VOICES OF OUR AYA COMMUNITY

CREATED BY AND FOR STANFORD'S AYA CANCER COMMUNITY | ISSUE 4 | 2024

PRESENTED BY

ELEPHANTS AND TEA | Stanford MEDICINE | Stanford HEALTH LIBRARY

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!

Contact

Email: SAYAC@stanfordchildrens.org
Call: (650) 498-9404

Follow us on Instagram

sayac.stanfordchildrens.org

Stanford Children's Health

Stanford HEALTH CARE

Stanford MEDICINE

PAM SIMON, NP

DEANNA BEYER

GILLIAN KUMAGAI

Welcome to Voices of Our AYA Community. This issue includes stories from adolescent and young adult cancer patients, survivors, and caregivers. This magazine is a space where you can tell your story, find support, inspiration, and a community who understands. We believe in the power of sharing stories and invite you to join the conversation.

We would like to thank our authors for their contributions to the magazine. By sharing your experiences, you've offered invaluable support to others who are facing similar battles.

The following letter is written by Ayana Rasteh.

Welcome

BY AYANA RASTEH

As a wide-eyed freshman just starting my high school career, a cancer diagnosis wasn't exactly on my agenda. When the doctors told me I had non-Hodgkin's lymphoma, I was completely and utterly devastated. My mind was a blur, and I felt as if I were being bombarded with so much information that my head was going to explode. I received pamphlet after pamphlet on therapy, treatment plans, and about cancer overall. Among those were papers about the Stanford Adolescent Young Adult Cancer (SAYAC) Program, something I didn't even know existed. One that stood out to me was a beautifully compiled magazine featuring a collection of adolescent and young adult cancer stories written by Stanford patients. At that point, it never really occurred to me that there would be other people my age going through the same thing. Of course, theoretically I knew that there must have been other cancer patients my age, but all the stories you hear about, unfortunately, involve young children or the elderly; never teenagers and young adults.

While flipping through the magazine, one story caught my eye. It was about a survivor in her mid-twenties who also had lymphoma. She battled through an intense treatment, and by the end, she wanted to give back to the community that gave her so much. She decided to become a nurse and work in the same oncology unit she was treated in at Stanford. After reading her story, I was inspired. It showed me that just because I had cancer, it didn't mean the world had ended for me. To know that other people went through this treacherous journey and ended up doing something so impactful in the end made me feel less embarrassed about my situation and more empowered.

Throughout my treatment, I engaged as much as I could in the AYA program, feeling as if I had been accepted into a new community. I was declared cancer-free on February 24, 2023. However, even over a year out, I find myself still wanting to engage in the SAYAC community. I am forever grateful to Pam Simon for giving me that magazine on my first visit. It opened the door to this amazing community that has allowed me to hear from others going through the same thing I was. To all the patients out there, I encourage you to share your stories. You not only can empower yourself, but also contribute to a greater understanding and support for everyone affected by cancer. Your voice matters, and your story can make a difference. ●

We are here to help you tell your story.

VOICES OF OUR AYA COMMUNITY

CREATED BY AND FOR STANFORD'S AYA CANCER COMMUNITY | ISSUE 4 | 2024

Stanford MEDICINE

Stanford Adolescent and Young Adult Cancer Program (SAYAC)

Program Manager
Pam Simon, NP

Instagram
@AYA_Stanford

Stanford HEALTH LIBRARY

ELEPHANTS AND TEA

Executive Director:
Nick Giallourakis

Senior Director
Kayla Fulginiti, LCSW, OSW-C

Director of Content:
Rachel Mihalko

Brand Director:
Lisa Orr

Copy Editor:
Heather Haemker

Art Direction:
CavedwellerStudio.com

Social Media Strategist:
Alexia Montgomery

Contributors:
Ayana Rasteh
Candace Benomar
Fiona Gutierrez-Dewar
Gal
Jocelyn Cervantes
Liz Menges
Mackenzie Cordova
Monica Hennings
Myra Punia
Pam Simon
Ranjit Steiner
Vivek Chotai

Office:
700 Heron Bay,
Avon Lake, Ohio 44012

FOLLOW *ELEPHANTS AND TEA* ON SOCIAL MEDIA!

X
@ElephantsTea

Instagram
@elephantsandteamagazine

Facebook
@ElephantsandTea

TikTok
@elephantsandteamag

LinkedIn
@ElephantsandTea

Cancer is a Bear

BY MACKENZIE CORDOVA

Photo by Roxy Avery

Welp, ya girl got thyroid cancer. This was the first bear I painted since I was diagnosed, featuring the thyroid cancer ribbon colors (I am an artist and LOVE painting bears). I was a little rusty with my painting skills when I did this, as it had been a while since I had the chance to paint. I was in recovery from my total thyroidectomy, and I had been trying to catch up on all the life I had missed once I was diagnosed. I liked experimenting and jumping back into digital painting after a bit of a hiatus. It is a bit cathartic, looking back on this piece over a year later. So much in my life has changed. I am a completely different person than the girl who painted this. I am still getting to know who that is—who I am—as someone who will live with cancer for a very long time, maybe even my whole life. But this painting reminds me of who I was, the strength I had when I was diagnosed and treated, and the resilience I had during the start of this journey. These things ebb and flow, but it is good to know that a younger version of me was capable of so much. ●

Caregiver

THE INVISIBLE FORCE BEHIND EVERY CANCER PATIENT

BY CANDACE BENOMAR

That "Ah-ha" moment, when I realized this is exactly where I am supposed to be in life. A timelapse of my life flashed before my eyes: all the happy memories of love, marriage, my kids' births, followed by divorce, death, and various moments of heartache. All the things I had encountered in life had prepared me for this exact moment. The mental, emotional, and physical challenges were there to build me up, to prepare me for this. It was so surreal to digest this realization and have this complete understanding and acceptance of my existence.

