

VOICES OF OUR AYA COMMUNITY

CREATED BY AND FOR STANFORD'S AYA CANCER COMMUNITY | SUMMER 2022

USING CREATIVE EXPRESSION
TO TELL OUR STORIES

PRESENTED BY



You Have Questions.

We Have Answers.



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.





ALISON CLAYTON



PAM SIMON, NP



DEANNA BEYER



GILLIAN KUMAGAI



NICK GIALLOURAKIS

Welcome to our first edition of *Voices of our AYA Community.*

You may be struggling with a new diagnosis of cancer, about to finish your last round of treatment, living with cancer, or looking back at cancer and thinking about the ways it changed your life. Whatever stage you're at, we want you to know that you're not alone. At Stanford there is a supportive community for adolescents and young adults who are affected by cancer.

The Stanford Adolescent and Young Adult Cancer (SAYAC) Program is collaborating with the Stanford Health Library and *Elephants and Tea* to strengthen this community by sharing stories of patients, caregivers and healthcare staff. Stories told through writing, poetry, photography, painting, and other creations help us all connect. Sometimes we find ourselves thinking "yeah, that's exactly how I feel!" Sometimes we are inspired to share our own story.

This is our first collection of stories and we hope you enjoy reading them, listening to the audio recordings, and looking at the artwork. We will be holding a second workshop on August 4, 2022 for anyone who wants to share their story in the next edition. At the workshop, you will have a chance to respond to several writing prompts in a small group and then we will share our thoughts, doodles, and ideas with each other. After the workshop, we encourage you to submit your art or story to us for the next edition of *Voices of our AYA Community.*

Welcome to the Stanford AYA Community.

ALISON CLAYTON AND PAM SIMON – SAYAC
DEANNA BEYER AND GILLIAN KUMAGAI – STANFORD HEALTH LIBRARY
NICK GIALLOURAKIS – ELEPHANTS AND TEA

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USING CREATIVE EXPRESSION TO TELL OUR STORIES

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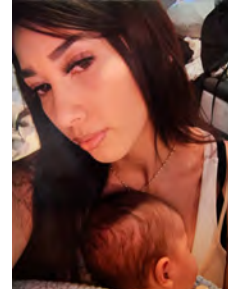
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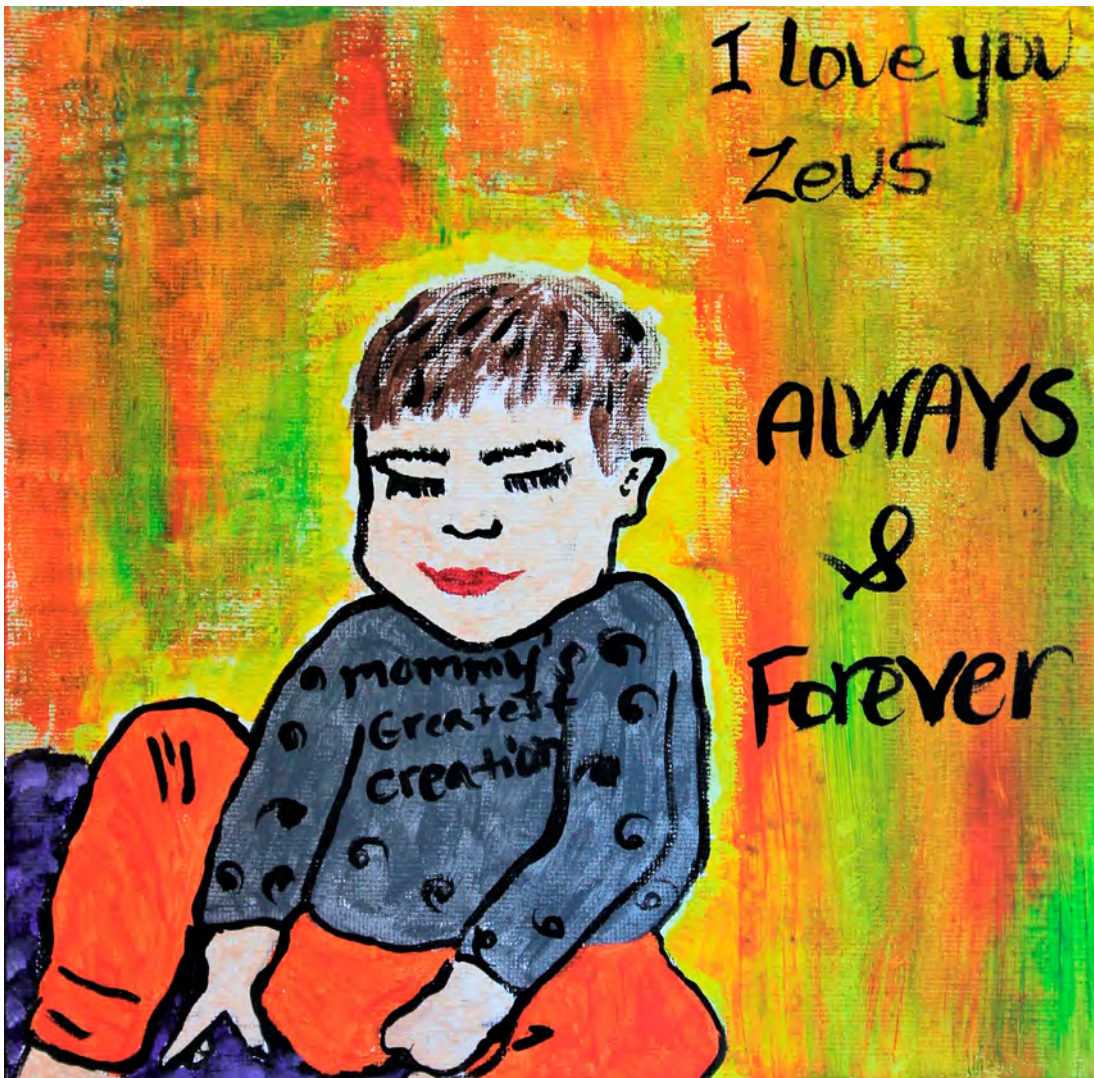
BY ZENAIDA C.

