EMPOWERING THE AYA CANCER COMMUNITY TO EMBRACE THEIR VOICE AND STORY

The Gabster Magazine

FEATURING: KEYNOTE SPEAKER

YOLANDA MURPHY

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Q&A WITH CARLO AND WENDY, THE HOSTS OF THE CANCER PATIENT PODCAST

THREE BENEFITS OF EXERCISE AFTER A CANCER DIAGNOSIS

THE HEALTH BENEFITS OF UNMINDFULNESS

ALSO:
THE GABFEST AGENDA

PRESENTED BY
ELEPHANTS AND TEA
CACTUS CANCER SOCIETY
formerly Lacuna Loft

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Welcome to YA Cancer Gabfest 2021!

Hey there! We are so glad you've found your way to YA Cancer Gabfest 2021! It is hard to believe that this will be year two of this extraordinary virtual week of bringing together the young adult (YA) cancer community to connect, share stories, and interact with one another. Our organizations, Cactus Cancer Society (formerly Lacuna Loft) and Elephants and Tea, have worked hard to create a week of community and connection. A week where those touched by YA cancer can come together, learn from one another, feel less alone, and leave with some new friends in hand. We've found the very best partnership between our organizations and are so proud of the event we've collectively put together for you.

Over the course of the conference week, you can expect more than plain old webinars, more than stuffy talks in crowded conference rooms. At YA Cancer Gabfest, we'll have crash courses where we learn from experts while also acknowledging the expertise found within the experience of each attendee, we'll hear from a diverse set of panelists on all sorts of YA cancer topics, and we'll connect in "After Hours" hangouts filled with trivia nights, cooking demos, stories from Emerging Voices, and more.

Plus, we already have a way of taking YA Cancer Gabfest home with you. At Cactus Cancer Society, we run year-round, online interactive programs for young adults facing cancer as patients, survivors, and caregivers. Art workshops, creative writing workshops, journaling workshops, game nights, hangouts, you name it. At Elephants and Tea, we are all about storytelling and community. We have the only adolescent and young adult (AYA) cancer magazine written for and by the AYA community, virtual events such as our monthly Perkatorys for AYAs to use their voice to talk about tough topics, and weekly Happy Hours for the community to come together and just have fun with each other. You can take what you learn during the YA Cancer Gabfest experience and continue to make friends and find community for the rest of the year in our organizations' programs.

On top of the amazing week of crash courses and interactive panels, you now also receive the first edition of *The Gabster Magazine*. Inside, you'll find stories from our presenters and YA Cancer Gabfest staff, giving you behind-the-scenes views into each of their lives. Together we'll learn more about who they are and why they use their voice to help the cancer community.

When Mallory's cancer relapsed earlier this year, it was her young adult cancer community that she leaned on most of all for support and understanding. They were the ones who 'got it' when the rest of her cancer muggle friends could not. For Nick, as a sibling of a brother with cancer, he has always received emotional support from those in the AYA cancer community. Whether it is himself or others that need support, this community is always there to help lift each other up. If you don't remember anything else from all of the talks and panels at YA Cancer Gabfest, take a new friend home with you.

Thank you to our supporters and sponsors, we could not have done it without you. And thank you to each and every attendee for being here. This event would be nothing without you.

Much love,

Mallory & Nick

MALLORY CASPERSON, CEO AND FOUNDER, CACTUS CANCER SOCIETY

NICK GIALLOURAKIS, EXECUTIVE DIRECTOR, STEVEN G. CANCER FOUNDATION + ELEPHANTS AND TEA

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Conversation

Wellness

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Sexuality

Caregiving

Healthcare and Nonprofit Professionals

CACTUS CANCER SOCIETY
formerly Lacuna Loft

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DID YOU REGISTER FOR YA CANCER GABFEST YET?

YA Cancer Gabfest

PRESENTED BY
ELEPHANTS AND TEA
CACTUS CANCER SOCIETY
formerly Lacuna Loft

A WEEK OF INTERACTIVE SURVIVORSHIP CRASH COURSES FOR FACING CANCER

COME SPILL TEA WITH US NO MATTER WHERE YOU ARE

WHEN: The Week of December 6th, 2021 at 7:30pm ET
COST: Free
WHO SHOULD ATTEND? The Young Adult Cancer Community

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REFLECTING ON GABFEST

BY RACHEL MIHALKO

I grabbed my notebook and laptop and wrapped myself up in a cozy cardigan sweater, a homemade hot chocolate in one hand and a pen in the other. It was early December 2020, and I had just finished finals week in college for the second to last time. After a grueling week of studying and projects, I was ready to decompress, and Gabfest was perfect timing for that.

When I first heard the concept for Gabfest, I was working as a summer intern for Elephants and Tea. I was very new to the world of AYA cancer support, and I was itching to connect with as many people within the community as I could. I began attending the Zoom planning meetings for Gabfest and spent two and a half months working with the team.

After my internship ended, I went back to school in the fall to complete my senior year of college. My internship gave me a glimpse into the world of nonprofit work and an idea of what life after graduation would look like, which made returning to school that much more difficult. While I've always enjoyed school, applying what I've studied to the real world had a new, shiny appeal after experiencing it for myself. It was much more exciting than sitting in a dimly lit classroom designing advertising campaigns that would never see the light of day; instead, this work with Elephants and Tea and our friends at Cactus Cancer Society would actually result in something. Something like Gabfest.

Curled up in front of my laptop in my room, I got to experience the event as a participant: one who had seen part of the planning process. However, there was still an air of mystery to the event; I had a sneak peek, but there was still so much to discover that I wasn't aware of.

Throughout the week, in order to absorb as much of it as I could, I took notes at some of my favorite sessions and later turned those notes into art journal spreads. I collaged quotes and imagery that corresponded with each theme of the day, with one spread per day. I can still picture the spreads now, even though I haven't looked at them in a while. Adding that visual medium made the experience that much more memorable and gave me something to look back at to remind myself of what a wonderful week it was.

It was incredible to see the bits and pieces that I helped with come to life, in addition to the work the team did once my internship ended, and I have my journal to remind me of what a wonderful thing Gabfest is. And now, as a full-time employee at Elephants and Tea, I get to be a part of the entire process. I can't wait for everyone to experience Gabfest 2021. So grab your laptop, and I hope you too can get cozy for the lovely week that awaits you. ●

GABFEST, HERE WE COME!