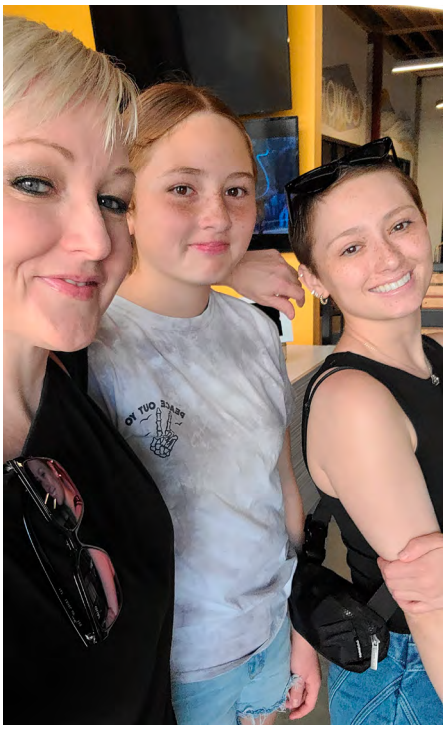
There I was, very aware of the diagnosis before the doctor even said a word. As a respiratory therapist, I understood the symptoms and the labs and knew it all pointed to cancer. In my line of work, I am accustomed to compartmentalizing my emotions. You must in order to get through your day. There was a part of me that was completely numb to the idea that my daughter has cancer; she was laughing and joking and just carrying on like normal. Then, the mom side of me was completely freaking out and trying not to show it because, HOLY SHIT, MY DAUGHTER HAS CANCER! As she lay there in the ER bed, all done up and dressed for her friend's college graduation, she was completely unaware of her reality. I even told her that she was the cutest sick person I had ever seen. She had no clue just how sick she was. However, she did know that if mom was freaking out, it was not good. I was pacing the room with a cold washcloth on the back of my neck and my blood pressure was up—I could feel it. Though I tried to hide it, I could feel everything. All the things I was not supposed to feel. Over the last 13 years of working in the hospital, I could feel what each patient and family member had felt. Uncertainty. The silence spoke so loudly. The whispering of my co-workers who were all figuring it out (or not, maybe it was all in my head). The waiting, oh the waiting was dreadful. She received three blood transfusions that night alone.

You think about a lot of different things while you wait. Somehow, thoughts of gratitude crept in, and I

was glad it was my daughter in this bed. If it had been her friend who was graduating, she would not have survived a week because her religion does not accept blood products. Scary thought, but I was thankful that option was there for us.

As I look back, I am grateful to shock, survival mode, and all the defense mechanisms put in place that allowed us to push through this extreme stress. Literally finding a task to focus on and then moving on to the next. My checklist and organizational skills went into overdrive. Full-on mom mode activated.

I have had many moments of feeling overwhelmed, exhausted, and broken. Trying to coordinate multiple tasks at once, from childcare for my other kids to figuring out how to manage home life from afar. With seven other kids at home, ages ranging from five to 17 years old, my husband and I truly



needed a village. There is so much more than just cancer happening. There are a lot of hearts needing love, and they were all coping as well. Dealing with doctors' appointments, insurance companies, pharmacy programs, fertility treatment, housing, financial planning, and multiple video calls to kids, just to check in. It is a lot to manage. It felt like I was working two full-time jobs. The reality is, I would not want to be anywhere else than by my daughter's side.

You find a whole new appreciation for life and for loved ones when you face a struggle of this caliber. As a caregiver, I have had to put my life on hold too. Thankfully, we live in a community that has truly supported our family in every way possible. The uplifting phone calls, meals, babysitting, donations, and so much love and kindness. Though life continues at home, roles have shifted, and in all of this, new bonds have been created. When mom has to leave, off and on for six months, every single family member feels it. Yes, you get that appreciation for all that you did while you were there. Ironically, much more is noticed when you aren't. That is beautiful in its own way.

Many times, I feel like others are more devastated than I am, the empathy and compassion has brought me to question my own feelings. Why am I not sad, why am I not crying, why am I not…? We all process things differently and choosing to find the positive is not something everyone can do. One's emotional intelligence can make or break them when cancer hits. Push through the hurt, the heartache, and the grief of all that was and could have been. Focus on today and the future, and you will be immersed in this calming inner peace.

This experience has been wonderful in so many ways. My daughter Jocelyn and I have bonded on a completely different level. At 21, she was this super independent, young woman, busy with college, work, the gym, and friends. We mostly saw each other in passing and occasional dinners. Now, she has become dependent on me to cook, clean, and drive her to appointments. Not to mention we became roommates in a studio apartment that serves as our new home within the safe zone. This experience has matured her beyond her years. It has taught her more than she ever expected to learn. It has also been a deciding factor in her career choice.

