund off-site recreational activities for children coping with serious illness at Lucile Packard Children's Hospital (LPCH); and offers scholarships for local high school athletes who have overcome illness and adversity; and support for Bellarmine seniors needing financial assistance to complete their high school education.

When Pam Simon, Nurse Practitioner and Program Manager of the Stanford Adolescent Young Adult Cancer (SAY-AC) Program approached the Frandsen family about supporting SAYAC, we jumped at the opportunity to help.

DJ was first diagnosed with Wilms Tumor at age six, then again at ages nine and 18, and lastly at age 23. DJ went through years of chemotherapy, months of hospitalizations, dialysis, and received a kidney transplant from his dad when he graduated from high school. He never complained and always looked forward to the next day. When DJ turned 18, he would NOT go to the adult hospital, he believed in his doctors and care team at LPCH at Stanford. It was a battle, but all in all, DJ and Dr.

Michael Link stayed together! DJ trusted Dr. Link with his life for 19 years and believed he would do everything possible to get his life back.

DJ hoped Dr. Link's team would find a cure so that other children wouldn't have to endure all the needle pokes, chemo, scans, etc.

DJ survived to finish college with the help of LPCH staff working with his schedule, etc. Before he retired (died), he graduated from Santa Clara University, where he enjoyed being the men's basketball manager for three years.

Among the others at LPCH who touched DJ's life was Dr. Steven Alexander. He also adored his nurses, especially Verna Mitchell, Pam Simon, Melissa Martin, and Cathy Costiglio, as well as Child Life advocate, Jamie Bruce.

DJ believed in helping others even when he had cancer, had a very competitive spirit, and a strong will to live.

His motto became the foundation's motto: GO THE DISTANCE, NEVER GIVE UP! ●

The logo for 19 for Life features the number '19' in a large, bold, blue font with a red outline. Below the '19', the word 'for' is written in a smaller, blue, cursive font. To the right of 'for', the word 'LIFE' is written in a large, bold, blue font with a red outline.

The mission of 19 for Life is to make a meaningful difference in the lives of children and their families who are coping with cancer or other serious illnesses.

We achieve this goal through a variety of means including:

- » Spreading awareness of childhood cancer
- » Granting scholarships to student athletes who have overcome physical adversity
- » Assisting families financially while their child undergoes medical treatment
- » Hosting fun, uplifting social outings for children and their family members
- » Connecting families with various beneficial Lucile Packard Children's Hospital Stanford programs such as CHEERS and AYA



GO THE DISTANCE. NEVER GIVE UP!

nineteenforlife.org

The First ‘A’

ON LONELINESS AS A
16-YEAR-OLD SURVIVOR

BY ALEXANDER LAMONICA

It was 7:31 p.m. on a Wednesday, and as I stared into the wall that night, the last thing I wanted to feel was sorry for myself. Against every word the doctor spoke to me that dripped with his implicit condolences, my mom crying on the windowsill beside my bed. With a quick post to Instagram, I was showered with attention—with likes, words of encouragement—everything I needed to get me through, or so I thought. And so, I jokingly complained about the bland hospital pasta and the IV in my arm to my concerned classmates, and I told my friends over text it was “just cancer” with a smile on my face, as if to insist I wasn’t afraid. As if fear is an admission of defeat more than anything else.



Feelings of Loneliness

I began chemo a month after my diagnosis, and in a sense, I was never alone. I was connected to more people than ever. I received countless cards, gifts, and offers to help—anything you can imagine. It's easy to appreciate these things when Hodgkin lymphoma is only a term printed on a pathology report. I felt more excited than anything else. I enjoyed my visits to the hospital, conversations with doctors, and talking with friends about my condition. I wanted to be a fighter.

The idea of cancer as a “fight” or “battle” has permeated our conception of the disease. To assume a combative nature is to claim a degree of control. When I was a freshman in high school, my grandpa died from cancer. For one week, I had come to his bed each day and convinced myself it wasn't over yet, that even in his frail body and the fragile hum of his voice, there was still hope. It's easier to reconcile the man who used to pick you up from school every week to a determined survivor than to a senseless victim. It's easier to say keep fighting. And as I watched him struggle for his last breaths, some part of me could only think he just didn't fight hard enough. Now, two years later, I wanted to be different; I wanted to fight hard enough.