BY AERIAL DONOVAN

My favorite part of my job as Chief Program Officer at Cactus Cancer Society is that I get to be innovative for our community of young adults facing cancer. I really enjoy throwing ideas at the wall and seeing what sticks. We're in our second year of Gabfest and things are feeling pretty sticky over here. We've got an exciting week planned, with everything from writing workshops, to an art workshop, to amazing speakers, both seasoned and new to the space. We start planning at the beginning of the year after we've had a chance to catch our breath after the holidays. We think through A LOT of proposals, like whether we can get an improv class to work over Zoom or how in the world are we going to play trivia when we're all located in different places? It is so much fun working through different scenarios so that we can bring the most informative, fun, interesting, inspiring material to the young adult cancer community. The best part, whether you're joining from your couch, a socially distanced coffee shop, or even a hospital bed, is that your experience will be the same as your fellow attendees joining from rural Manitoba to urban Chicago.

Use this week to learn from the experiences of those speaking and break out of your shell to connect with your fellow attendees. Easier said than done, I know. I am super awkward at being the first person to walk up to someone and introduce myself. Usually, I'm wondering if I remembered to check a mirror to make sure I didn't have anything stuck in my teeth or I practice saying their name over and over in my head to make sure I think I've got the pronunciation down if they've got a name tag on. The best part about joining from your computer or smartphone app is that Zoom takes some of that social awkwardness away. You don't have to worry about things being stuck in your teeth (selfie camera mode makes a great mirror) and the chat function means there's no stuttering or mispronouncing if someone says something interesting that you'd like to comment on! So, step out of your comfort zone. Introduce yourself to that survivor who went out on a limb and shared about how they've had a hard time getting back into an exercise routine because of their neuropathy when you can relate as well. I promise that you'll get as much as you put into Gabfest, and if you're willing to be vulnerable on some level, you'll be surprised at the results.

One of the guest faculty that's part of our team at Cactus Cancer Society, Jean Rowe*, often says to our participants that *you never know who in the room needs to hear what you have to say.* I don't believe anything could be more true. So come to Gabfest, listen, share, and introduce yourself knowing you don't have to stress about the spinach you had for lunch being in your teeth. I hope you have a fun and impactful week at Gabfest.

Thanks, Gabsters, for being such a fun community to plan for. ●

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*JEAN ROWE IS AN LCSW WHO IS NOT ONLY PRESENTING THIS WEEK AT GABFEST BUT FACILITATES JOURNALING WORKSHOPS AT CACTUS CANCER SOCIETY (FORMERLY LACUNA LOFT) YEAR-ROUND. ALL OF OUR PROGRAMS TAKE PLACE ONLINE, OVER ZOOM OR ON OUR WEBSITE, AND JUST LIKE GABFEST, YOU CAN JOIN FROM WHEREVER YOU ARE LOCATED. WE HAVE PROGRAMS COMING OUT OF OUR EARS, AND THEY'RE CONSTANTLY CHANGING. CHECK THEM OUT AT CACTUSCANCER.ORG!

HOW CANCER SHAPED MY STORY

BY LAUREN CREEL, MSW, MPH

Did you have Career Day in elementary school where you were supposed to dress up as what you want to be when you grow up? We had Career Day every single year. The problem was, I never had any clue what I wanted to be! I went as everything under the sun, from a veterinarian to a teacher to the president of the United States. I didn't know what I wanted to be when I grew up; I only knew that I wanted to help people in some way. So, you probably won't be surprised to hear that I changed my major three times in college. I started as an engineering major and ended up with a degree in sociology, which taught me about all the world's problems: poverty, racism, homelessness, hunger, mental illness, immigration, crime, globalization, gender disparities, and so much more. There were so many issues in our world and so many areas that needed help. My problem was choosing one that I was really passionate about.

After graduating college, I decided to do a one-year volunteer program living and working in a low-income neighborhood of Atlanta, Georgia. I was hoping the experience would expose me to a multitude of social issues so that I could find my passion, the thing that pulled at my heart-strings the most. Well, my time in Atlanta did half of that. I was indeed exposed to many issues, but as I learned more about each one, I started to see how interconnected all of these problems were. Instead of finding one passion to focus on, I realized that you can't solve issues of crime without solving homelessness. You can't solve homelessness without solving poverty. You can't solve poverty without solving mental illness. But poverty and mental illness feed into problems with the educational system as well. Every issue was deeply intertwined with all the rest. Instead of ending that year with clarity, I was even more confused and overwhelmed than before.

So, on to graduate school, I thought! I applied and was accepted into a Master's of Peace and Justice Studies program. Maybe that will give me more clarity, I thought. But then…

But then came the part of my story that may be all too similar to yours. I fell ill and was eventually diagnosed with Hodgkin lymphoma. Grad school would have to wait. I left Atlanta and moved back to California to live with my parents while I underwent four months of chemotherapy.

One day while sitting in the waiting room at the cancer center, a man walked in and sat down across from me. He looked emaciated in his ripped-up jeans and oversized, stained white t-shirt. He scrambled to put his bus pass away in the pocket of his tattered black backpack. At that moment, it hit me – cancer doesn't discriminate. Cancer is a hardship that falls on rich and poor alike. Cancer doesn't care if you're homeless or live in a mansion. Cancer doesn't care if you're Black or white or Asian. Cancer doesn't care if you have a college degree or didn't finish middle school. Cancer doesn't care if you have a mental illness. And cancer doesn't care if you're in your 80s or if you're only 23 years old, like I was. It was at that moment that I decided what I wanted to do when I "grew up." I wanted to get through cancer and then help others get through it as well.

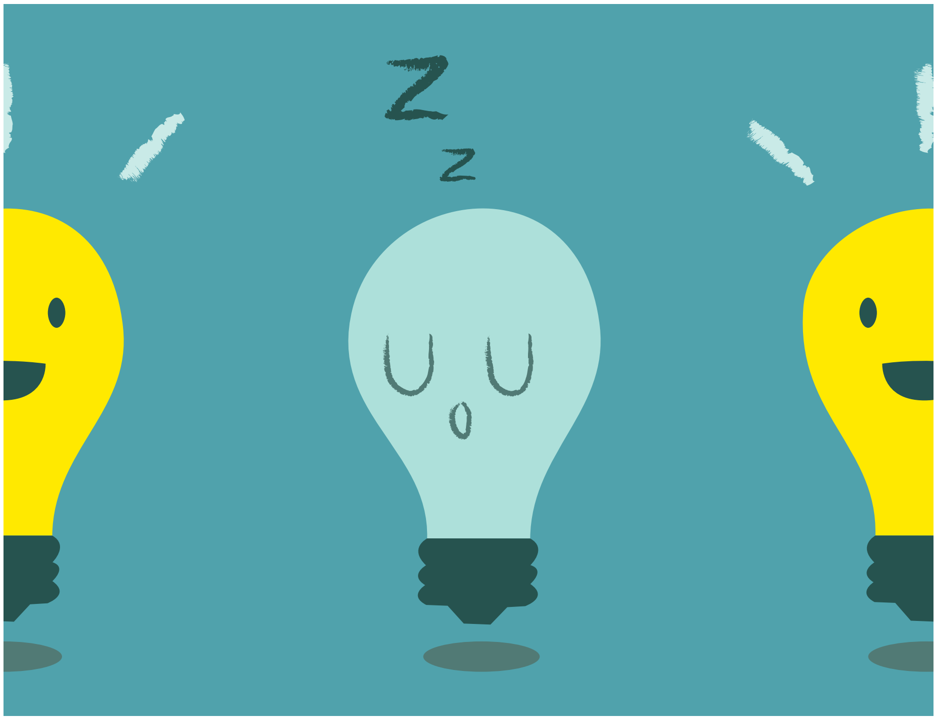
After treatment, I did end up going to grad school, but for a Master's in Social Work and a Master's in Public Health instead. I used every project and paper as an opportunity to focus on issues related to cancer patients and survivors and how to make life a little better for them. I personally struggled with the fear that my cancer would come back, so I did a few projects on fear of recurrence, even writing my thesis about it. I spent a year as an intern at the cancer center where I was treated, designing a program dedicated to young adult patients facing cancer. After graduation, I was hired to help build a survivorship program at a large cancer center near Los Angeles. And now, more than nine years after my cancer diagnosis, I'm excited to be the newest member of the Cactus Cancer Society team!