The moment you find gratitude in your situation, you calm your fears and that positive emotional shift frees you. I wouldn't have my life any other way. We have gained so much from this experience. The kindness surrounding our family has been profound, from the hospital staff, friends, family and even complete strangers. Yes, cancer sucks, but we will continue to fight the fight together. I would take on this job a million times over, even knowing what I know now. I love you Jocelyn!

Love, Mom ●

Acute Lymphoblastic Leukemia

BY JOCELYN CERVANTES

Describe something or someone that you were grateful to have during your cancer experience and why.

JC: I am grateful for my family during this journey and the support system I have surrounding me. I am most grateful for my Mom, especially because she has sacrificed a lot for me during this time. I love that she always has an organized schedule and knows exactly who to talk to or what appointments to schedule for me.

What is a quality that you notice about yourself now that you didn't notice before your diagnosis? What about this quality are you thankful for?

JC: That being a good person to every single person who comes across your life is important. It will come back to you in an even more positive way. I didn't realize the impact I had made on those around me. I am very thankful for my support system.

Did you find gratitude in your cancer experience? Why?

JC: Yes, I found gratitude. I've learned to really appreciate all the little things in life. For example, just being able to go outside and feel the fresh air and see the outside world. It is so nice after being stuck in a hospital room for so long. I've learned to appreciate everything in life, no matter how big or small it may be.

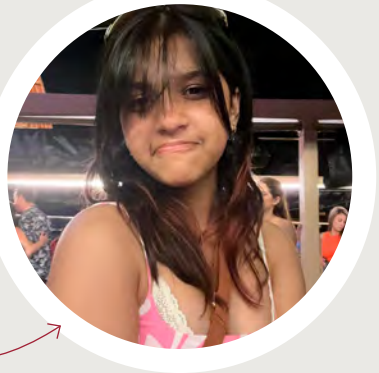
Write about something you appreciate in your life now.

JC: Something I appreciate now is that God chose me to go through this experience, which has not only helped me grow as a person and understand the medical field, but also made me thankful that I was chosen instead of anyone else in my family. I don't know how I would've handled this situation if it had been someone else.

What makes you smile?

JC: Something that makes me smile is seeing how kindness goes a long way. In the cancer community, I have met so many amazing people who were going through a similar situation or had a family member going through cancer. They still showed their love and support toward me. It makes me happy knowing that random people I didn't know before are so willing to show their support, as it makes a difference in this journey.

Healing Through Art



BY MYRA PUNIA

1 "THE TALK SHOW"

The hospital "talk show" holds a special place in my heart. During my lengthy hospital stays, often lasting a week or more, I craved engaging activities beyond TV. Discovering this talk show was a game-changer. It lets patients actively participate, playing games and interacting with hosts and viewers from their rooms. It was a fantastic way to connect with others who shared similar experiences and brought much-needed joy and interaction into my days.

2 "THE BELL"

The Bell—oh, how we all eagerly anticipate this moment. This drawing of the bell is so special; it marks a significant milestone in a cancer patient's journey. Ringing it signifies that you have fought and conquered cancer, showcasing your incredible strength and resilience. It also symbolizes personal growth and the ultimate triumph over adversity.

3 "6 WAYS TO STYLE A BALD HEAD!!"

Losing hair isn't easy. Who wants to see themselves bald? Hair is important to us all. But guess what? Styling a bald head can be fun! This journey taught me to see things differently. Though it was hard at first, I eventually started styling my bald head and felt so pretty.

I created this drawing so kids can skip the struggle and dive straight into the fun. These doodles offer creative and playful ways to cover and style a bald head, helping them feel great and confident.

Vivir en el Presente
(To Live in the Present)