I am 22 and my son, Zeus, is 15 months old. He's really my motivation to continue to get strong and get out of the hospital. This picture is of Zeus when he was about 12 months old.

I am from the Bay Area and I have always loved to paint and draw. Being in the hospital has allowed me to explore my creative side. Any form of art is a great way to express yourself, and it really helps me relieve stress. ●



See Zenaida's artwork throughout this issue of *Voices of our AYA Community*





The Importance of Community

WORKING WITH AYA CANCER PATIENTS

A CONVERSATION WITH PAM SIMON, NP AND ALISON CLAYTON
ART BY ZENAIDA C.

Pam Simon and Alison Clayton talk about their work with adolescents and young adults with cancer and the importance of community.

Pam Simon (PS): We sort of try and figure out where the patient is at and what information they need. One of my patients once said to me, “You know, we don’t know what we don’t know.” That thought was so inspiring to me because it is true. If we don’t give them the information, they can’t make a decision. How can you make decisions about cancer when you have never gone through it? So, you don’t know what you don’t know. I feel like our program is here to help cancer patients get the information they need to make the best decision they can make. Many times patients will say, “I don’t know how to make this decision. I don’t know how I am going to know if I need to do fertility preservation or not.” What I always tell them is that there isn’t a right or wrong answer. The answer is whatever is right for you, right now. That’s where we can help patients

Our Staff

understand and provide them with all the information we know. Here's the information, what is important to you, and how can we help you make these important decisions?

Alison Clayton (AC): Obviously, the physical outcome is hugely important. All the doctors at Stanford are working on that, but we need to make sure that people can navigate all the psychological and psychosocial issues that come with going through cancer treatment, as well as surviving and moving on with their lives.

We are segregated into pediatrics and adult medicine, helping people on both sides better understand what some of the issues are as well as understand the patients' stories and what it feels like to be a young adult or an adolescent going through cancer.

Part of what's so special about the adolescent young adult (AYA) community is that it allows people to be with somebody else who really understands their story. I think there's so much support in building that community and watching people experience it, even if it's just sharing it with one other person. Being part of a community helps people understand that they are not alone.

I think an important part of helping AYAs get through cancer is knowing they are not alone. We hear from peo-

ple all the time say, "Oh, I wish I had asked for a mentor when I was first diagnosed. It's only now that I am five years out from treatment that I realize how valuable that would have been." But I think it's valuable at any time. I think it's always valuable to have somebody else who shares your experience and who knows what you have been through.

PS: I hope the pandemic has shown the rest of the population how hard it is to go through cancer treatment and be isolated, constantly worrying about getting infected. All the things that the general population has had to do over the last few years, these patients do on a constant basis. Hopefully, we have all lived a little bit and are more understanding, and maybe some of the friends and relatives of patients who are diagnosed with cancer during this time can help them understand a little bit as well.