Sometimes it's the unexpected things in life that shape us the most. Cancer sucks, and I'm not going to say it was a blessing, but I wouldn't be the person I am today if it weren't for having had cancer. It has led me down a path that I wouldn't have chosen for myself. I am so grateful that I have ended up here, doing something that allows me to use my terrible cancer experience for good. Cancer enabled me to find a whole new community – not just one to serve as a social worker, but one that I am passionate about because I am also a part of this community.

Each of us has a choice of how our cancer experience will shape our lives. I love the quote, "the difference between an adventure and an ordeal is your attitude," and I think this is true of our cancer experience. Even though cancer is painful and difficult, I want to encourage you not to let the darkest parts of your cancer experience be the only things you hold on to. And I know that can be hard, but that's exactly why we're building programs and events like YA Cancer Gabfest that can help you find the support you need. I don't know where you are in your cancer journey. Maybe you're just trying to get through another day, and that's okay! Keep going! But if you're feeling like I was and wondering what comes next, have you thought about how your cancer experience uniquely positions you to help someone else in your community? Give it some thought and see if you might be able to use your cancer experience, however terrible it might have been, to help someone else. ●

The Health Benefits of Unmindfulness

BY DAVID VICTORSON, PhD



Before you get too excited by the title and think that I'm going to be bashing mindfulness in some way, this is actually not that kind of essay. Sorry. Sure, there's an insane pop-culture-propagated feeding frenzy of daily mindfulness clickbait claims that this ancient Buddhist practice is beneficial for just about anything and everything related to your health and wellbeing in some new way. As if having lower stress, improved mood, a more fulfilled sex life, better communication with your partner, a more meaningful professional life, a stronger immune system, greater attentional focus, and more gratitude and compassion toward yourself and others weren't enough.

Adding insult to this evidence-based laundry list is the gross and ubiquitous commercial appropriation of everything mindfulness in marketing and product placement. Did you know you can eat a mindful burger? Get your dog bathed at a mindful doggie daycare? Drink a mindful microbrew, martini, or cup of coffee? Eat a mindful nut (pistachios)? Knit with mindful yarn? Apply mindful makeup? Paint your wall the color mindful grey? If you don't believe me, check out my personal collection of commercially appropriated mindfulness products and send me any that you find along the way: https://www.consciousnessinhealth.org/commercially-appropriated.html.

For those who are students, teachers, and researchers of this ancient practice, all of this hype, embellishment, and over-selling can be a little much at times. We try to set the record straight and keep it real when we can – that while beneficial to our health and wellbeing in many ways, these benefits aren't really that different in type and magnitude than the benefits of other known health behaviors, like getting enough z's, steps, staying hydrated, or increasing our intake of green leafy veggies. And that this comparison to these other powerhouse health behaviors alone is to be celebrated and extremely cool, because sleep, movement, hydration, and whole foods are massively good for us. That's why it's always kind of weird whenever I encounter people who are almost giddy when they defensively (or aggressively) tell me they've heard or read something not so rosy about mindfulness, almost sending a vibe like, "*AHAH! See! Told you so! Take your quiet, noticing, in-breathing, awareness-proselytizing self and sit with THAT!*" There's probably some hyperbole in that last statement, but that's how it can feel sometimes, and I always wonder…*why*? Maybe it's the same for diet and exercise researchers. Maybe the cognitive dissonance is just too great when we're constantly being told what is good for us, making us "should" all over ourselves, and struggling daily to actually do any of it with any semblance of consistency. This in turn perpetuates a "feel bad about myself" health behavior feedback loop of "*I should – I want to – but I just can't seem to*", along with all of the accompanying head trash. What if being *unmindful* was actually the answer to all of this? Wait…*what*?

As someone whose research career has focused on studying the value of getting off of autopilot every now and then and instead being intentional with where our awareness is directed (present moment experiences), and more importantly, with *how* it is directed (with curiosity, openness, acceptance, and self-compassion), it is all too ironic that one of the best ways to actually engage in this health behavior with any regularity is to be unmindful about it and to just autopilot it. The same is true with exercise, diet, flossing, hydrating, and getting enough sleep.

I often say that starting any new positive health behavior can be as difficult as quitting any long-standing negative one. We know that starting a new health behavior like meditating or eating differently requires more than just knowledge or good intentions but rather happens when we transform a goal or a wish into an unthinking, unfeeling, un-deciding automatic habit that just takes over because we've re-programmed ourselves to let it do the *hard* work for us. "Habitizing" our intentions and goals requires unmindfulness because paying attention to them is the last thing we want to do. Once it goes from automated to deliberative, the health behavior can be doomed by a slew of negative thoughts and feelings about it, rationalizations and justifications for not doing it now, self-negotiating tactics about doing it at a later time, feeling unmotivated, being too busy, etc.

"It is all too ironic that one of the best ways to actually engage in this health behavior with any regularity is to be unmindful about it and to just autopilot it."

So that we're on the same page, let's just take a moment to clarify some of the similarities and differences between goals, habits, and new identities that emerge from habitizing one's life. A goal is an aim or an objective – something like "be more mindful to the moments of my life." A habit is a practice or a custom that leads to the goal happening, something like "practice meditating three times a week." A new identity is when how we begin to see ourselves changes because of these goals and habits, something like "I'm a meditator." While you might check a completed goal off of your list at some point, healthy habits and new identities, once they are formed, can be around for the rest of your life so you'll never have to put that goal back on the list again.

