

VOICES OF OUR AYA COMMUNITY

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



Physical 
Emotional
SCARS

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Welcome to the second edition of Voices of our AYA Community

Facing cancer is incredibly difficult and the physical and emotional experiences extend beyond diagnosis and treatment. Stanford Adolescent Young Adult Cancer Program (SAYAC) collaborated with Stanford Health Library and Elephants and Tea, bringing AYAs together to reflect and share personal stories about aspects of their cancer experience that are especially significant to them. AYAs shared their perspectives about physical and emotional scars and what they mean to them. Sharing one's story can be a healing experience for the storyteller and offer support and connection to others.

Thank you to all of the contributors in this magazine for being vulnerable in sharing what you are going through to help others in the Stanford community know that they are not alone in facing cancer.

Everyone has a story. We will continue to offer workshops and welcome you to join and invite a friend or family member. We encourage you to share your story through writing and other forms of art to be featured in the next edition of Voices of Our AYA Community.

PAM SIMON – SAYAC

DEANNA BEYER AND GILLIAN KUMAGAI – STANFORD HEALTH LIBRARY

NICK GIALLOURAKIS AND LISA ORR – ELEPHANTS AND TEA



We are here to
help you tell
your story.

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PHYSICAL AND EMOTIONAL SCARS

1 LETTER FROM THE TEAM

3 HIPPOCRATES SOUP

BY MAIA EVRIGENIS

4 SURVIVE TO TELL THE STORY

BY VIVEK CHOTAI

6 CANCER STORY

BY JUAN CARLOS
HERNANDEZ

8 ONE YOUNG ADULT'S SYMBOL OF RESILIENCE AND HOPE: KIRSTEN'S STORY

BY ABBY WESTERMAN

10 HOW IT STARTS

BY RAIHA SANDERS

13 HAPPENS

BY GARY DAHL, MD



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Hippocrates Soup

BY MAIA EVRIGENIS



Hippocrates soup boils on the stove top, and I'm thinking about my grandparents again. I never really mourned their loss. When I was in middle school, my grandpa died, and my grandma died shortly after. Two months later, I was in an ambulance to the Lucile Packard Children's Hospital at Stanford. I wonder if I had cancer cells in me at their funerals. I don't think I ever understood as a kid that my grandparents died pretty young, and I thought they were always coming back. I thought once my cancer treatment ended, I'd go back home to Sacramento, California, and my life would go back to normal, in that my grandma and grandpa would be coming home too.

Putting a hand on my belly, my baby kicks. I'm 27 years old now and eight months pregnant with my first child, alone most of the day and soaking up my last bit of quiet before her arrival. I turn the Hippocrates soup to a simmer and look at the photo of my grandpa on the fridge. Since becoming pregnant, I have been obsessed with my grandparents who passed away: who they were and what they would think of my life now. I put a hand on my stomach as my baby moves again, flipping over and over, it seems. I wonder if she will look like I do in this photo with my grandpa. It's of me as a baby with my dark hair and eyes, sitting on my grandpa's shoulders. His hands hold my ankles in fists, firm and supporting me. I wear a onesie and a bib with a lion on it. My grandpa has two gold rings on either ring finger, thick glasses, and is wearing a flannel shirt. My little hands rest on his bald head.

My grandpa's friend told me that when my uncle died so young, long before I was even born, my grandpa was so depressed that he wanted his life to end. Looking

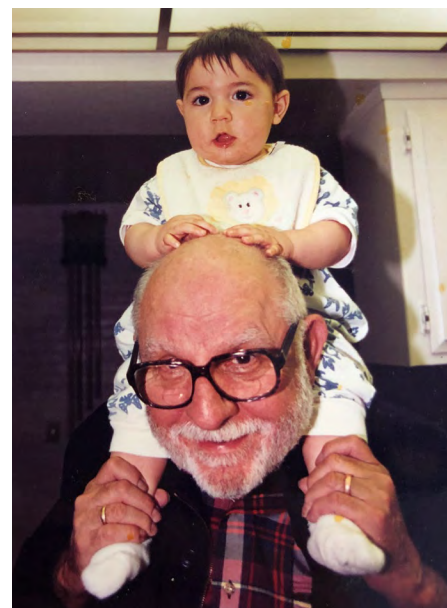
at my grandpa in the photo now, you'd never guess that he'd gone through such great pain. He looks so happy there with me, so strong and supportive. When his son died, my grandpa had no idea that my mom would get older, get married, and have three girls; that I'd even exist. My mom always said my grandpa loved us more than anything. You can see that in the photo, how happy he is just to be with me. I think the photo symbolizes that we do move through great pain.