As such, in my time as a patient, I worked hard to preserve a sense of normalcy. Between 12-hour visits to the hospital every week, I was determined not to surrender an inch of ground where I could help it. I went to school every single day I could physically manage. I put a hat on my head to cover the bare skin where hair should be, and I pushed through profound pain and exhaustion just to make it out of bed. Against all odds, despite missing over a fifth of my classes, I excelled at my schoolwork and received a perfect academic record. But I soon realized that if I was not the sickly, emaciated child from every Saint Jude commercial, then to everyone else, I was just, well, normal. Worse than being the kid with cancer is being the kid who just wears a hat every day.

Maybe then, our loneliness hides in our perceived normalcy. No one will ever

know what I felt showing up to school each day, they will only know that I looked good enough. But in the same way that drowning is undetectable to an untrained observer, the worst pain doesn't leave you screaming, it drowns you in silence. Lying helplessly on your bed after school as you reach for the faint traces of words and ideas that you once called yourself. You don't have to look scared to be alone.

How many hours have you lost to a particular spot on the wall, staring into the void as you try to drown out the pain? How many times have you been too tired to feel any emotion at all? Sitting and waiting in steroidal delirium for the next thing to happen, you have since forgotten what it was, desperately reminding yourself that only time heals all things. Is there any palatable way to communicate this, experience to be gained, or lesson to be learned? Is this really what fighting looks like? Cancer then, at its worst, is not a fight, but a waste of time. I think this, above all, makes cancer so isolating. I can describe in vivid detail the searing pain of mucositis, or the nausea I feel when I smell hospital soap. These are communicable concepts that elicit an intense emotional response. But how then do I say that the worst pain of all hides behind a simple “I'm just tired”? A phrase I've uttered countless times to classmates asking how I'm doing. These words are all I'm offered to express a dull reality.

As a 16-year-old, from a medical perspective, I am at an incredibly awkward, liminal phase between pediatric and adult medicine. Because of this, we teens are often forgotten. I am either the oldest or the youngest in any given waiting room, something that's reflected in the quality of psychosocial support provided. Resources for teens with cancer are few and far between. To this day, I have never met a single survivor my age. In the absence of language, empathetic connection is vital to feeling understood, but that's something I've hardly been afforded. I spent hours scouring the internet for any trace of connection



“We teens are often forgotten. I am either the oldest or the youngest in any given waiting room.”

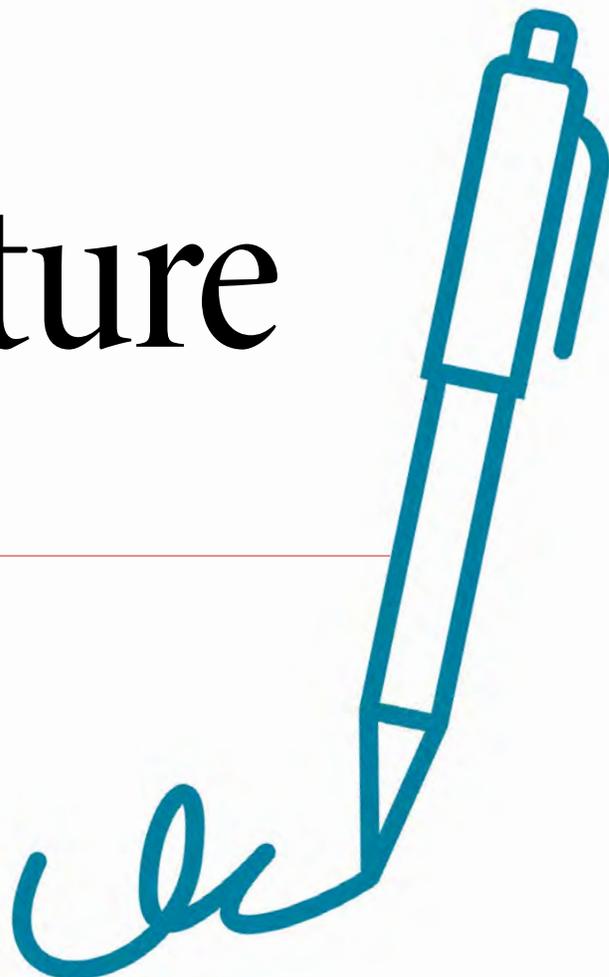
to anyone my age, but every resource I was referred to seemed to forget the first “A” in AYA. Because of this, I was left to manage myself alone. I still believe strongly that teenagers are one of the most underserved age groups in this regard, and I'm willing to do whatever it takes to advocate for others my age. Our current support networks need to do more to reach out and proactively facilitate these types of connections, so that no child is left behind. So that every teen has the opportunity to bring meaning to the time cancer hopes to rob from us.