AC: I do hope that the pandemic has taught all of us a little bit about how we can be there for somebody else, even if we can't physically be there. We can still be a friend. Helping people understand that they are not alone is an important part of helping AYAs get through cancer. They are not alone. ●



Alison Clayton, Program Coordinator, Stanford Adolescent and Young Adult Cancer Program



Pam Simon, NP, Program Director, Stanford Adolescent and Young Adult Cancer Program



Listen to Alison's and Pam's conversation here.

Carrying My Patients in My Heart

BY JENNY KWAK, LCSW, OSW-C
ART BY ZENAIDA C.

The last eight years have been a profound learning experience. I have learned more about cancer diagnoses and treatment options. I know more than I ever cared to about relapse and terminal illness. I have seen many people die during my 31 years as a social worker, and I have worked with many oncology and palliative care teams to help my patients cope through the dying process.

I see patients at the brink of death before they fall into the abyss. Yet, I come back week after week because they keep me motivated. I see the tears behind their eyes and I may tear up as well. When they cry my heart breaks just a little, but I am able to say these words, “I am so sorry you have to go through this right now. I want you to know that we are available to help and provide support.” Then I give them the appropriate resources, provide supportive counseling, listen to their fears, and provide coping mechanisms and tools to help them in crisis. I hope to prepare my patients to get a better handle on the process. I provide cognitive behavioral therapy (CBT) tools so they can track their moods and get help if needed. Self-care is so important. Reaching out is too. We can all drown together or save each

other, one person at a time. The costs are high in this work. Having compassion for one another is key.

What we can do is focus on a patient’s strengths and identify areas of growth and focus on our gift as healers. Social workers are healers. We are not doctors or nurses who know how to give medication or administer the right treatment or surgery. What social workers do is heal with our kindness, love, knowledge of resources and the system, and advocacy skills. We have been called to do this work. For some of us, it’s because we are spiritually inclined, for others it was because a mentor or role model steered us in this direction, and some just knew early on they were excellent listeners, and everyone turned to them for advice. Each social worker came on this path for personal reasons because monetary ones



“We can all drown together or save each other, one person at a time. The costs are high in this work. Having compassion for one another is key.”

were never guaranteed. The identity of social workers in healthcare is profound. Most healthcare providers know what social workers do and see their impact on patients and their families’ lives. They get it. My colleagues see how calm a patient is after a social worker talks with them or how they can de-escalate a situation. They see the impact in a group setting. In oncology, staff often don’t feel prepared to comfort a patient who is wailing, or in most cases, just crying—social workers can provide the time and space to ease that burden.

Patients, like the ones I see during their radiation treatments have been my guides during the pandemic. They have led me on their cancer journey and have often taught me how to navigate the turbulent storms the past few years. As we have all felt the effects of COVID and are now in the third year of feeling exhausted by the rising tide of deaths, fatigue, and cumulative burnout, the patients that we serve have continued to show grace, compassion, and gratitude. Patients share their suffering, and I carry my cancer patients in my heart. On this Valentine’s Day 2022, I am reminded why I love my profession. I want to continue to share the stories of my patients and be their voice long after they are gone. ●

From Patient to Nurse

WHAT THE STANFORD AYA CANCER (SAYAC)
PROGRAM HAS MEANT TO ME

BY FIONA GUTIERREZ-DEWAR



My name is Fiona Gutierrez-Dewar, and I was a patient at Stanford Hospital about four years ago when I was 22 years old. I was treated for non-Hodgkin's lymphoma. I did about five months of chemotherapy treatment. I would stay in the hospital for five days, go home, and then come back two weeks later for another round; six cycles total, a countdown you pay very close attention to when going through treatment.

Days and months didn't exist for me that year; instead, the seasons were measured in cycles: one, two, three, four, five—it was undeniably a life-changing experience to not only face my own mortality at a young age, but also to meet so many roommates and see the intensity of people diagnosed with cancer all around me. No one close to me had ever gone through cancer treatment, now every new person I was meeting had cancer. It felt like most of the people around me were my grandparents ages. I usually felt like the youngest person on the unit and like no one my age—friends, co-workers, classmates—could understand what I was experiencing daily.