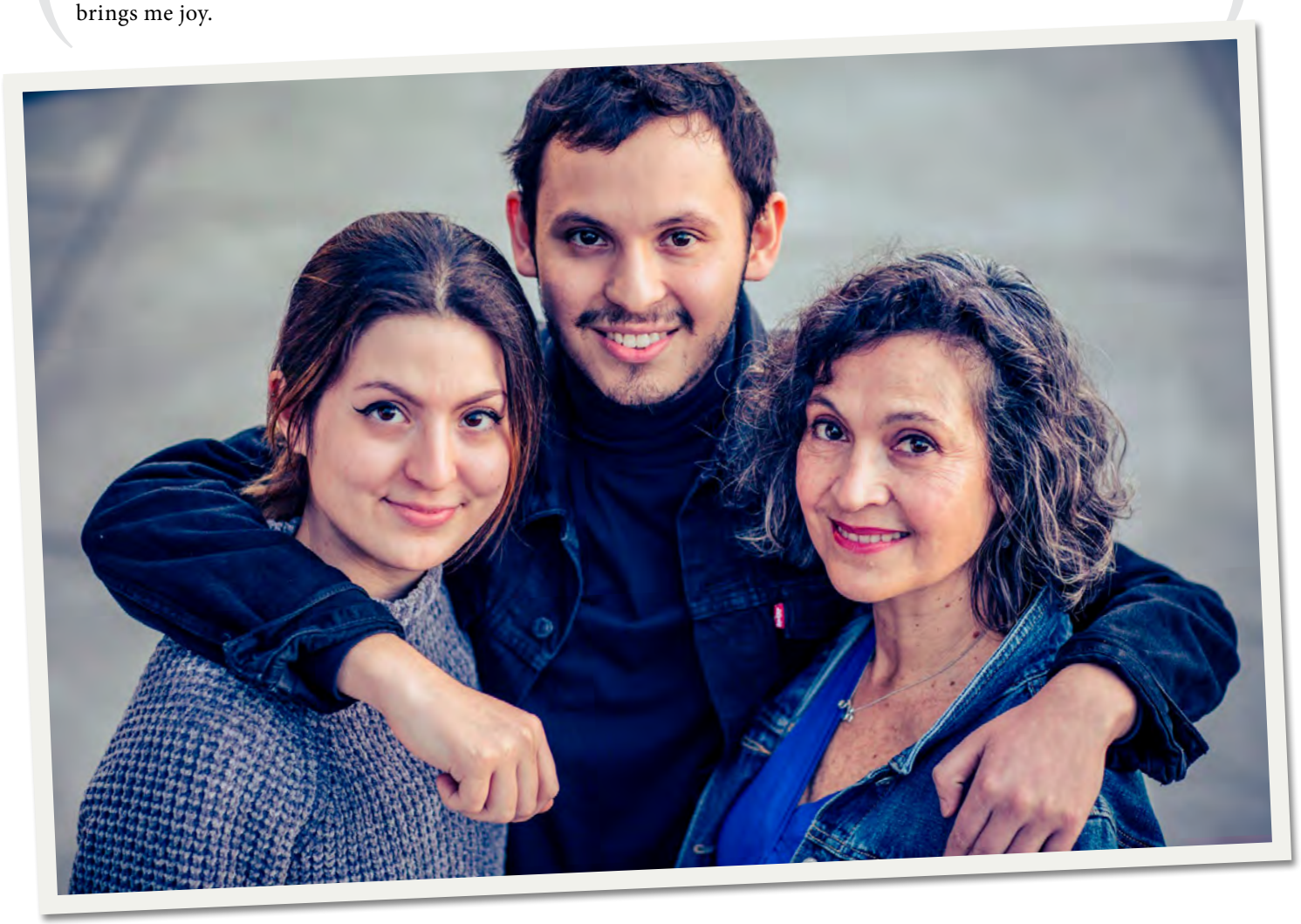
MÓNICA HENNINGS

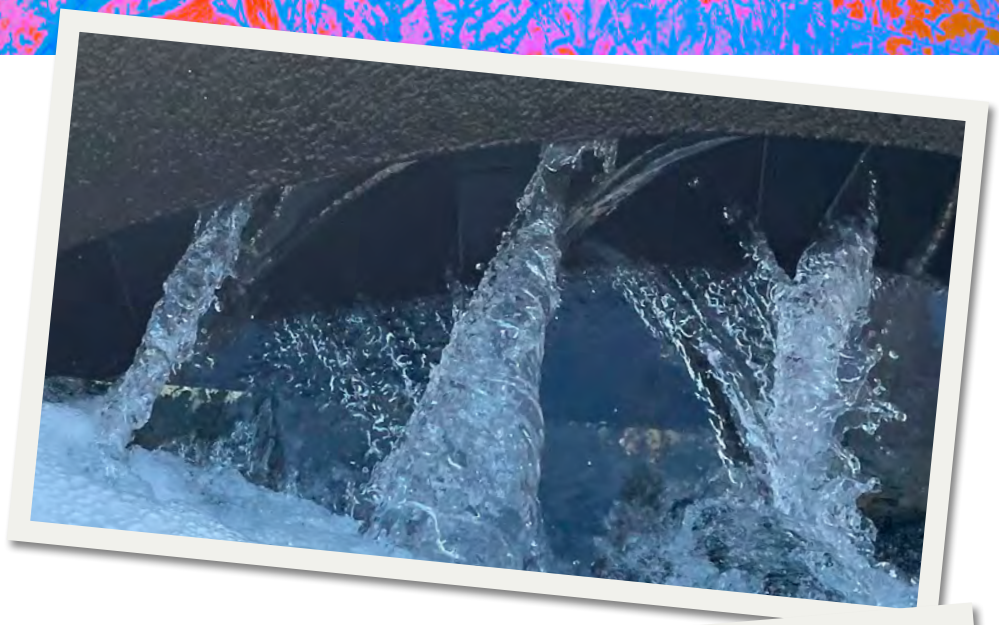
Aunque parezca mentira hay muchas cosas que me ha dado el cancer, a pesar de no haberlo experimentado personalmente, yo simplemente cuide de mi hijo, David. El cancer me ha dado la capacidad de fijarme en las cosas simples de la vida, me ha enseñado que el mañana no existe y que único que tengo es el ahora.

Admiro el mundo con un lente diferente y capturo el momento de las grandes y pequeñas cosas de la vida a través de mis fotos, eso me da felicidad.

Although it may seem unbelievable, cancer has given me many things, despite my not having experienced it personally; I simply took care of my son, David. Cancer has given me the ability to focus on the simple things in life. It has taught me that tomorrow does not exist, and all I have is the present.

I admire the world through a different lens and capture big and small moments in life through my pictures, which brings me joy.





kids & art™

healing pediatric cancer through the arts

The Kids & Art Foundation uses the power of the arts and creativity to mitigate stress, anxiety, and trauma induced from the diagnosis and treatment of cancer. Our specialized art programs are designed and led by artists and art educators, art supplies are provided, and projects are tailored for patient and family circumstances as needed.

Join us online to Create 1-on-1 with Professional Artists during a 1.5 hour art experience.

Scan the QR code to learn more.