I hear the front door unlocking. My husband walks through, smelling the soup.

"Hippocrates soup?" he calls out.

"Yep, your favorite!" I joke.

I can tell that he's not that excited about the dinner, but he hasn't felt well lately. He knows I'm caring for him through this healing meal filled with potatoes, celery, leeks, onions, and tomatoes. This is something I'm an expert in, something I know how to do very well. I know how to care for somebody, because when I was a kid, I watched my mom care for me.



He comes over, wrapping his arms around me, giving me a backwards hug, and places his hands on my stomach.

"How's Baby Girl?" he asks.

"Kicking like crazy," I laugh.

"Just a few more weeks," he says, pulling away and pointing to the calendar, where her due date is highlighted, starred, and underlined.

We sit down to eat. It's dark and the apartment feels quiet as fall turns to winter, the season that at one time felt so far away, the season our baby is going to be born. We're both tired from the day and don't talk much. As we eat, I think about my grandparents again, how they never saw me go through my leukemia treatment or how they wouldn't know how much this pregnancy means to me and what it symbolizes.

Or maybe they do know. Maybe they are here, watching over me from above and protecting me. I wonder what my grandpa would say to me now if he could, and I think I know. He'd say that we do move on through great pain. ●

Survive to Tell the Story

BY VIVEK CHOTAI

I remember the night of June 25, 2020, exactly. I walked the stage of my high school graduation the day before, and finally my dreams of going to college were coming true. Yet here I was at the wrong ER room, waiting six hours for the doctors to tell me I had anemia or something, so I could finally go home. When the night shift fellow—who was on his last 72-hour rotation—told me I had leukemia, my first instinct was to say, “Does that mean my family could have it too?” Then, as a true American, I wondered “Can I afford this?”

During my first cycle, I was at the worst point of my life. I suddenly found myself crashing into the first wave of chemotherapy and radiation. There was nothing I could have done to prepare my life to feel so dead. On top of being injected with the most aggressive form of controlled poison into my central line, I was also being isolated in a worldwide pandemic. I remember asking my social worker Mike, “I can’t even leave my room? No visitors, not even my brother?” This dwelling sense of fear and isolation snowballed as my limited days passed, piling up until they stripped me of any motivation. What was the point of going through so much suffering if my stem cell transplant wouldn’t work? Why should I fight today when in the future I don’t even know if I’ll be alive? As life unfolded naturally, John, one of my (male) night shift nurses, introduced a new perspective. As a cancer survivor himself, he lives one day at a time. And if that’s too hard, he focuses on an hour at a time. If the anxiety persists, minute

by minute, second by second, focus on today, this step in your life. The rest is out of our control.

It’s common for doctors to hide their tears in front of patients. I was waiting two weeks, and here was Dr. Richards with the results. Mutation 5Q, with a high risk of relapse and risk of tumor cells not responding to treatment. *Fuck. This was it. This was really it.* I’m not one who cries often, but that day, I wasn’t the only one in the room who was. Just another patient, another statistic, to be added to some dataset and forgotten. Couldn’t they see that I was a human, someone who had a life and a family, not just some barcode blended in with the rest of life’s products?