Let's go over habits a little more. What habits do you have, both positive or negative? How do some of your habits support your health and wellbeing? Do you have any habits that aren't so healthy or supportive? Some people bite their fingernails or grind their teeth at night, and their dentists would say those aren't great habits for strong teeth and gums. Other people brush and floss their teeth every day without exception, habits that same dentist would applaud. By definition, a habit is a natural tendency or usual manner of doing something.

You might wonder, how do habits form? Well, science tells us that all habits have four main components. The first component is a Cue, which leads to the second component: a Craving. This in turn leads to the third component: a Response, and this leads to the fourth component: a Reward. So that's: 1) Cue, 2) Craving, 3) Response, and 4) Reward.

You might be wondering how these components translate to healthy lifestyles and behaviors. One real life example is the habit of brushing our teeth, something we all do at least twice a day (I hope). Let's apply Cue, Craving, Response, and Reward to this example. An obvious cue for some of us might be having bad morning breath, which then leads to an attractive craving to have a clean and refreshing taste and feeling inside of our mouths. An easy response that requires very little effort is to put some toothpaste on our toothbrush and brush our teeth for about two minutes. Finally, a satisfying reward from all of this is that squeaky clean, smooth, minty fresh experience we all get when we're done.

The bestselling book "Atomic Habits" by author James Clear states that habits are not that different from a financial investment that earns interest – both can grow incrementally over time. If you're a finances person, you might be familiar with compound interest, which is when you earn interest on both the money you invested or saved (called the principle) as well as the interest that you earn. Habits are like the compound interest of self-improvement. They incrementally build upon our daily accomplishments one day at a time.

For example, if we decided to begin a new walking habit on January 1st, we might start with 250 steps on the first day. That's a quarter of a mile. Then we'd increase this by 1% every day that follows for a certain period of time. By the end of the first week, you would walk 265 steps in one day. If you kept increasing your steps by just 1% each day throughout the rest of the month, by January 31st you would walk 340 steps in one day, 90 steps more than you took when you started. Now suppose you kept this pattern going. By the middle of the year on June 30th, you would be walking 1,514 steps in one day, which is three quarters of a mile, and by the end of the year on December 31st, that number would be up to 9,446 steps in just one day. That's about four and three quarter's miles. If we think about building onto our habits by as little as 1% each day, you can go from walking just a couple blocks to walking close to five miles in one day.

This last example shows us how tiny, incremental changes can make a huge difference. But the improvement we experience may not always be in line with our expectations. When we start a new healthy habit, most of us hope and expect to start seeing results right away, in a positive, linear direction. But in real life, we know that progress can be much slower in the beginning, because we're building the foundations of the habit. Only seeing meager results can be frustrating at best. In fact, this early period is often referred to as the valley of disappointment because change isn't happening as fast as we'd like. But if we stick with it, at a certain point, progress begins to take off and go well beyond our expectations.

Going back to our example of starting a walking habit, this means that early on, and even at the halfway point, we'll probably not experience the big improvements we had hoped. We just have to remind ourselves to keep at it, as around the three-quarters mark our experiences and our hopes finally begin to align. After this point, we may start to notice that our improvements happen substantially faster. Of course, habit deterioration works the same way, but in reverse. If your habit experienced a compound interest reduction of -1%, by the end of the year, you would be down to six steps in one day. The take home is this – tiny, incremental changes can make a huge difference. We just need a little patience and perseverance to help us get to the progress.

Because tiny, incremental changes can make a huge difference, we can afford to start small. In the beginning, we want to start with what's called a gateway habit, which is something so easy that you barely notice the effort. Like meditating for 30 seconds or even one minute. We then build that gateway habit all the way up in baby steps until we reach a level that would have probably sounded very difficult in the beginning. Starting with 250 steps probably sounds a lot more doable than starting with 9,446 steps.

So just remember, while mindfulness can definitely have its health benefits, it's really being *unmindful* that is at the root of our long-standing, regularly occurring health behaviors. Unmindfulness is essential to reprogramming and habitizing our goals so that they can do the real hard work for us. ●

Stress Relief and Release through Yoga

YOGA TOOLS THAT RELEASE STRESS

BY TARA O'DONOGHUE

These days stress and anxiety float around so abundantly that it can feel palpable and even contagious! Everyday challenges coupled with cancer make it even more difficult to stay afloat in stressful seas. Whether at a doctor's appointment, awaiting a scan, enduring physical stress of treatment, or returning to a new normal after treatment is over, it may feel like a life vest is needed.

Once upon a time, I kept stress, grief, and trauma bottled-up inside. Some days I felt numb and was just going through the motions. Other days it was quite the contrast, like my top was about to pop! This went on for a while when caregiving for my husband who eventually passed from cancer. I was overwhelmed by the toll his cancer journey took on both of us and was also faced with profound grief of losing my partner of 16 years. The cloudy lens through which I viewed life made it difficult to see clearly, feel fully, or sense the stress within that I desperately needed to release. It was during this time that I began practicing yoga therapeutically, which helped me connect with my body, mind and soul. Now I feel passionately about teaching yoga in ways that make it feel accessible, efficient, and transformative.

For Gabfest this year I am bringing some yoga tools to the table that can help release stored stress. I will be co-teaching a workshop with Cactus Cancer Society called Release, Relax, Rewire. Together we will "Release" whatever feels stuck through yoga therapy, "Relax" while learning about mindfulness, and finally "Rewire" with a creative zentangle activity.

Contrary to popular belief, stress itself isn't bad. It's how we react to stress that can be harmful. Stress can also be helpful. Think about the last time you had a deadline for work or were playing a competitive game and how that perhaps motivated a focused response. The sympathetic nervous system becomes activated in response to everyday stress and with more intense challenges, such as a life-threatening diagnosis or intense cancer treatments. Sometimes stress can give us the push we need to succeed, or it can feel like too much and it's time to put on the brakes. It's important to know when to slow down and activate the parasympathetic nervous system, which initiates "rest and digest."

There are many ways to release stress, and you may already have some helpful ways to do so. Yoga is a way to practice mindfulness and also provides various tools to cope with stress by connecting to body and breath. Mindfulness involves noticing how we feel, think, and respond throughout the day. It's a practice of tuning-in rather than tuning-out. Sometimes we may realize we don't feel quite ideal, and that's okay! We all notice ups and downs and must deal with the downs to appreciate the ups. No judgement or criticism necessary. The good news is that we can learn to release emotions and stress that feels stuck if we can first identify that it's happening. Cultivating mindfulness can lead to more conscious control over how we handle difficult situations in life.