Phone: 650-877-2750 / kidsandart.org

Families, Caregivers, and Care Centers/Hospitals – programs@kidsandart.org

A Perspective Shift

BY FIONA GUTIERREZ-DEWAR AND PAM SIMON

Fiona Gutierrez (FG): When I received the news that I had cancer, I was 22 years old. I had just finished college and felt so free, like, "I'm done with school, I have a job now," and I was just so excited for my life, adulthood, and all the possibilities. When I got the news, there was a lot of sadness, anger, and even bitterness, and feeling like I was just missing out on so much. But I feel like I was also lucky. Looking back now, I'm so grateful for the support I received, and that includes you, Pam. Just having you prepare me mentally for the things that no one in my life knew about was amazing. We've had hour-long phone calls where I was just asking, "What does chemo feel like, Pam? Oh wait, what is that word you're saying?" I feel like you could just calm us down and ease those nervous jitters when we don't really know what's coming our way—that anticipatory anxiety. Having an AYA advocate or an expert there to talk to was so essential, and even though it was scary, I was never alone.

I think there's a lot of scary things that having a cancer diagnosis brings up and exposes, and I do think some part of yourself is just kind of like, "I have to be strong," so you are. That doesn't mean it doesn't hit you later, or that it won't creep up into your head when you're going to sleep at night like, "What happens if this doesn't work?" But I think cancer puts a lot of things into perspective.

For so much of my young adulthood and teenage years, I was kind of on the hamster wheel—get straight A's, go to a good college, get a really good job. I feel like having this very hard stop, where everything comes to a halt and treatment is required, allowed me to slow down and develop a better sense of what matters in life. I think it helped me get my life on a path that was more congruent with my values and priorities. I felt like, "Well, no matter what happens after treatment, I just want to live with the things that matter most at the end of the day, which is always people at the forefront. Also, cancer led me to my career.

I went back to nursing school with a fire under my butt to get my degree and start giving back to the people who had helped me get through my cancer diagnosis. I ended up getting my first job on the unit where I had been a patient, so I got to start working right away where I'd just been a patient a few years before. Given how hard it is to be a new nurse, I feel like I can work twice as hard because it's so worth it to put in that extra love and care with patients, knowing what they're dealing with. Sometimes I think, "Well, I don't know if patients need to know that I had cancer or how it'll make them feel," but my nursing superpower is that I can empathize and relate to patients so they don't feel so alone. For some people, knowing I had cancer and made it through chemo, even though it sucks, can help give them a sense of hope.

Pam Simon (PS): I'm grateful for that, because when I meet a patient, often I'll say, "There's a nurse, her name's Fiona. She will probably pop by and say hello at some point when she's working. She was in the same position as you going through chemo, hopefully she can help you get through this."

FG: Yeah, definitely. It's special that you have developed this program for us here at Stanford and that you're always looking for ways to connect us with another patient. You're looking out like a guardian angel for so many AYAs, getting them to the right resources when they need it. So, we are very grateful for you, Pam.

PS: Well, thank you. We hope we can make it bigger and bigger every day. ●

Scan QR code to listen to the conversation

Produced by Stanford Health Care with interviews recorded in collaboration with StoryCorps, a national nonprofit whose mission is to preserve and share humanity's stories in order to build connections between people and create a more just and compassionate world.

Reflections on a Mother's Grief

BY LIZ MENGES

I've been told that there are stages of grief, and that one must experience and pass through them all to grieve "appropriately" (whatever that's supposed to mean) and adapt to a new reality. I dodged some of those grieving stages, while I've been stuck in others the whole time and I remain there to this day.

Although Bobby died in 2017, it dawned on me recently that my grieving process actually began 14 years earlier in 2003, on the first day of his first cancer diagnosis. This revelation caused me to contemplate the nature of my own grief.

To start with, I skipped right over **Stage 1, Denial**—and never looked back, if only because our situation was impossible to deny. Here was my little five-year-old who had been exhibiting strange and persistent symptoms for weeks, and after endless tests and scans, the resulting cancer diagnosis was, well, undeniable. (That said, I do have frequent, recurring dreams that Bobby is still alive. Perhaps my subconscious is the one in denial. I'm not sure what to make of it.)