Being in a hospital at 17 puts you in a weird position—you’re young enough to be on the pediatric floor, but old enough to realize no amount of cards or gifts will change your outcome. On the bright side, being under 18 qualifies me for more benefits than an adult, for example, Make-A-Wish. It’s kind of

unfair that one year of life makes the difference in saying no to someone’s dream. Speaking of unfair, being placed next to a baby’s room. I was forced to listen to the screams of agony this innocent individual was crying. I said to my mom “I’ve been told my whole life that everything happens for a reason. Well, what’s the reason for this?” My mom believes in karma, that if you do good deeds, good things will happen to you. And if you do bad things in life, bad things will find a way back to you. But all I could think about was how the babies just born were powerless to make their own decisions. If there was any form of reason in this world, *what the hell did the babies do to deserve this?*

I made only one (patient) friend during my hospital stay. We weren’t allowed to leave our rooms, but one of my nurses hooked me up with another transplant patient’s number. She was two cycles of chemo ahead of me, and I would text her, asking if she experienced the same side effects and feelings that I did. Especially in a time of isolation, having someone to relate to and validate my thoughts was extremely impactful. She even stopped by my room to wave goodbye when she got discharged, which was probably more motivating than I realized back then. Some sort of survival instinct kicked in, and I felt like I didn’t want my life to end. There wasn’t any reason, but biologically, my body just didn’t want to die. Around two months later, after being discharged from the hospital myself, I texted her to ask how she was doing. Two weeks passed without a response, so I looked her up to see if it was because she started college. I found her obituary.

Nowadays when people find out I'm a survivor of childhood cancer, they become elated and tell me how inspiring and strong I am. But it wasn't my decision to survive. I was just lucky that my body responded to the treatment, down to the molecular level. There's nothing I did to ensure this, and nothing I did that made me stronger than my friend. But by being a survivor, my story is the one that is heard, even if there were more impactful people than me. Having survived does not make me better than anyone else. I make sure to remember those who aren't here anymore. Almost two years into remission, sometimes I wonder if it is easier to exit this life or survive and live to tell the story.

As a survivor, I volunteer to deliver cards to the hematology/oncology floor at UCLA. The patients are often reserved at first, but after learning that I am a survivor, perk up and start conversing with me. They start sitting up, begin to show interest, and open up about their feelings. Sometimes they even start smiling. Being able to help someone forget about their pain, even if just for a few minutes, makes me feel really proud of myself. When I was in the hospital, what helped me was talking to other survivors. Now I'm the survivor talking to other patients. Being able to give someone hope is the only intention behind my shirts. What started as a form of art therapy in the hospital—designing shirts—has become my way of converting my thoughts as a survivor into a form of impact. I hope that these designs can be validating to patients in the hospital and let them know that their feelings are understood. I imagine these designs as something you could give to someone going through their own journey, whether that's cancer or any other disease.

I partnered with Macy's and Make-A-Wish to sell these shirts nationwide. Half of the money that you pay will go to fulfilling other kids' wishes. I do not make any money from this. My only intention is to help other kids going through a similar (if not same) type of suffering that I did. ●



Find Vivek's shirts at Macy's here.

Cancer Story

BY JUAN CARLOS HERNANDEZ



Juan Carlos Hernandez and his kids at El Portillo, Oaxaca, Mexico in 2022.



Hi, my name is Juan Carlos, and I am here to share my cancer story.

In August 2003, I was diagnosed with bone cancer (osteosarcoma) in my right leg. At first, I was thinking, “What is cancer?” I grew up in a small town in Arizona, and at the age of 15, had never heard anything about this illness. So, I asked, “OK, what meds do I need to take, and for how long?” Then I saw my mother and older brother start to cry; I told them “It’s OK, we are at Lucile Packard Children’s Hospital (LPCH) at Stanford, they can cure me, right doctor?” The doctor began by telling me that cancer was hard to cure but that she would try her best to help me. Still not understanding what was going on, I asked again, “What is cancer and what is osteosarcoma?” After what seemed like hours, I started to understand what was happening.

This experience started after playing football one day. My knee started hurting and started to give out. Basically, my knee would fall asleep, and I would collapse to the floor. I couldn’t even walk for a few minutes—my knee started to swell, and the pain was really bad. From this point, it took my primary care provider two months to find a mass behind my knee.

I started my first chemotherapy regimen in August 2003 after being diagnosed—two IVs, one in each arm. I was still waiting to get my port but my doctor wanted to start the treatment as soon as possible. That day became, and still is, the worst day of my life.