Through my personal experience, yoga has become the number one way for me to release whatever stress feels stuck. Yoga can be something that is done by anyone, anytime and anywhere. All you really need is yourself. A yoga mat is not even needed because it's not necessary to bend into pretzel-like poses in order to feel a sense of relief. Whether you're at home, work, a doctor's office, or in between, there are short, simple ways to stop, drop, and yoga when you feel the need to release the pressure valve.

For the Gabfest workshop, I will have 15 efficient minutes to share three simple ways to release stress. It is my intent that the practices I teach can be available anytime, anywhere. So when you're at the doctor's office and feeling scanxiety or about to start treatment, you can drop in and experience a sense of relief through release. One tool is a Mindful Check-in that involves briefly meditating while tuning into body, breath, mind, and intention. I will also teach a simple breathing practice I call "2 Minutes to Peace." A third way to release stress is "Shake and Stack," which lets the stress response out so we can come back into a more mindful, peaceful presence.

There is great strength in vulnerability. The first step is acknowledging when we feel pent up stress, grief, or trauma. Once we are mindful, we can do something about it and perhaps practice a positive response to stress through yoga. This is simply an invitation to take some stress relieving tools on a test-drive during the Release, Relax, Rewire workshop because yoga is best when experienced. Join us for Gabfest 2021 where releasing stress will be fun! ●

Session Summary: It's no secret that life is stressful and a cancer diagnosis makes it even more stressful! Yoga is one of many ways to release stress, process grief, and tune into trauma. The best part is yoga can be practiced by anyone, anytime, anywhere! During our time together I will show you three effective tools that can help you release stress that feels stuck.

YOUNG ADULTS AND CANCER

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Three Benefits of Exercise After a Cancer Diagnosis

BY JAY CARTER

While sometimes necessary to increase chances of survival, cancer treatment can often leave patients with a body composition that is drastically different from their pre-cancer days. I found myself in this situation after completing eight rounds of chemo and a stem cell transplant for a diagnosis of Chronic Myeloid Leukemia. While treatment was successful, I found myself 70 pounds overweight, and with a body that could not move as gracefully as once before. As a former athlete with a background in kinesiology, I knew how to work out and get in shape as a healthy young adult. I did not, however, know how to work out as a cancer survivor. Quickly, I discovered that there is a difference. As I began my journey to get back into shape after treatment, I drew upon prior knowledge to design workout programs. These workouts did not take my survivorship into consideration, and as such, I did more harm than good to my body. I often experienced fatigue, dehydration, and an unusual amount of soreness. I was even hospitalized twice with rhabdomyolysis. Clearly, I had no idea how to work out as a cancer survivor.

Luckily, I heard about a study designed to help cancer survivors safely increase their physical activity over time to promote health, wellness, and overall well being. UNC's IMPACT Study was exactly what I needed to achieve my health goals after treatment. Over the course of the year-long program, I lost 40+ pounds, I learned how to safely exercise as a young adult cancer survivor, and I learned how to maintain my weight and physical activity levels. While I joined the study to learn how to exercise as a cancer survivor, the study also taught me reasons why exercise is important for cancer survivors. These reasons are so powerful that to this day, they are what keep me motivated during my daily workouts. So without further ado, I present my top three benefits of exercise after a cancer diagnosis.

> *As a former athlete with a background in kinesiology, I knew how to work out and get in shape as a healthy young adult. I did not, however, know how to work out as a cancer survivor. Quickly, I discovered that there is a difference.*

1. EXERCISE CAN REDUCE ANXIETY AND DEPRESSION

Having been active in the young adult cancer community for the past seven years, I've had the opportunity to meet and chat with YA survivors from various parts of the country. I have yet to meet one whose mental health has not been impacted negatively by their cancer diagnosis, or side effects from treatment. This is a huge problem in the community. Luckily, a growing body of literature is showing that regular exercise can reduce anxiety and depression for cancer survivors.

2. EXERCISE CAN LOWER THE RISK OF RECURRENCE AND CAN LEAD TO LONGER SURVIVAL

Several studies have found that exercise could lower the risk of cancer recurrence and improve mortality, exercise capacity, physical and cardiovascular function, strength, and quality of life in patients with cancer. For me, this benefit is closely intertwined with the benefit exercise has of reducing anxiety. Recent advances in medical technology have many YA cancer survivors outliving diagnoses that would have caused death previously.

While prolonged life is great news, we are now left with a population of young adult survivors who have had their lives upended by cancer and are expected to resume normal life once treatment is complete. To borrow a line from Stupid Cancer's Manifesto, doctors are essentially teling us, "You're cured. Go home!" But, we all know that is not the end of the story. How do you just go home and pretend everything is normal after experiencing such trauma? Spoiler alert: you don't! Post treatment, the main contributing factor of my anxiety was the fear of relapse. It is a hopeless feeling of impending doom. Exercise was one of the tools I used to manage and eventually reduce this anxiety. And knowing that exercise can lower the risk of recurrence and lead to longer survival caused me to be more determined than ever to ensure I always get in some sort of daily physical activity. I find inner peace when I exercise because for me, exercise is life.

3. EXERCISE CAN IMPROVE SLEEP QUALITY

Anyone who has experienced the joys of inpatient cancer treatment knows the havoc it can wreck on your sleeping schedule. From the constant flow of nurses in and out of the room for lab draws at ungodly hours of the night, to early morning chats with the doctor, to the nonstop beeps of the machines, to the steroids that keep you up all night, getting a solid six hours of sleep is impossible. Being awake all night and alone in a hospital bed with nothing but your thoughts is a lonely place to be.

For me, the insomnia continued post treatment. Being immunocompromised and more susceptible to infection, I frequently found myself taking steroids for severe respiratory infections. Although I was in the peace and quiet of my home, the results were the same – I spent many nights awake all night with a random show on Netflix playing in the background as I tried to fall asleep. If I was lucky enough to fall asleep, I would often wake up suddenly an hour later to a panic attack. The sleeping pills prescribed by my doctor were of no use. The one thing that did provide relief to the insomnia was physical activity during the day. I found that on days where I worked out, I just slept better. Many studies are finding the same. One study in particular found that patients who exercise reported significant improvements in sleep quality and the mental health dimension of quality of life. ●

References

Craft LL, Vaniterson EH, Helenowski IB, Rademaker AW, Courneya KS. Exercise effects on depressive symptoms in cancer survivors: a systematic review and meta-analysis. Cancer Epidemiol Biomarkers Prev. 2012;21(1):3-19. doi:10.1158/1055-9965.EPI-11-0634

Morishita S, Hamaue Y, Fukushima T, Tanaka T, Fu JB, Nakano J. Effect of Exercise on Mortality and Recurrence in Patients With Cancer: A Systematic Review and Meta-Analysis. Integr Cancer Ther. 2020;19:1534735420917462. doi:10.1177/1534735420917462

Stout NL, Baima J, Swisher AK, Winters-Stone KM, Welsh J. A systematic review of Exercise systematic reviews in the Cancer literature (2005-2017). PM&R. 2017;9. doi:10.1016/j.pmrj.2017.07.074

Tang, MF., Liou, TH. & Lin, CC. Improving sleep quality for cancer patients: benefits of a home-based exercise intervention. Support Care Cancer 18, 1329–1339 (2010). https://doi.org/10.1007/s00520-009-0757-5

The impact of cancer can be felt across various aspects of a survivor's life. From weight fluctuations, to mental health issues, to lack of sleep, cancer is the gift that keeps giving long after treatment is complete. While there are many interventions to treat these issues, the one I have found to be most useful is at least 30 minutes of daily, moderately vigorous exercise. You may be compelled to start a workout program of your own after reading this, but have no idea how to get started. If that is the case, I've compiled a list of tips below on how to get started on your fitness journey as a cancer survivor.