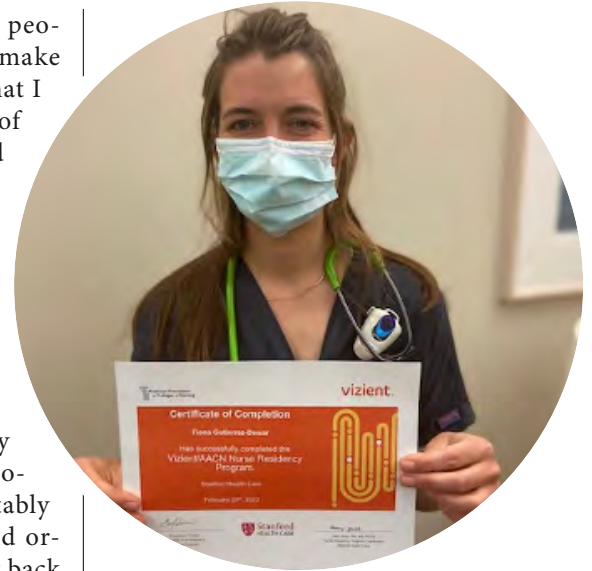
At that time, I was just trying to keep my spirits high and get through seemingly endless days of chemo treatment; the nausea, anxiety, fatigue, beeping alarms, and IV lines. I was scared of not knowing how each cycle of chemo would impact my body physically. I was stressed about losing my fertility. I felt heavy and guilty witnessing the impact of my sickness on my mom, dad, and sister's lives. I was also confused about who I was, not being able to plan for my life anymore. At 22-years-old, I had imagined a life full of adventure, travel, odd-jobs, and creative pursuits. Now all I could think about was how important it would be to have a reliable job, good health insurance, and family close by for the day that crisis struck again. It made me feel so alone to wonder if I would live to be 30, and not able to keep up with my friends, or relate to their conversations and priorities anymore. A sweet friend visited me the day after

my chemotherapy finished with lemon frosted cupcakes and asked if “I felt like a changed person?” I scoffed at that question and wanted to snarl back, “Not at all, I am definitely the same person.” I hated a question like that. More than anything I just wanted to be “normal” and for people to not look at me and my shining bald held with strange pity, concern, and awkwardness anymore. I did not want to feel “changed” or alienated by this diagnosis, I just wanted to feel like everyone else my own age. But now, years later, I can accept and appreciate how much cancer has changed me. My outlook on life and what mattered most were forever impacted. Being a few years out of treatment and in remission, I can say that I am quite grateful for the perspective cancer gave me and the experience I went through. My dad always said I would find the silver lining out of having cancer, and of course, in the moment I was frustrated he was trying to force positivity out of one of the worst chapters of my life. I still believe finding the silver lining is something each person must do for themselves. No one, other than the affected individual, has the right to identify the redeeming aspects of having cancer. But of course, as my dad had correctly predicted, I did find dozens of silver linings from having cancer.

One of those silver linings was getting involved in the Stanford AYA community! Pam Simon is the program director, and she would come check in on me regularly during my cycles in the hospital. She helped me navigate the process of freezing my eggs before chemo started and could explain what to expect with everything cancer related—from getting a bone marrow biopsy to going back to work early during chemo. I could talk with her about my real experiences as a young person with cancer: trying to date, wanting to go surfing, and getting back to life or school after chemo was over. As my treatment wrapped up, I was eager to make the experiences of future young people with cancer better in some small way, or at least less lonely. Pam

connected me with other young people and nonprofits where I could make an impact and also meet peers that I could relate to. Becoming a part of the Stanford AYA community and helping contribute to the growing program made all the difference for me. While chemotherapy had ensured I was physically healed of cancer, the SAYAC program gave me a place to heal emotionally and psychologically. I was finally able to find meaning out of being sick, and I could slowly process the existentialism and emotional crisis having cancer inevitably triggers. Through mentoring and organizing AYA events, I slowly got back to living a normal life while still being involved in something that had such an impact on me.

Another silver lining that came out of having cancer at a young age was that it helped me find a new career direction I would not otherwise have discovered! After treatment ended, I decided to become a nurse myself, and not surprisingly, chose the specialty of oncology nursing. Now exactly four years since I finished chemotherapy treatment at Stanford, I get work on the same unit where I was lying in bed myself just a few years prior. I work alongside the nurses who gave me my own treatments and get the privilege of giving back to other patients with cancer. One of my favorite parts of working as an oncology nurse is getting to meet other AYA patients. I feel passionately about trying to connect other young patients with the SAYAC community. I hope that through connection with their peers, participation in events, and involvement in cancer-related groups, everyone can find a sense of belonging, humor, understanding, and hopefully even a bit of meaning in the seemingly senseless disease of cancer. I am still on the SAYAC Advisory Council at Stanford, and my hope is to make the experience of having cancer feel less overwhelming and isolating for all young cancer patients treated at Stanford. ●



“After treatment ended, I decided to become a nurse myself, and not surprisingly, chose the specialty of oncology nursing. Now exactly four years since I finished chemotherapy treatment at Stanford, I get work on the same unit where I was lying in bed myself just a few years prior. I work alongside the nurses who gave me my own treatments and get the privilege of giving back to other patients with cancer.”