After the first set of treatments the cancer started to grow and grow fast. At only 15 years old, I was faced with an ultimatum—the most significant decision I would have to make. It was between keeping my leg and living less than a year or giving up my leg and having a better chance to live past the next year. On October 10, 2003, just two months later, I underwent the amputation of my leg, a.k.a., above knee amputation.

After the amputation I did not want to see my leg for days. One day, my leg had become unwrapped in the sheets, and I woke up to see what I thought was a face on the remaining amputated part of my leg. I told my doctors that my leg looked like a face with scars, so I had to name it—I named it “Scarface.” That became our inside joke for the rest of my treatment.

HIGH SCHOOL

Putting it lightly, returning to school was not easy. I had been given an old prosthetic that made a clicking noise with every step I took. Being back after missing one year of school was hard. It seemed like I was in a new school at a different time. My old friends did not know what to say, or how to talk to me. I felt alone and lost. My new life was different from my old life. I had different worries and different outlooks. I felt like I was the same person but, I wasn’t.

So much had changed, and I had to let go of old goals and old friends. It was time to find the “new me.” This did not go well. Before cancer, I had played sports

and I loved baseball, but now I couldn't even walk without crutches. Additionally, I couldn't focus during class—my memory was not there. Someone from LPCH went to my school and told my teacher and me about the many long-term side effects of high dose methotrexate, and its effect on learning and focusing. I was done with cancer but not with the side effects of the disease and the aggressive treatment I went through. This side effect followed me to college.

COLLEGE

In college, I didn't see the point in pursuing any long careers because I was afraid that my cancer would return or that due to the cancer and treatment, I was not going to live long. I went in and out of college due to the many illnesses and issues that would pop up. It wasn't until I met my wife that I started to take college seriously. She motivated and supported me. I switched majors from psychology to business. My goal was to create and open a nonprofit to help young adults with cancer. I learned that many organizations offered grants and help for cancer survivors, and I wanted to bring awareness and help young cancer survivors navigate college. There was not a lot out there for young adults. I had experienced this first-hand.

In 2011, the cancer returned aggressively, this time to my right lung. I was diagnosed right before Thanksgiving. In December 2011, the lower part of my right lung was removed. On December 19th, I started my first chemotherapy treatment. Twelve hours into my first treatment, my wife gave birth to our second child, she was 100 miles away. As doctors were trying to save my life—my particular treatment was extremely toxic—and my newborn could not risk being around me.

I had to wait 10 days before I could touch him, but when I did, he still ended up getting very ill from the exposure to my body, which was still full of chemicals. He ended up being admitted to the hospital for five days. This was crushing.

I made it back home to celebrate Christmas with my family. Then I got

sick, and so did my baby. I returned to LPCH, and my son was sent to Children's Hospital Central California. Now we were 162 miles apart. This made me feel more fearful than before. That day I promised myself I was going to finish the treatment before the month of May was over.

This was unlikely, as the treatment was so aggressive that doctors expected that like most others receiving treatment, there would be breaks—a period where we would back off and postpone treatment due to extreme reactions. But I felt determined, and my mind was set.

Proposing a May end date to finish treatment would accelerate it by three months. With my family's support, I remained strong enough to keep battling and continue receiving treatment. I did it—I finished my last treatment in May 2012. As soon as my immune system improved, I returned to school in the fall of 2012, determined to complete my education.

It was an enormous struggle and continues to be so. The side effects of treatment manifested themselves constantly, but I remained determined to reach my goal. My motivation to pursue my education was to make up for the harmful memories I felt I had caused my family. I imagined the satisfaction they would experience on seeing me achieve great things.

COLLEGE 12-15

My major was Business Administration. My overall goal in pursuing this major was to open a nonprofit organization to try to ease the pain of those unfortunate young adults who undergo cancer. Having been one of them, I lamented that there was not much financial or other support for those that are 18-30, because in absolute error, they are considered "healthy young adults." I transferred to San Jose



Juan Carlos Hernandez and family at Uruapan National Park, Michoacán, Mexico in 2022.

State University, where I completed my Bachelors in Business Administration.

Currently, the energy of my life has been focused on trying to be the husband, father, and provider that I know I can be. However, like many others I know, the fallout from my cancers and their treatment has prevented this.