- Consult with your doctor before beginning any program
- Find a trainer that has experience working with the cancer patient population
- Set goals
- Use a fitness tracker to track your progress
- Find what works best for you
- Utilize fitness programs designed specifically for cancer survivors, like Livestrong at the Y
- Remember to have fun!

YA Cancer Gabfest 2021 Agenda

EACH DAY STARTS AT 4:30PM PT / 6:30PM CT / 7:30PM ET

MONDAY, DECEMBER 6, 2021 - STORYTELLING

12:00 pm ET

Scavenger Hunt Begins

Join your fellow Gabsters in a scavenger hunt! No matter where you call home, you can join this completely online scavenger hunt through the free app, Goosechase. The game name is "Gabfest Scavenger Hunt" and the password is "Gabster."

5:30 - 7:00pm ET

Pre-Gabfest Workshop: Advocating, Validating, Empowering: Cornerstones of Survivorship

Sponsored By: The Leukemia & Lymphoma Society

Moderator: Elissa Baldwin

Panelists: Michelle Rajotte and Kelly Laschinger

Join The Leukemia & Lymphoma Society as they explore various challenges of survivorship – mental health, body image, planning for the future, and more. In this interactive webinar, we will discuss strategies and tools to help you learn how to advocate and empower yourself and validate your cancer experience. Survivors of all cancers at any stage of their journey are welcome.

7:30 - 8:20pm ET

Opening Keynote: Your Voice, Your Story, Your Way!

◀ **Speaker:** Yolanda Murphy

Life has a way of knocking you down and making you either face reality or run from it. Join our opening keynote speaker Yolanda Murphy as she opens up about facing cancer head on and using her voice to help those of us who feel they have no voice!

8:30 - 9:20pm ET

Healing Through Writing: A Virtual Workshop

Speaker: Nick Giallourakis and Lisa Orr

Writing and journaling can be helpful strategies towards healing and communicating with others about difficult experiences. Join this interactive session to practice some writing of your own and learn about creative writing prompts with Elephants and Tea and Cactus Cancer Society.

9:30 - 10:30pm ET

After Hours: Emerging Voices

Come hear from new speakers to the AYA community as they share their stories with their fellow Gabsters.

TUESDAY, DECEMBER 7, 2021 - WELLNESS

7:30 - 8:20pm ET

Interactive Panel: Exercise After a Cancer Diagnosis

◀ **Moderator:** Jay Carter

Panelists: Cary Kim, Rachel Walker, and Beau Whitman

Exercise can play a vital role in overall health and well being. After a cancer diagnosis, one can find many lifelong benefits of regularly engaging in physical activity. In this panel, we will discuss the benefits of exercise after a cancer diagnosis, and discuss ways to get started.

8:30 - 9:20pm ET

Crash Course: Release, Relax, Rewire

Speakers: Tara O'Donoghue, Aerial Donovan, and David Victorson, PhD

Join a crash course designed to help you release, relax, and rewire through young adult cancer. We'll be joined by experts, sharing their knowledge on being 'unmindful', building your own yoga practice, and relaxing through zentangles.

9:30 - 10:30pm ET

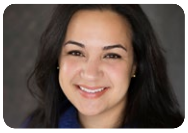
After Hours: Cooking Demo

Speaker: Steven Giallourakis

Steven will be cooking up something delicious and you can follow along with him virtually.

WEDNESDAY, DECEMBER 8, 2021 - HEALTH INSURANCE

7:30 - 8:20pm ET



Health Insurance Doesn't Have to be Confusing

◀ **Speaker:** Monica Bryant, Esq.

Trying to figure out how to pick a health insurance plan that actually covers your medical expenses? This session will explain your health insurance options, current laws regarding pre-existing conditions and other consumer protections, how to pick a plan that works for you, and how to get financial assistance to help you pay for health insurance.

Please note: Agenda is subject to change

8:30 - 9:20pm ET

Health Insurance Workshop

Sponsored by: Bristol Myers Squibb

Speaker: Monica Bryant, Esq.

Now that you have the tools to understand our health insurance options, its time to put what you've learned into practice. This workshop will provide hands on practice for picking the right health insurance policy for you.

9:30 - 10:30pm ET

After Hours: Cancer Cards

Come use these fun conversation starters as a way to hear from other Gabsters and share your own story. The Cancer Cards were developed by Hopelab and Stanford University.

THURSDAY, DECEMBER 9, 2021 - SEX

7:30 - 8:20pm ET

Crash Course: My Sexual Self

◀ **Speaker:** Sage Bolte, PhD, LCSW, CST

My Sexual Self: Join us for a casual and interactive discussion with Dr. Sage Bolte, certified sex therapist, to explore the many ways a cancer diagnosis and treatments can impact the various aspects of our sexual selves. From body image to dating and disclosure. From sex to emotional intimacy. Nothing is off limits as we discover together ways to help improve the ways we feel and think about our sexual bodies and intimate relationships. Come prepared with questions – this discussion promises to be a safe place to explore some of the most challenging issues young adult survivors face.

8:30 - 9:20pm ET

Interactive Panel: Relationships and Intimacy in Survivorland: A Fireside Chat

◀ **Moderator:** Marloe Esch, BSN, RN, OCN, CSC

Panelists: Mary Clare Bietila, Stephen Heaviside, and Brandie Sellers, MS, LPC, NCC

Join Oncology Certified Nurse and AYA cancer survivor Marloe Esch for a lively panel discussion exploring the challenges and triumphs of navigating relationships and intimacy after a cancer diagnosis. Marloe will be joined by Brandie Sellers, an AYA cancer survivor, licensed professional counselor, and founder/owner of Mind Your Heart Counseling, and fellow AYA survivors Stephen Heaviside and Mary-Clare Bietila. Panelists will share their experiences and advice on topics such as dating and relationships, body changes, and those pesky sexual side effects from various cancer treatments. Bring your questions and a cup of cocoa, and get ready to cozy up for an honestly sexy conversation!