Reflecting on My Experience

BY MYSHKA JAVIER

Oftentimes, we take things for granted and don't really have time to self-reflect when we get caught up in busywork and life events. However, in the blink of an eye, life can change at any moment and bring everything to a halt. On September 26, 2018, I was diagnosed with non-Hodgkin's lymphoma, a type of blood cancer.

When I had first received the seemingly unreal news, I was not exactly sure what emotion to feel. My mind went blank, and my body felt numb. When my doctors reviewed my diagnosis and proposed treatment steps with me, I did not cry. I cried after they left the room because they said I would not be able to attend my junior year of high school due to the chemotherapy cycles ahead. I was looking forward to my third year of high school—preparing for the kind of hard work that creates memorable experiences—but my diagnosis had interrupted all my traditional school plans.

A few days into my first cycle of chemo, I had a couple of friends and family come over to visit where I broke the news to them. I am not sure they knew how to take this news, but I know they were ready to be there for me no matter what and to support me as I went through treatment. I had to get used to taking a lot of pills throughout the day to support my body through chemo, and I was in the hospital receiving a cocktail of three different chemo medicines in one bag to be infused for twenty-four hours a day for six days.

I experienced a good amount of nausea and severe fatigue, and although I was already having a hard time swallowing because of a mass in my chest area, the chemo temporarily changed my taste buds in a way where everything tasted bland and I didn't really want to eat anything. At home is when the post-chemo side effects hit me harder. When I first got home from the hospital after my first cycle, I took one step up the stairs and sat down and told my parents I couldn't do it. They both helped me get up and get to my room where I immediately laid down, and I have never felt so exhausted in my life. For the next week at home, I had immense fatigue, body aches, and bone pain. It felt like I got hit by a truck.

Every two weeks after I had chemo, I would go back into the hospital to be admitted for another cycle of chemo which lasted about six days. On my days at home, I would have to get weekly labs and clinic visits, along with EKGs. One of the other side effects of the chemo I had caused me to have a prolonged QTC in my heart. There were a couple of times where I had to be admitted to the cardiology unit

to monitor my heart rhythm. I had to get a shot every day to help bump up my neutrophils, or white blood cells that were lowered by the chemo and continued for about a week. I also had to be on high doses of supplements to support my body since the chemo was depleting my electrolytes.

In the cycles that followed, I got used to treatment a bit more, as I knew what to expect in terms of my side effects and how I would feel after. But I also expected to lose my hair, and for some reason when my hair started to shed in bulk after my second cycle, I didn't get sad or feel horrified. I thought it was fascinating in a way. It was not really something I worried about, but as I progressed in treatment my scalp became more and more visible, which often caused me to feel cold, so I wore a beanie wherever I went. I didn't lose all my hair by the end of treatment, it just got thin. As I progressed through more cycles, I went into each chemo session with a stronger, more optimistic attitude, knowing that I could take this head on and fight through.

Preparing mentally, physically, and emotionally for cancer treatment was a different type of junior year hardship than I had ever faced or anticipated, but I knew I was not alone.

Having to confront my diagnosis and the realities with which it arrived caused me to approach school with great motivation to stay engaged in my education. Despite the treatment being difficult and challenging, I enrolled in my local



Myshka Javier is an ambitious and vivacious student who currently attends the University of California (UC) Irvine as a sophomore. Her humorous and positive character applies not only to her interactions with others but also to her extracurricular passions. She learned Polynesian dancing at the age of five and loves singing, playing the piano and the ukulele, dancing hip-hop, and songwriting. Through sharing her personal experience with cancer treatment, she hopes to encourage optimism through life's adversity, using it not to discourage, but rather to fuel tenacity.

district homeschool while receiving six months of chemotherapy treatment along with hospital admissions every 14 to 21 days. I had frequent oncology clinic visits twice a week, constant imaging and blood tests, and several ER admissions in between. During the whole summer, I had taken online classes to complete the rest of my credits as I was not able to be in public places since I was immunocompromised. Working through cancer treatment and the entirety of summer,

I was able to complete all the required courses, enrolled back into my previous high school as a senior, and resumed my extracurricular activities with resilience the next year.