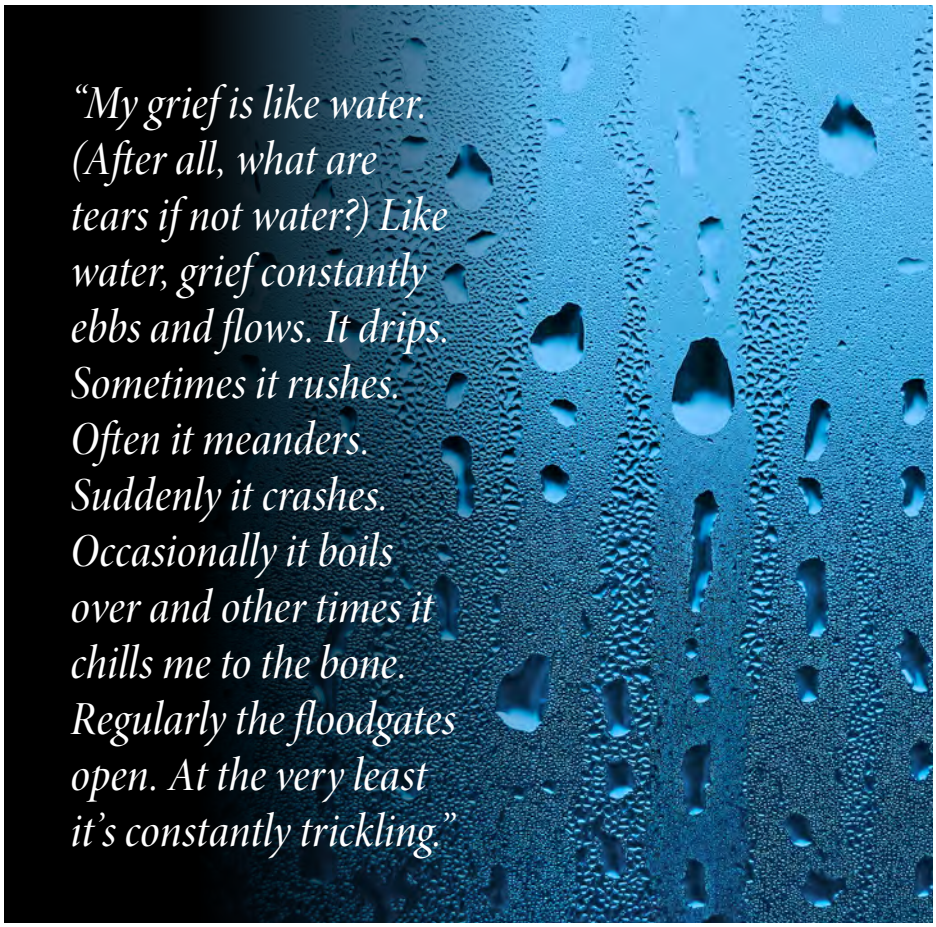
Stage 2, Anger (which could also be called Despair), I entered immediately and haven't left since. It often surges into a fury, maybe it simmers as irritation, but it's never totally gone. I despaired at what this innocent little person was being forced to endure. I was angry that my other three kids' lives were going to change forever, never to be the same. I've been irritated at thoughtless things some people say. I am outraged on behalf of young patients who can't afford treatment, who are without adequate support, and who have no insurance. I despair about the lives that Bobby and other young people like him have missed, are missing, and will continue to miss. I'm furious that meaningful treatment breakthroughs are so rare. And as his mother, I will always despair at this unanswerable question: Why him when I would have given anything to have it be me?

Perhaps the one stage where I showed up in the traditional sense (in truth, I shamelessly barged right in) was **Stage 3, Bargaining.** Bargaining "with whom" was always unclear, but the "for what" requests were endless.

If only…

- his next scans are clear…
- his pain could subside…
- he doesn't relapse…
- he can have a good night's sleep…
- his new chemo will work…
- he's healthy enough to go to the birthday party…
- he's energetic enough to play in his soccer game…
- his white counts are high enough to go on spring break…
- his pain could subside…
- he's strong enough to return to college…
- he can be comfortable…
- his fear will subside…
- he wouldn't feel so lonely and isolated…
- his pain could PLEASE subside…

…then I will/I won't/I promise to/I promise not to… whatever it took; I was willing to do anything.



Thankfully, I avoided **Stage 4, Depression.** I think that's just pure luck.

The final, and absurdly named, is **Stage 5, Acceptance.** Acceptance connotes agreement or welcoming: accept a gift, accept a job, accept an invitation, accept a marriage proposal. At the very least, I'd rename this stage Resignation. If you resign yourself to something, you're submitting to the reality of it while not necessarily accepting it. I've resigned myself to the reality that Bobby has died, but I will never, ever accept it.

So where does that leave me in my grief?

It turns out that it can't really be described in stages. My grief is like water. (After all, what are tears if not water?) Like water, grief constantly ebbs and flows. It drips. Sometimes it rushes. Often it meanders. Suddenly it crashes. Occasionally, it boils over and other times it chills me to the bone. Regularly the floodgates open. At the very least it's constantly trickling.

I've tried— and of course, failed—to dam it up, and there's no finger big enough to plug its dyke. Reroute it? Maybe, temporarily. But water always finds a way to make itself known. As does grief.

I was a terrible chemistry student—and I really do mean terrible. But there are a few things I remember about water. Water is cohesive—it likes to stick to things. My grief has bonded itself to me.

I was a slightly less terrible physics student, and I learned that water always finds its lowest point. Is there anything on earth lower than a grieving mother?

My grief is like water. But the one thing my grief will never do is evaporate.

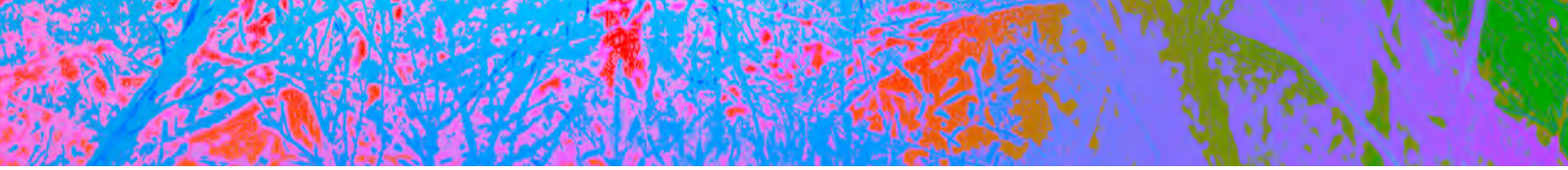
And THAT I can accept. ●

hurry up, my friends are dying

BY VIVEK CHOTAI

There's a difference between a savior complex and empowerment. A savior complex is when you think you're helping someone else by changing their life for them. Empowerment focuses on changing someone else's life by informing them how they can change. This means the person you're trying to help has control over their decision, and it is their responsibility to make the change. Both methods come from good intentions.