Today, as my hair slowly begins to transform into its first semblance of a passable haircut, and my scars begin to heal, the loneliness cancer brought still burns within. I still claw on to any study, any program offered that gives me another excuse to return to the hospital to cling on to my experiences, and to bring meaning to the senseless—in a world where the very concept cannot be related to those around me. ●

To My Future Nurse

BY RAIHA SANDERS

Dear Future Nurse, Before you come into this room, take a breath, slow down, and realize you're about to go in and care for a human in need.



Before you see my skin color, know that I am a human being, I am not alien and I am not “other.” I am just like you, except that I am vulnerable, and I am in a crisis. You won’t be able to see my pain, but you will be able to hear it in my voice. You can’t touch my pain but come close, don’t you notice something in my joints? Oh right, you can’t feel it. Would you like me to attach a magical device that simulates the pain of a sickle cell crisis, or better yet a technology that lends you the gift of knowing what it feels like to be in my body, no? You have all you need to know. Enough to initiate empathy in your heart and consume your mind? I don’t think so, perhaps these futuristic and otherworldly machines are needed then. They’re needed before you tell my mother to, “calm down, we’ve given all the medications we can give her

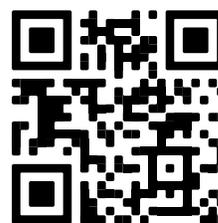
now and the doctor will see her soon.” Before you pass the room I’m in five times within the hour, ignoring my eye contact as I lay crying in pain. No, I think there’s more you need to know.

I need you to know that I’m not lying, I am sincere. I need you to know my mother is not an addict, neither am I. I need you to know that I am black and this is severe. I need you to come close and listen, so you can really hear me. I can’t help but think that this goes against the physician’s Hippocratic Oath and your Florence Nightingale Pledge. Do those words mean anything to you? Do you even remember them ... let me recite my favorite part for you. I shall be loyal to my work and I will dedicate myself to devoted service to human welfare. I hope you feel that beneficence and moral obligation to do good on behalf of the patient. Although

this doesn’t feel good, and even though I don’t know you, I know that you can understand what it’s like to feel good and what it’s like not to. So please be good to me. Please don’t forget me and please don’t dismiss my plea for help. Here, I’ll walk you through it.

Dear Future Nurse,

Please check yourself at the door, take a breath, slow down, and realize you’re about to go in and care for a human in need. ●



Listen to
Raiah's story

Healing Through Art

BY NICOLE CROMWELL, RN

As an artist, I know firsthand the power of creativity and imagination. When I paint, I am able to express my thoughts and feelings in a way that words alone cannot convey. I can tap into a part of myself that is both vulnerable and strong, and create something that is truly unique and meaningful.

Each one of us has the ability to create, imagine, and express ourselves in a way that is uniquely our own. And when we do, we can tap into a wellspring of strength and resilience that can help us face even the most difficult challenges.

So, my message to you is this: don't be afraid to embrace your own creativity and imagination. Whether you pick up a paintbrush, write in a journal, or simply daydream, there is power in the act of creating. By expressing yourself in your own unique way, you can tap into a source of inspiration and hope that can help you through even the toughest of times.

So, paint, imagine, and keep fighting. You've got this. ●

Paintings by Nicole Cromwell, RN

Visit Nicole's
website



Healing Through Art

BY ZENAIDA C.

As someone who has always appreciated self-expression through art, immersing myself back into it throughout my healing process has been profoundly helpful to me in my cancer journey. My experience through diagnosis, treatment, and now remission has not been linear, and I often forget how far I've come. Finding this outlet, or rather rediscovering it, allowed me to release stress during my journey; being able to create provided life to my hopelessness. The ways in which you can create are endless, and I would urge anyone in treatment/recovery to explore the many ways you can create during your journey. ●

Paintings by Zenaida C.