9:30 - 10:30pm ET

After Hours: Trivia

Come and join your fellow Gabsters as we enjoy each others' company with some trivia.

THURSDAY, DECEMBER 9, 2021 - HEALTHCARE + NONPROFIT PROFESSIONALS

7:30 - 8:20pm ET

Crash Course: Hello? This is Your Life Calling! Targeted Journal Therapy for Inviting Self-Care Back into That Already Jam-Packed Schedule.

◀ **Speaker:** Jean Rowe, LCSW, OSW-C, CJT

Making up stories that you don't have time to take care of yourself? Choosing email and returning phone calls over a 10 minute walk around the block? Chugging down gallons of caffeine while your water bottle becomes a decoration? Join this session to learn how even one small step can make a big difference in feeling better.

8:30 - 9:20pm ET

Interactive Panel: Burnout as a Cancer Professional

◀ **Moderator:** Diana Cejas, MD, MPH

Panelists: Liz Harms, DNP, RN, CMSRN, Kara Noskoff, and Stephanie Scoletti, MSW

Being a healthcare provider or a nonprofit professional in the young adult cancer world is challenging. Burnout can show its self in many ways and affects the ways we live and work. This panel, made up of healthcare providers and nonprofit professionals, will tackle burnout, its challenges, and the ways that they over come it in their everyday lives as professionals.

9:30 - 10:30pm ET

After Hours: Trivia

Come and join your fellow Gabsters as we enjoy each others' company with some trivia.

Please note: Agenda is subject to change

YA Cancer Gabfest 2021 Agenda

EACH DAY STARTS AT 4:30PM PT / 6:30PM CT / 7:30PM ET

THURSDAY, DECEMBER 9, 2021 - CAREGIVERS

7:30 - 8:20pm ET

Crash Course: Caregiver Self-Preservation

Sponsored By: Servier Pharmaceuticals

◀ **Speaker:** Sharla Moore, MPH, and Ellen Polamero, LCSW

If you are a caregiver, you have undoubtedly heard more than one person remind you to "make sure you take care of yourself, too!" But wait, before you write this off as just another caregiver session, we'd like to invite you to join us for a real conversation about the impact of being a caregiver, what self-preservation might look like at different times and for different people, and how it might just be possible (and maybe even essential) to figure out how to address some of your own needs during this time. Bring your questions, your frustrations and your BS detector!

8:30 - 9:20pm ET

Interactive Panel Discussion: The Caregiver Toolkit

Sponsored By: Seagen

Moderator: Amelia Baffa, APRN, PMHNP-BC

Panelists: Vijay Anand, Angie Giallourakis, PhD, and Pat Taylor

Planning for the "what if" scenarios are extremely difficult. This panel has seen a lot and they will talk about what they have been through to help prepare you as best as possible for different scenarios as a caregiver. Join Amelia Baffa, a Pediatric Adolescent Young Adult Psychiatric Provider, as she leads a discussion with parents of AYA patients on lessons learned, boundaries with your loved one, and other important topics to have ready in your toolkit.

9:30 - 10:30pm ET

After Hours: Trivia

Come and join your fellow Gabsters as we enjoy each others' company with some trivia.

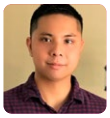
FRIDAY, DECEMBER 10, 2021 - USING YOUR VOICE

3:00am ET

Scavenger Hunt Ends

Join your fellow Gabsters in a scavenger hunt! No matter where you call home, you can join this completely online scavenger hunt through the free app, Goosechase.The game name is "Gabfest Scavenger Hunt" and the password is "Gabster"

7:30 - 8:20pm ET



Closing Keynote

◀ **Speakers:** Carlo and Wendy, Hosts of The Cancer Patient Podcast

Join the hosts of The Cancer Patient Podcast as they close out YA Cancer Gabfest with a live support group/live podcast! The audience will help shape this closing session so be sure to join and bring questions.

8:30 - 9:20pm ET

101 Tasks in 1,001 Days: A Goal Setting Workshop

◀ **Speaker:** Amanda Marsh

Do you like making lists? Do you like having goals to reach for? Join the 101 Tasks in 1,001 Days list making session! This workshop is designed to help you create a list of 101 tasks to complete over a period of 1,001 days. It'll be a fun session of goal setting and inspiration. This workshop is designed to help you create a list of 101 tasks to complete over a period of 1,001 days. You'll get examples on how a real list was structured and there will be time for some people to share some of their goals and to help get your creative juices flowing! Join us for a session of goal setting and inspiration! Enjoy a social setting and a fabulous motivational activity while hanging out with your young adult cancer peers!

9:30 - 10:30pm ET

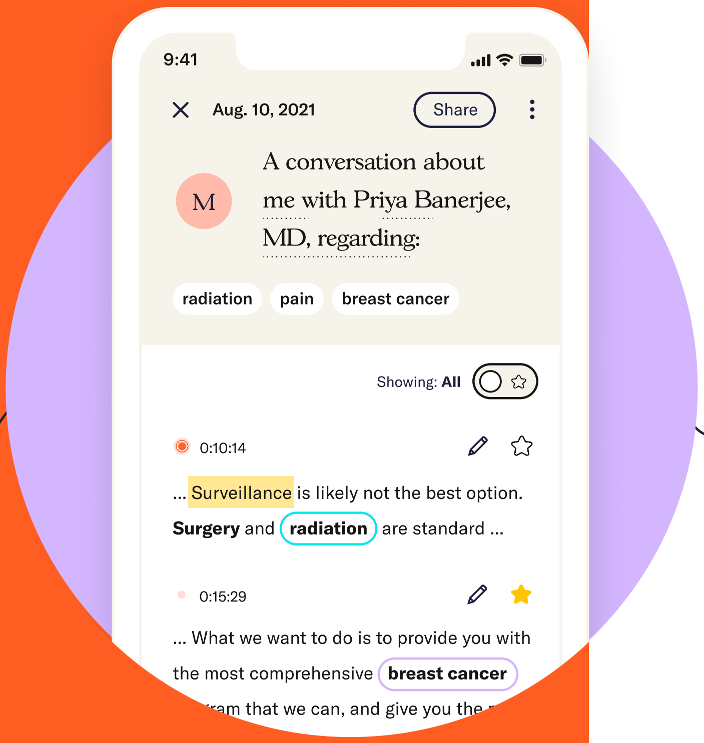
After Hours: Scavenger Hunt Wrap Up

Join your fellow Gabsters during the last activity of the week. We will be announcing the scavenger hunt winners as well!