I have had jobs, ones that I liked and where I was well-received. However, those jobs were left behind, as I couldn't keep up physically. This has been a very daunting disappointment.

My goal is to return to a career and be a productive member of my community. Not being able to do so has resulted in trying to balance my desire to return to the workforce, and to be the family man I always was, against the current limitations of physical disability, and its resulting disappointment.

I keep a good attitude, but it requires attention and effort, and sometimes it's quite hard. Others who have achieved this are inspiring to me, and I hope to follow in that path, becoming the man I know myself to be.

Meanwhile, it is a difficult balancing act, and I take it day by day. I try not to feel impatient with myself or discouraged. All in all, it is going OK, and I will figure out just where and how I fit into this world of managing illness and limitation. Ever forward. ●

One Young Adult's Symbol of Resilience and Hope

KIRSTEN'S STORY

BY ABBY WESTERMAN

Cancer was no stranger in my family, and my first experience started 40 years earlier when my oldest brother was diagnosed with colon cancer at the age of 16. I was barely seven at the time and have vague memories of the mayhem at home as my 14-year-old sister was handed the unthinkable task of watching her other five siblings, ranging in ages from four to 12, while my parents were at the hospital.

It wasn't until my 19-year-old daughter Kirsten was diagnosed with acute myeloid leukemia (AML) that I would truly appreciate what my brother endured, and how hard it is to be a young adult with cancer. Within four hours of receiving the devastating news in July 2015, I was on a plane from our hometown of San Diego, California, to be with Kirsten at Stanford's Lucile Packard Children's Hospital. Three of her college friends were there when I walked into her hospital room. She was in surprisingly good spirits, which gave me hope that this might be over soon—we were both completely unprepared for what was about to unfold.

The first month was the most difficult. Neither of us was prepared for the sights, sounds, and emotions we would experience in the hospital. The nights were especially difficult, alone with our thoughts, trying to sleep despite the eerie glow of the IV machine and its sleep-depriving beeping. Kirsten often

woke up frightened by nightmares, and I was grateful to get off the green couch (you know the one) and let her know she was not alone. Those memories are burned into my brain forever, tiny little scars that will always be with me like movies in my mind. But I also have the comforting memories of what would happen after the nightmares, when I would comfort her back to sleep with a calming massage, or the times when we would get lost in life's many conversations. Those moments are also burned in my mind and make me smile.

Kirsten was this intelligent, hilarious, spirited young woman that cherished her independence, lived to make people laugh, and deeply valued being around her friends—laughter and people were her sources of positive energy. Kirsten especially loved to take her sense of humor to new heights as she kept the hospital staff in stitches, talked about every subject imaginable, and asked questions that kept them on their toes. Even feeling her

worst, she could make them smile. But as the days turned to weeks and months, the weight of Kirsten's diagnosis started to settle in, and the isolation took a toll on her mental and emotional health. Yes, she was grateful to have her parents by her side, but not all the time. And we didn't always get it right.

It was frustrating to lose her independence and depend on everything and everyone coming to her. Away from college and her friends—her two greatest sources of joy—her battery started to drain. The long quiet days and limited distractions as an adult in a children's hospital meant she had plenty of time to watch life pass her by on social media. Without the daily stimulation of life's experiences and social interactions, she started to lose her hope and her identity. That was a turning point. Kirsten started to search for other young adults in the hospital, and thankfully, the staff quickly realized how important it was to facilitate these connections. Visiting with others going through similar experiences helped her stay hopeful and cope.

In addition to finding other patients, I can't imagine Kirsten's experience without the hospital nurses and psychosocial team by her side. They served a vital role in providing normalcy, support, and companionship when she desperately needed it. They listened without judgment, allowed her to speak her mind, and gave her the space to be her authentic self in her new home. Those simple conversations about normal things mattered,

A Caregiver's Story

Kirsten and her favorite purple wig



on the water's surface. Like the story of the lotus flower, Kirsten had endured the harsh cancer journey, finished treatment, and rang the bell to celebrate. She made it to the surface and was basking in the light of resilience, renewed hope, and a life to be lived. Unfortunately, that optimism would be short-lived.