This additional piece created by Zenaida was featured in the Winter 2023 Stanford Magazine





A Conversation

BETWEEN VIVEK CHOTAI
AND MAIA EVRIGENIS



Vivek Chotai (VC): Maia, do you remember the day that you were diagnosed?

Maia Evrigenis (ME): So, I was diagnosed when I was in seventh grade, I was 13 years old. I didn't know that leukemia was cancer. I just hadn't been exposed to that specific word "leukemia" before, so I didn't even really get what was going on that day until a couple of hours later when somebody came in and said, "All right. You're going to lose your hair, the chemo is really intense." And I was like, "Oh, I'm one of those people." That's what happened? What about you? Do you remember your specific day?

VC: Yeah, I definitely remember that day. I went to the wrong ER. I was 17 when I was diagnosed, so we weren't sure whether to go to the pediatric side or the adult side. We ended up on the adult side and I had to wait six hours. The nurses kept checking in, and I showed them my blood test results and the nurses looked at me and their eyes were just so wide open after reading the results. At that time, I just started laughing. I was like, "Oh man, it was that bad?"

ME: Oh my gosh. It's really interesting. I feel like I acquired this vocabulary and this knowledge from being an adolescent cancer patient. I recently had to get blood work done and it's crazy how I can read the blood work so well.

VC: Yeah, you had to learn to interpret your test results because your life depended on it. Right? And I feel like especially since it happens during your childhood, you're forced to kind of grow up fast.

ME: Yeah. It's really, really complicated because you're forced to grow up but at the same time you're sort of being taken care of as if you were a baby. To have a nurse come in and have you go poop in a plastic thing and they test it, I was so embarrassed. I think I felt that a lot, especially at the beginning, but now when I look back, I'm like, "There's nothing embarrassing about this."

VC: Yeah, I totally agree. Before my diagnosis, I was the captain of my wrestling team, so I was really athletic. Going from that to now, not having the strength in my core anymore to even sit up, I thought it was embarrassing. But then I talked to my nurses, I'm like, "I'm sorry you guys have to do this for me. I can't do it myself." And they're like, "Nobody expects you to be able to do it by yourself, and you shouldn't have to do it by yourself. People are there to help you."

ME: Right. I think that this topic of embarrassment is so interesting because there's the cancer way of how you're supposed to act and behave and talk about this topic, and it was very challenging for me to share my experience with people. So, what advice can you give someone who's having trouble sharing that?

VC: You kind of have to decide who you want to tell and what you want them to know. You can't control the other person's reaction. And it's kind of a blessing

in disguise because you find out who your real friends are. Be straightforward about it, so tell them, "Hey, I had leukemia." But then the most important part is to tell them that you're OK now. So, I'd be

like, "Hey, Maia, I had leukemia, but it's OK because I'm in remission now." Or if you're a patient in the hospital, "I have leukemia right now, but it's OK because I'm getting treatment and I'm fighting through it. But there are days where I have to stay in the hospital." And then if there's anything you need help with, you should tell them and ask them. And if they ghost you or if they judge you, then it's probably best that you don't keep them in your life. You want to surround yourself with people who believe in you.

ME: I think sometimes this AYA experience feels really unique, but we all have pain, and we all have struggles, and we have to invite people and share our community.

VC: Take it one day at a time, and don't let cancer define you, you get to define cancer.

ME: Amen. ●



Listen to the conversation between Vivek and Maia.



Stanford Adolescent and Young Adult Cancer (SAYAC) Program

You have big plans for your future—school, work, family. A cancer diagnosis is a huge disruption to those plans. The Stanford Adolescent and Young Adult Cancer (SAYAC) Program is here to help you navigate the challenges of treatment and everything else. Our goal is to get to know you and ensure that what matters to you remains front and center during your treatment and beyond.

Ask us about:

- Fertility, sexual health and changes to your body
- How to find other people your age who also have cancer
- Feelings of anger or depression, and difficulty dealing with friends and family
- Going back to school or work
- What to do when treatment is over

You may have other questions too!

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