I wasn't aware of the difference until after high school. Back then, I had some friends who had attempted to end their own lives, and I thought I could save them by talking them out of it. Then I got cancer, which reinforced my savior complex, viewing my doctors and nurses as the drivers of my ability to continue life—people who were responsible for my decisions during treatment. It wasn't until I was discharged that I started thinking we might not have much control over who gets "saved" and who doesn't.



My first experience with death in my circle was through a friend I had made in the hospital. Since we were both treated during the pandemic, our communication was mostly through text. I remember the day she was discharged, she stopped by my room to talk to me through the glass door and wave goodbye. I had been waiting for her, thinking I was cool by sitting on top of an exercise bike I never used, excited to put a face to a name. When she came over, her message was selfless: she told me that I would make it out too and encouraged me to stay positive. The nurses cheered as she walked out the fifth floor, and I wondered if we would ever meet again on the outside. Time passed but I didn't text her much after she left, feeling guilty that I would remind her of the hospital. Two months later, I was discharged, and I sent over a text asking how she was doing. By that time, I had waited too long. She was gone.

This year, I lost another friend. I thought the previous experience would numb this one, but it didn't feel any better. It felt worse.

I met her through a cancer survivorship adventure camp, where I had the privilege to learn what it felt like to live life as a single mother with terminal lung cancer. Even with an exceptionally burdened life, she boasted an altruistic personality—a motif I keep noticing more and more as I age, providing a sense of irony I can't seem to comprehend. She had a rough childhood, and her purpose to keep living was to create a better one for her son. I have the utmost respect for her tenacity—to think of the strength required to even get out of bed every day, attempt to play the worst cards you've been dealt, and push for progress, knowing it would all end someday, is unimaginable. Coincidentally, the news of her peace came to me once again through a text message. I write her story to immortalize her memory.

I'm three years in remission now, and I still don't know what to make of these thoughts. At 21, none of my classmates really have anyone who has died in their lives, so I can't ask them about how they cope with it. One part of me feels guilty because my friends went through a similar journey as me, but didn't get to live, so what makes me worthy to be the one who does? But then I think, even though I did live, my outcome had no effect on theirs and was completely independent. Another part of me feels like I'm next, that I should really hurry up and get everything I want to do in life done before my time comes. I went to college nine months after my treatment finished, even though it was recommended I wait two years to transition back to school. I ran away from the hospital as fast as I could, enrolling in college, thinking I would someday go to medical school and be on the other side (as if that would keep me safe). This way I could learn the mechanisms and cellular interactions behind all the treatments and side effects to eventually empower myself and others to prevent such outcomes in the future. I think I ran so fast that I started to suffer from the speed. I put my absolute maximum effort into achieving everything I imagined would make me happy—a solid support system, good grades, a purpose to live, a strong position in social circles—but it didn't work. I wasn't happy. No matter how far I progressed, I couldn't escape my diagnosis—the late effects of my treatment caught up to me. I was allowed a taste of what it was like to live with a healthy body, just to reopen the wound with my freedom being taken away from me again. This wound had been healing with time, but the "late effects" ripped off the gauze, stripping away control over my health.

At 21, none of my classmates really have anyone who died in their lives, so I can't ask them about how they cope with it. One part of me feels guilty because my friends went through a similar journey as me, but didn't get to live, so what makes me worthy to be the one who does?

The doctors told me that after two years in remission I would be safe. I could drop my mask. Feel the sunlight. Not have to bleed out. It doesn't feel true. I'm one year past that requirement, and I thought I had enough of a lead, I even started setting limits and pacing myself. But no, I still can't exhale. Not because I didn't run fast enough, but because there isn't an equal finish line. How can I believe in a future if I can't even trust my own body?

It's inevitable, I have to walk. Take time off. Not because I want to, but because I don't have a choice. I can't take the savior complex; it's too much to handle. I can only speak to empower and place the responsibility on those who are trained to bear it. To my friends who passed, can you hear me? I never said I was sorry, but my thoughts make it overwhelmingly clear. To my fellow survivors who I can only try to empower, can you feel me? I'm numb to the good parts of life but affected by its disruptions. To the readers who care, can you see me? I'm losing my vision but compensating with more emotion. To the health professionals and scientific researchers who I give my burden to, can you hurry up? My friends are dying. And I think I'm next. ●

Cancer Isn't Easy

BY RANJIT STEINER

I think the day we found out I had cancer, we had already been prepping for it because. Initially, I had torn my ACL, and then they found the tumors, so we were kind of anticipating it. But going into the hospital that day, there were some things I didn't anticipate. Being 16 years old at the time, I had a one-track mind. I just cared about sports and hanging out with my friends and didn't really think about the magnitude of the situation.

It was obviously a little bit shocking to be diagnosed. But even when they went through the survival rates and treatment protocol of 10 months of chemotherapy and multiple surgeries, that stuff didn't bother me that much. Receiving the news that I wouldn't be able to play sports anymore, after dealing with my diagnosis, was devastating. It felt like all the other challenges I would face over the next 10 months didn't even compare to the loss of not being able to play sports, which was such a big part of who I was and really my identity at that age.