After being in remission as of March 2019, I had begun to reflect on my experience on dealing with cancer. Throughout the many aspects of my treatment, including many days in the hospital, the support of my friends, family, school, and medical team gave me newfound

strength. I still had days where emotional breakdowns seemed to come out of nowhere, but throughout treatment, I had a lot of time for introspective moments. No matter how weak or mentally drained I was, I was still able to go through it with a more positive attitude than I would have ever thought. This has taught me that having optimism is essential during life's hardships, along with having the support of others to nourish that fighting spirit. I was able to stay positive amidst the circumstances, because even though I was at my lowest point and at my most vulnerable, I did not isolate myself nor shut people out. Rather, I welcomed every visit—whether it be friends, family, or teachers—and tried my best to stay connected with others.

Striving to sustain perseverance and staying connected with my loved ones sparked motivation and hope, and personally affected the way I handled my experience with cancer. Before, I used to stress about many minuscule things and every single detail about my life. Usually, we take our bodies for granted and forget the privilege of being healthy. We forget to be grateful and appreciative of the people in our lives who support us, and cancer had jolted me into no longer taking anything for granted. I have come to realize that in life, when we are faced with adversities, it is important to look inward; to recognize that all the optimism and determination you need is already within you; you just need to focus on harnessing that strength. I now encourage others to not let life challenges discourage us, but rather let them fuel our determination, just as I took each chemotherapy cycle as a challenge and charged at it head-on with perseverance. It is also vital to encourage and welcome others' support and to leave your heart open during life's adversities, as this allows you to be surrounded with love during a vulnerable time and helps you polish your lens on life. Through my story of treatment and my experience with cancer, I hope to inspire others to charge at life with gratitude and determination. ●

I will never forget the day...

BY LARA FARHAT
ART BY ZENAIDA C.

*I will never forget the day
I went into surgery during COVID,
No one was allowed inside with me.
Alone with the fear of what was to come.
Carrying the burden of my perceived strength
And the hope of others on my shoulders.
Tired of my life playing out like this again.
Feeling isolated, separate in my mind,
And seeing that reflected in the world around me.
Facing uncertainty with my health and,
Once again,
Having no control over the outcome.
Hating my body for what it was doing to me.*

SHARE
YOUR
STORY



Building AYA Community Through Storytelling

FREE Virtual Workshop with Elephants and Tea

Presented by Stanford Adolescent and Young Adult
Cancer (SAYAC) Program and the Stanford Health Library



Sharing your story can be a helpful strategy toward healing and communicating with others about your experiences. Join us for a virtual storytelling workshop with Elephants and Tea to learn and apply creative prompts to guide you through telling your story, however you choose.

Writing. Poetry. Photography. Painting. Audio. Other forms of art.

August 4, 2022 | 6:00 PM - 7:30 PM

Scan the QR code to register

or visit healthlibrary.stanford.edu/shc-storytelling/sayac.html



Mi experiencia como madre de un joven con cáncer

POR MÓNICA HENNINGS

Cada ser humano forma una idea o concepto diferente de algo o alguien. Con base en nuestra experiencia, aplicamos distintos filtros y lentes para interpretar la realidad que nos rodea. Por eso, este texto estará escrito desde mi perspectiva como madre de un joven que tuvo cáncer.

Cuando la enfermedad aparece sufren todos: padres, hermanos, pero, sobre todo, el paciente. El diagnóstico de que mi hijo David tenía esta enfermedad nos llegó un viernes 13. Para la mayoría, el viernes 13 es una fecha cabalística de mala suerte. Para mí, no. De hecho, es al revés: me encanta el número 13 y me ha traído buena suerte. No me equivoqué con eso. Más adelante entenderán por qué.

Escuchar las conclusiones médicas de la doctora fueron como un petardo al corazón. Tenía miles de preguntas que entraban y salían de mi cabeza, no solamente relacionadas con la enfermedad. Me angustiaba el hecho de estar viviendo esa situación en un país extranjero, del que desconocía cómo funcionaban los asuntos médicos. Aparte, en un momento de estrés como ese, el idioma se convirtió en una barrera para mí. Cuando me pongo nerviosa, no entiendo nada y pierdo la concentración con facilidad.