When complications emerged a few weeks later, Kirsten would enter the hospital one last time. Reunited with her favorite extended family of hospital nurses and staff, they would be the trusted friends that would speak to her with compassion and honesty, allowing her to calmly come to terms with her fate. When it was clear there was no turning back, they came to her side to say one last goodbye. Those countless moments of compassion and support brought Kirsten hope, joy, laughter, and in the end, peace. The hardest thing we had to do after saying goodbye to Kirsten was saying goodbye to our extended family. Our connection to the only world we knew for the last seven months ended as abruptly as it began, and it felt like we lost more than a child that day.

The lotus flower and my memories of Kirsten are inextricably linked. It represents the emotional scars left behind from the harsh and unforgiving journey that cancer took her on, as well as the transformative power that adversity can have on the human spirit. She had become a beautiful and compassionate person, filled with kindness, hope, and determination to help others like her. She is and always will be my lotus flower. ●

restored hope, and kept her smiling and upbeat in a place that could otherwise be very lonely and sad. The hospital staff knew when to go the extra mile or facilitate connections that put the wind back in her sails. They made time during their busy shifts to walk the halls with her, take a break in the garden, or just hang out in her room and joke for a few minutes. Defining moments like her 20th birthday, and the bell-ringing ceremony at the end of treatment were special thanks to the beautiful colorful posters and singing.

At some point during Kirsten's journey, when she was starting to feel hopeful again, she began planning for life after treatment. Among the big life choices, such as a career change to become a

nurse and advocate for other young adult cancer patients, she was making smaller but equally important decisions, like getting her first tattoo to celebrate cancer survival. On one of her many quiet days in the hospital, she started to search the internet for just the right imagery to encapsulate her experience and discovered the story of the lotus flower. That was it. Her search was over.

If you are unfamiliar with the lotus flower, it is the perfect symbol for the transformative beauty and light that comes from facing and overcoming adversity. The lotus flower has survived over 100 million years and symbolizes an unparalleled resilience and ability to survive, as it rises from the muddy dark waters and emerges as a beautiful flower



ABBY WESTERMAN IS CO-FOUNDER AND CEO OF B-PRESENT FOUNDATION, ESTABLISHED IN MEMORY OF KIRSTEN, TO IMPROVE SOCIAL SUPPORT SO THAT NO YOUNG ADULT FACES CANCER ALONE.

How It Starts

BY RAIHA SANDERS

It starts with an idea. An idea I can now boil down to one word, invulnerability. The *Cambridge Dictionary* defines this word as, “the quality of being impossible to damage or hurt in any way.” I believe this idea, or rather this word, is felt by many young adults. It’s hard to imagine being vulnerable when you’re young, healthy, and have the world at your fingertips. The possibilities start to easily and quickly feel endless, and eventually so do you. You feel endless and at times superhuman, like nothing can take you down, nothing can really hurt you. Sometimes I believe this is why—as young adults—we do all the stupid things we do, such as skip class, drink ourselves into a coma, make the wrong decisions, and jump off that dreaded bridge our parents told us not to jump off of.

Or maybe I got it all wrong and it has more to do with living in the present moment while you’re young. Taking advantage of every opportunity and moment to have these experiences while we can, all while being able to function off this feeling of invulnerability that keeps us safe. Like a kind of superpower that keeps us protected with no consequences. Even with my condition, it was inevitable that I too would have this feeling that would linger in my subconscious and rule my decisions. I’ll do what I want now. I’ll worry about the effects later. After all, that’s the only thing I was seeing around me. It was only a matter of time before I would catch on.

So, that’s how it starts. I want to do things that my peers are doing, experience things my peers are experiencing, and it feels like I can because I *am*

young. Right? So, I do it. I make plans for a week out of town with college friends. A week celebrated in college annually that’s specifically catered to drinking and going out as much as you possibly can. The number of times I’ve seen people push their limits every weekend and still come out on top felt very familiar to me. It almost felt like I did the same every single time and succeeded in pushing past these boundaries. Almost like a shared experience.