And then, with chemo coming up four or five days later, there was all this planning and other aspects that we had to manage, which I also didn't really expect. Hearing that news was obviously difficult and upsetting due to the diagnosis and everything else they said. Then, to have to get up and prepare within four days was overwhelming. We had to do all these things, such as going to the sperm bank, undergoing fertility treatments, and completing other tasks. It was kind of quick and it came out of nowhere. That shock was hard to deal with.

There were moments where I couldn't do stuff. I couldn't, obviously, play sports, but there were other ways to participate. There were a lot of other things I was able to discover by not being able to play sports anymore. I had to put my attention into other things, and it helped me explore other elements of myself. I honestly felt like I had to do that because it was difficult. As much as we talk about the positives, especially in our family, it was extremely difficult, and not just the chemo, but afterwards. Going through high school and dealing with depression wears on you. I often felt like the kid with cancer, but people don't see the other side of it. We were so positive throughout the whole experience through high school and even after treatment, a lot of people didn't realize how challenging some aspects of it were.

To put it into perspective, you have these positive elements and these things that help you get through it, but behind the scenes, the reality is still there. A lot of this stuff is extremely challenging to deal with. In my mind, it's OK, especially now that I'm older and I've

started to process a lot of these feelings 16 years later. I never allowed myself to go through the difficult emotions and let them settle in. I think it's OK for people to say it's horrible and not feel the need to find a silver lining for every single thing that's happening because it is a shitty experience. It is a difficult and challenging experience not just because of the treatment and physical aspects, but also the mental toll that stays with you for the rest of your life. That's something that I think you don't realize in the moment. My cancer diagnosis was probably the worst thing that's ever happened to me.

It's a hard thing to deal with; it shapes who you are and gives you a different perspective. Too often when you talk about things like this or about any hardship, the immediate response is to say it's inspirational or it's amazing that we went through that. This is just the cards that I was dealt. I always think about, "Yes, we went through it, but until you get hit in the mouth, you don't know how you're going to respond." You'd be surprised how quickly and capable you are of adapting and being able to deal with the challenge. ●

Scan QR code to listen to the conversation

Produced by Stanford Health Care with interviews recorded in collaboration with StoryCorps, a national nonprofit whose mission is to preserve and share humanity's stories to build connections between people and create a more just and compassionate world.

Untitled

BY GAL

People always congratulate you on beating cancer. But they never step back and think, "How is she feeling? "My name is Gal, and my story with cancer began on February 2, 2011. I had just moved to California at the end of 2010. I was acclimating to a new language and a different culture. My life had just changed dramatically, and I did not know how much worse it could get.

My story started playing on the Nintendo Wii with my friend Ido. We were just dancing and giggling. I was not prepared for what came next. After 30 minutes of dancing, my body felt numb. I fell to the floor. The following days were filled with pain in my legs. I would scream from the pain. It was the worst pain I have ever felt in my life. My Mother took me to the doctor, but the doctor did not want to believe an eight-year-old who said something was terribly wrong. It took a month to get a diagnosis. People finally believed me when the following symptoms became evident. My legs were full of bruises, my bones hurt deeply, I was extremely pale, and I had the highest fever you could ever imagine. The doctors took blood tests, and by that afternoon, my parents got the worst call of their life. The phone call said, "Please come to Lucile Packard. Your child has cancer. She has leukemia." We packed as fast as we could and were greeted by at least 10 doctors. I was shown to a room, and it felt like I was poked for hours. On that day, February 2, my life changed forever. I was taken out of school and spent 21 days in the hospital. My family was scared. My Mom would cry every day. It was followed by many chemo sessions and lumbar punctures. It was scary for my family, but I never cried. I stayed strong for them. My family would joke with the nurses about me because for some odd reason, I loved looking at the needles when I was being poked. I found it fascinating. The nurses thought I was a very odd patient. My treatment lasted two years and seven months. There were bad days and good days. Most of my treatment became a blur in remission, but the one thing I will never forget is Jake, the child life specialist at Stanford. He always made me laugh. He even helped my brothers cope with their sister being sick. I will always consider him my friend.

I finished chemotherapy in 2013 and received a cake, unlike the bell-ringing tradition you often hear about. I will always be thankful for being treated with so much love. Cancer was hard for me, but I like to look at it in a positive way. I got to spend many days with a team that cares deeply about their patients. I also can be an inspiration to other young people.

But I would also like to acknowledge the negative effect it had on me. That effect would be PTSD (Post-Traumatic Stress Disorder). I proudly tell people that I beat childhood cancer. That is one of the biggest accomplishments of my life. But I also wish people would not treat life after cancer as easy. Even though the cancer is gone, it affects you physically and mentally for life. We have to live with the toxic side effects of our treatments, which brings with it the constant fear of getting sick again. There is one message that every cancer survivor and patient should hear. It is OK to feel the guilt of surviving because no fight is easy, and as AYAs, we have a big future in the world to fight for. ●

You Have Questions.

We Have Answers.

Stanford
HEALTH LIBRARY

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.

- **Learn more.** We can answer your health-related questions! Our librarians have access to scientifically based information you won't find on the internet.
- **Focus on self-care.** We can link you to classes and workshops including yoga, pilates, tai chi, mindfulness, and more!
- **Connect with others.** We can help you and your caregivers find support.
- **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.

650-725-8400 | healthlibrary@stanfordhealthcare.org