Algo que me sirvió y asimilé con el transcurso de los meses fue preguntar

cuando no entendía. Si era necesario, lo hacía cien veces. Poco a poco le fui perdiendo el miedo al sistema médico. Necesitaba adecuarme rápidamente y buscar apoyo en lo que necesitase, sin tener miedo a pedirla. Soy una persona de fe, así que esta situación me sirvió para reafirmar mi confianza, un sentimiento que considero necesario en cualquier proceso de sanación propio o de un ser querido.

Un temor que me asaltaba con frecuencia era lo que podía estar pasando por la cabeza de mi hijo. Me cuestionaban qué tan fuerte era emocionalmente, cuáles pensamientos aparecían en su mente y qué podía hacer yo para ayudarlo. Me llevé una gran sorpresa en relación con esas inquietudes: descubrí que es más fuerte de lo que pensé. Él había decidido luchar contra el cáncer con una sonrisa en los labios. Su actitud fue un gran regalo para nosotros. Comprobamos, en medio de esas circunstancias, que la actitud hace una gran diferencia y puede cambiarlo todo. Y así fue.

Así que David decidió estar acompañado, hablar con otros pacientes que estaban atravesando el mismo proceso que él, algunos de ellos de su edad, pero que, sin duda, eran más reservados. Los empleados del Lucile Packard Children Hospital, donde recibió su tratamiento, comentaban que

era un “social butterfly”, como suelen decir los americanos. Yo digo que es mi ave fénix. Su carácter extrovertido y sociable lo ayudó a seguir adelante y a mí también.

Otra estrategia de mi hijo para no sentirse solo fue asistir a la escuela que está en el tercer piso del hospital. Aunque, en su mayoría, eran los pacientes pequeños los que asistían, David pronto se convirtió en una especie de hermano mayor para ellos. Eso lo ayudó a mantenerse entretenido y no deprimirse. Si bien hubiese sido ideal que compartiera sus experiencias con otros pacientes de su edad, se adaptó y supo sacarle provecho a las circunstancias que le tocaban vivir.

De alguna u otra forma, buscó no estar solo, ya que la mayoría de jóvenes suelen pasar esta enfermedad con pesar y melancolía, porque creen que son los únicos. Lo cierto es que hay muchos como ellos y necesitan una comunidad que les dé soporte y en la que puedan buscar refugio, empezando por los miembros de su familia. Hace siete años, David superó el cáncer y el año pasado se graduó en la Universidad de Longbeach. Hoy, está postulando a una maestría para ser “Child life specialist” y convertirse en el apoyo de tantos jóvenes con cáncer que -como él en su momento- lo necesitan. ●

My Experience as the Mother of a Young Person With Cancer

BY MÓNICA HENNINGS

Every human being forms different ideas or concepts about something or someone. Based on our experiences, we apply different filters and lenses to interpret our surrounding reality. Thus, this text has been written from my perspective as the mother of a young man who had cancer.

When someone falls ill, everyone suffers—parents, siblings, but most of all, the patient. We received my son David’s diagnosis on Friday the 13th. Most people consider Friday the 13th to be a cabalistic date and a harbinger of bad luck, but not me. In fact, it is quite the opposite. I love the number 13 and it has brought me good luck; I was not wrong about that.

Listening to the doctor’s medical findings felt like a dagger to my heart. I had thousands of questions flying in and out of my head, and not just those related to the illness. I was distressed at the fact that we were going through this in a foreign country where I was unfamiliar

with the workings of the medical system. Additionally, at such a stressful time, language became a barrier for me. When I am nervous, I do not understand anything and easily lose my concentration.

Something I found helpful, and came to put into practice over the months, was to ask questions when I did not understand. If necessary, I would ask 100 times. Gradually, I was able to let go of my fear of the medical system. I needed to quickly adapt and seek the support I needed without being afraid to ask. I am a person of faith, so this situation helped to strengthen my confidence, a feeling that I consider essential in any self-healing process or for that of a loved one.

I feared what could be happening inside my son’s head. They would ask me how emotionally strong he was, what he was thinking about, and what I could do to help him. I was in for a big surprise regarding those concerns; I found out that he was stronger than I had thought. He had decided to fight cancer with a smile on his face. His attitude was a great gift to us. We realized, amid such circumstances, that attitude makes a big difference and can change everything, as indeed it did.

So, David decided to be with people and speak with other patients that were going through the same experience. Some were his age, but without a doubt, were more reserved. The staff at Lucile

Packard Children’s Hospital, where he received his treatment, would mention that he was a “social butterfly,” as Americans often say. I say that he is my phoenix. His extroverted and social personality helped him—and me—carry on.