It gave me the confidence to seek out the adventures I always imagined in my life. Although some of them never came to fruition, I always tried. So, I made that decision and committed to going through with that week out of town. I bought my plane ticket and felt an immediate sense of accomplishment. I was bound to go now, and before I knew it,

I was checking into my flight, awaiting the call to board, and preparing for takeoff to fly over California.

I was fully ready, except something significant happened on the plane when preparing for takeoff that continued during the ascent into the sky. Takeoff is the time when the air pressure is changed inside the cabin because there’s simply not enough oxygen in the air for people when flying into the atmosphere. The air is too thin and would cause passengers to pass out, hence the pressurized cabin. However, the air pressure isn’t adjusted to the air pressure on the ground. In most planes it’s only 75 percent of normal air pressure, which is also the equivalent of being 8,000 feet in elevation, not quite on the ground.

Even for a completely healthy person this could cause feelings of lightheadedness, shortness of breath, and headaches, among other things. This is because a person’s blood has a hard time absorbing oxygen at this air pressure. Being a patient with sickle cell disease, the amount of oxygen in my blood is naturally low, even at normal air pressure my blood has an incredibly hard time absorbing oxygen. So, this is how it starts. It starts with the air pressure in the cabin and causes the level of oxygen in my blood to get even lower inevitably causing a pain crisis.

It starts with a feeling as though a giant rubber band is tied around my midsection, and someone just squeezes. Then that squeezing sensation goes a little deeper as if the rubber band made its way through my skin, in between my ribs and wrapped around my spine. Whatever phantom is holding onto that rubber band pulls and pulls and pulls, slowly increasing the tension. This same

Patient Stories

feeling occurred just as it had many times before and it started to get a little hard to breathe, with every breath it felt as though that rubber band was being constricted. The tension in my back became even tighter.

I knew this routine though, and thought of all the times I had temporary pain crises on flights all for it to subside as soon as we prepared for descent. So, I'm prepared for this, I just planned to take my medication and pull out the small portable heat packs I use. Until I realized that the heat packs were confiscated at TSA.

"You can't bring these on the plane, there's too much liquid."

"The liquid turns to solid when compressed look," I had shown her by squeezing one and it made a quick popping sound.

"I don't care, and you can't bring it on if it makes that sound."

"Wait, but I use these for possible pain crises, I have sickle cell disease."

"Sorry you're going to have to use something else." She had thrown away my four heat packs.

I didn't have anything else.

What I did have was my actual heating pad that needed to be plugged into an outlet. It was big and took up too much space; I wouldn't be able to use it comfortably. Although there was an outlet right in front of my chair taunting me to just plug in and use the heating pad while my ribs started to feel compressed. No one would even know, but I just couldn't do that. A quick conversation with the flight attendant revealed that it probably wouldn't be a good idea to use that on the plane since it could be a possible fire hazard.

So, without the help of heat to soothe my back and encourage blood flow to the sickle shaped cells that were obviously being clogged in my veins, I just went to sleep. Waiting for the medication to bring me comfort and take me adrift. I closed my eyes to quicken the process and became very still waiting for the tension in my back to slowly release. Yet the more I silenced the rest of my

"Taking advantage of every opportunity and moment to have these experiences while we can, all while being able to function off this feeling of invulnerability that keeps us safe. Like a kind of superpower that keeps us protected with no consequences. Even with my condition, it was inevitable that I too would have this feeling that would linger in my subconscious and rule my decisions."



Raiah and her friend Jevannie

Patient Stories

body and kept still, the more I noticed the squeezing pain was not subsiding.

I decided to keep my eyes closed and eventually I was able to doze off, until I noticed it was hard to catch my breath. It was waking me up, so I checked my phone hoping I had slept for some time. I was disappointed when I saw it had been less than fifteen minutes. I was feeling very uncomfortable and trapped at this point, so I thought maybe going to the bathroom in the back of the cabin was a good idea to stretch my legs. As soon as I stood to my feet, I felt this paralyzing pulsating pain spread throughout the whole of my back. As if all the veins and capillaries in my back constricted at once. I imagined my back would light up a glowing red, a rhythmic beam every time this pulsating pain hit.