Another one of my son’s strategies to avoid feeling lonely was attending the school located on the third floor of the hospital. Although it was mostly younger patients who would attend, David soon became like a big brother to them. This helped keep him entertained and prevented him from becoming depressed. Although it would have been ideal for him to share his experiences with other patients his age, he was able to adapt and learn how to make the most of the hand he was dealt.

He somehow looked for a way to not be alone, since most young people tend to go through this illness full of sorrow and melancholy, believing they are the only ones in that situation. The truth is that there are many like them, and they need a community that supports them where they can find refuge, starting with the members of their family. It has been seven years since David beat cancer, and last year he graduated from Long Beach University. Now, he is applying for a master’s program to become a child life specialist, and to provide support to the many young people with cancer who need it, just like he once did. ●



Why I Do What I Do

BY KYLE CLAWSON



WHAT HAVE YOU LEARNED ABOUT WORKING WITH THE AYA COMMUNITY?

Working with these patients and families has been amazing, they have taught me what resilience means in many ways. I am grateful for the experiences and challenges we have overcome together. One thing I am always talking about is accountability, and if patients stay focused on their goals, we can get there together.

WHAT DREW YOU TO YOUR CURRENT ROLE? WHAT IS YOUR WHY?

My role as the Stanford adolescent and young adult cancer (SAYAC) program educational specialist started at a challenging time—not only for me—but for the world. The pandemic changed everything we knew about “normal life.” It was stressful, confusing, and sad; we could not do the things that helped us be ourselves, so at times I felt lost.

When Pam and I first spoke about this role, we talked for a while about how we wanted to help grow the program and service for patients who don’t always have the support they need to be successful to grow into the next chapter of their life, regardless of when treatment occurred.

As we all know, cancer leaves its mark. I know from my own experience when I lost my sister, Megan, to neuroblastoma when she was one year old. I also lost my cousin, Hannah, to rhabdomyosarcoma when she was eight years old. When I say “leaves its mark” I think of when my niece had some type of lump on her back. My entire family was immediately in panic because of our family history. Thankfully after a few different tests and specialists we found out it was just extra growth tissue. Again, the mark cancer left on our family reminds me of why I do this work.

WHAT DO YOU DO AS AN EDUCATIONAL SPECIALIST? WHO ARE YOUR SERVICES AVAILABLE TO?

As an educational specialist, my area of support focuses on an AYA's educational goals, career goals, and life goals. Sometimes cancer—no matter when the patient was diagnosed or if they are currently going through treatment—can cause extra challenges in school/life that are related to their diagnosis and/or treatment. I currently have patients whose ages range from 14 to 37 years old.

If an AYA is currently in school, I can help them by contacting the school's accessibility department or the school district and providing documentation of the student's need for accommodation. I can attend Individual Education Program (IEP), 504, or Student Support Team (SST) meetings to advocate for student's needs and recommend school interventions to bridge the gap between the hospital, home, and school. I also work to help AYAs obtain their GED and improve their study skills.

I can assist AYAs who are applying to colleges with essay writing, goal setting, and helping them find scholarships for cancer survivors after the student is accepted.

Young adults who are working when they are diagnosed with cancer can receive help with disclosing disabilities to their employer, self-advocacy, and career planning.

I also provide general support for AYAs with social skills/coaching; holding them accountable for their goals; and improving executive functioning with self-monitoring, time management, organization, and self-control. When needed, I can provide educational assessments and referrals to other professionals or agencies for further assessments, therapy, and support.

I am also part of the Hospital Educational Advocacy Liaisons (HEAL) program at Stanford, which provides neuropsychological testing based on referral from a Lucile Packard Children's Hospital physician.

WHAT ADVICE DO YOU HAVE FOR AYAS?

Sometimes it is hard to get started with big pictures goals, but if you can take them one step at a time and focus on each step individually, the journey seems less scary. Especially if you have someone rooting for you and pushing you in the right direction.



Kyle Clawson is an educational specialist for the SAYAC and HEAL programs at Stanford Children's Health. He has worked within the educational and hospital systems for about seven years with experiences in behavior health, sever disabilities, and working with those who are medically fragile. He uses his skills to not only help patients and their families, but to also teach them skills to be successful both in and out of the hospital. Knowing how to advocate for yourself and others is truly powerful, and he enjoys providing the tools that assist patients in their success during and after treatment.



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



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