I squeezed the head of my chair for balance trying to keep my composure. My eyes closed simultaneously as the pain was too much for me to try to focus on anything. I opened my eyes as the pulsating pain slightly went away after about 40 seconds. For 40 seconds I stood up gripping the chair with my eyes closed. I opened them looking around slightly embarrassed, but no one noticed, everyone was in their own

spaces. Why didn't anyone notice?

This feeling of being unnoticed continued for the rest of the flight and the rest of the day. Experiencing what felt like immeasurable pain but keeping it under control enough that not a single person would consider anything wrong was strange. I wasn't quite sure how I felt about that except I knew it would allow me to keep pushing myself uninterrupted.

The plane landed and I didn't feel the usual relief that comes with having a somewhat normal amount of oxygen in my blood. The pain lingered and the medication didn't do anything to get it to budge. I picked up my carry-on bag and threw it over my back as I walked across the tarmac to the shuttle that took us all back to the airport. I imagined this is what it felt like to put pressure on a bleeding wound to make it stop. This image helped get me through the walk from my gate by somehow convincing myself that the pressure from my carry on was helping with the pain.

I sent a heads-up text to my friend, warning her that I had a bad flight and would just need a short nap when I made it to her place. She was one of those friends who understood the val-

ue of a good nap and indulged in them herself, so she agreed without hesitation. Especially when I put it as "just having a little bit of pain and need to lay down for a sec" in the text. The amazing thing and what I'm grateful for is we stayed and rested for hours before going on with the day. Except that wasn't enough.

I laid there and we caught up and laughed, but the phantom never let its grip from my spine, maybe just loosened it a bit. When we had talked about getting lunch and going shopping, I wanted to go. I felt like I should go to not waste the day and I knew I would be mad at myself if I did. Wasting experiences and not taking advantage of my youth. The phantom slightly loosened its grip, so I believed that would be enough for me to get through the day.

Still, I trailed behind the group when walking, sat uncomfortably as we ate our food in hard restaurant chairs, and took breaks while shopping in the mall. I just couldn't keep up, as hard as I tried. I even went to a club that night thinking the pain wouldn't get out of control. That is until I woke up in the middle of the night and realized I couldn't move. The pain was far more severe than it was on the plane. I tried speaking up to tell my friend but no words came out and the pain flooded into my stomach. I couldn't talk. I knew this was the beginning of an excruciating pain crisis.

By the time morning came, I needed my friend to help me pack my things and to even get up to use the bathroom. She took her time walking me down the stairs and pushing me in a wheelchair into a hospital I'd never been to before. She was forced to give me up to a medical staff and team who had no idea what to do with me but told her she needed to leave me in this place alone. All while they sat by and watched as I screamed through the pain and ignored my pleas for relief. Unfortunately, that is how it ends. Me in a hospital bed for days wondering where all my young adult invulnerability went, and why it had decided to leave me. Where was my superpower? ●

*"Unfortunately, that is how it ends.
Me in a hospital bed for days
wondering where all my young
adult invulnerability went, and
why it had decided to leave me.
Where was my superpower?"*

Happens

BY GARY DAHL, MD

Happens !!

It Happens !!

As one goes upon their regular way

There are many pathways to take that just appear each day

No planning day by day

Things just happen and reality can sway

On ones leg some pain can occur

Making you think it's a sharp plants burr

Trip to the hospital to see what's up

The doctors thoughts are filling his cup

Could be infectious or inflammation it seems to me

Not really anything major enters my dream

First is the work up with blood work and scans

Possibilities are numerous and nothing out of hand

Then they tell me straight face to face

You might have cancer and need to start a race

The tumor entered my life pushing its way in

My thoughts were many and beginning to spin

I am given a plan step A through Z

Will I make it to a path heading back to real life

Each day is new and quite unexpected

The future is different and totally not directed



GARY DAHL, MD, PROFESSOR EMERITUS
OF PEDIATRICS AT STANFORD MEDICINE
AND A PEDIATRIC ONCOLOGIST AT
PACKARD CHILDREN'S FOR 32 YEARS
UNTIL HIS RETIREMENT IN 2022.



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

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