Please note: Agenda is subject to change

abridge

Revisit your doctor's advice, anytime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Aug. 10, 2021

M

A conversation about me with Priya Banerjee, MD, regarding:

radiation pain breast cancer

Showing: All

0:10:14

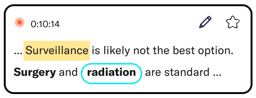
... Surveillance is likely not the best option. **Surgery** and **radiation** are standard ...

0:15:29

... What we want to do is to provide you with the most comprehensive **breast cancer** ram that we can, and give you the

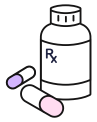
Abridge is a free app that securely records conversations with your doctor and transcribes the important details of your care.

1. **Review key moments**
   Revisit your medications, treatments, and follow ups.


0:10:14

... Surveillance is likely not the best option. **Surgery** and **radiation** are standard ...

2. **Stay on top of your medications**
   Add meds, dosages, and instructions, and view basics like how to safely take the medication.



3. **Share your conversation**
   Keep family and your care team on the same page.

Download on the App Store

GET IT ON Google Play

Abridgeapp.com/gabfest21

Cancer Rights Attorney

BY MONICA BRYANT, ESQ.

Adulting. It's the one class I wish I could have taken in high school. A prerequisite, if you will, to venturing out into the real world.

The curriculum would cover financial basics like credit scores, applying for and using credit, building savings, how to write a check (yeah, that's still a thing), how to pay for higher education, and so much more. Maybe this class could also cover things like how to address a business letter, format a resume, and negotiate a salary. **But the one thing it would unequivocally cover is health insurance.**

Studies show that health insurance status has a direct correlation to health outcomes. Yet, who is ever taught how to choose and use health insurance? Most of us are covered under a parent's plan, then, if we are lucky, our first employer will offer us coverage. But what if that doesn't happen? What options are there to purchase health insurance? How do you know what the right plan is for you? How do you afford it? Once you have the plan, how do you make sure that you are using the policy effectively? What if you are denied coverage? Who do you turn to if you have questions?

It can be a lot to navigate, and then you add in a cancer diagnosis.

This is why I chose to become a cancer rights attorney.

I know, you may be thinking, "A *what*-rights attorney?" It's a conversation I have had at professional networking events, in Ubers, at baseball games, and even in bars.

People have no idea what I mean and often follow up with, "Oh, do you sue doctors?" Absolutely not. I help people who are coping with cancer, and their caregivers, understand what their rights are.

The next question is typically, "But what is legal about cancer?"

The simple answer is, almost everything. When trying to navigate any serious medical diagnosis, treatment decisions, and how to maintain financial health, understanding the law is critical. The challenge is that most laws are convoluted and difficult to decipher.

I believe that people shouldn't need a law degree to access care, survive their diagnosis, or maintain financial health. So, I co-founded a non-profit called Triage Cancer. Our goal is not just to explain what the law says, but also to illustrate how the law can be used as a tool.

The Patient Protection and Affordable Care Act (aka Obamacare or the ACA) is over 1,000 pages long and filled with legal jargon. Normally, that wouldn't be an issue except that the ACA provides all of us, as consumers of healthcare, with some of the most important rights we have. Like the fact that insurance companies cannot charge someone more, or deny selling them a policy based on a pre-existing condition. Or that young adults can stay on their parent's plan until they are 26 years old. Or that most insurance policies are required to cover the routine costs associated with participating in a clinical trial. My job is to take the law and translate it into practical terms that everyone can understand. Often, having a basic understanding of the law makes the difference between someone accessing cancer screenings, feeling free to leave a toxic job without fear of losing insurance coverage, and maintaining their financial health after a cancer diagnosis.

President Biden is credited with trying to get his aides to stop using complex and elitist language, saying, "Pick up your phone, call your mother, read her what you just told me… If she understands, we can keep talking." I couldn't agree more. The law doesn't need to be complicated, and it just takes some guidance and practice to be able to translate it. However, at a point in one's life when time feels finite and there is already so much to wade through, that may not be possible.

We hear from hundreds of young adults each year who are trying to figure out their health insurance options after a life change. Perhaps they are aging out of a parent's plan, graduating, moving, getting married, and so many other life scenarios. If they are lucky, they have come to us before making any decisions. At that point, we can share information and tools to help them understand their health insurance options and why one option may be better for them. Unfortunately, sometimes they don't come to us until there is an issue. At this point decisions have been made and there may be fewer options. The worst thing I can hear is, "I wish I would have known."

That is why I am so honored and excited to be presenting at YA Cancer Gabfest 2021! I will break down the options for picking the best, and most cost-effective, plan for you based on your circumstances.

If you aren't able to attend, or if you have questions after the session about health insurance, or other cancer-related legal issues, you are invited to reach out to our Legal and Financial Navigation Program. Through that program we are able to provide YAs who are diagnosed, their caregivers, and health care professionals with free one-on-one help in the areas of health insurance, disability insurance, employment, finances, medical decision-making, estate planning, and more. Head to triagecancer.org/gethelp for the intake form and more information about all of our services.

I know that health insurance is probably the *last* thing most young adults want to spend any energy thinking about. I also know the stress and anxiety that not having the right insurance can cause. My goal is to arm every person that I can reach with the information and tools *they* need to make the best decisions for *them* – about health insurance, employment, finances, medical decision making, and more. ●

> *"The law doesn't need to be complicated, and it just takes some guidance and practice to be able to translate it. However, at a point in one's life when time feels finite and there is already so much to wade through, that may not be possible."*

TRIAGE CANCER

Health Insurance Comparison Worksheet

This worksheet will help you compare different health insurance plan options. You can use this worksheet to compare different options your employer gives you, you can compare different plans sold in the State Health Insurance Marketplace, and you can compare your employer plans to what is available in the Marketplace.

Health Insurance Terms to Understand

Monthly premium: what you pay each month to have health insurance coverage – you pay these costs even if you never get medical care.
Annual deductible: the amount you have to pay out-of-pocket each year, before your health insurance policy kicks in.
Co-payment: a fixed dollar amount you pay each time you get certain types of medical care (e.g., office visit).
Co-insurance (aka cost-share): a percentage difference in what the insurance company pays for your medical expenses and what you pay.
Out-of-pocket maximum: a fixed dollar amount that is the most that you will have to pay for your medical expenses out-of-pocket during the year (e.g., plan pays 80% / you pay 20%). Once you reach your out-of-pocket maximum, your insurance pays 100% of your medical expenses for the rest of the year. Most insurance companies only count expenses towards the out-of-pocket maximum that are from in-network providers. Marketplace plans have out of pocket maximums that include co-payments, deductibles, co-insurance, and out-of-pocket prescription drug costs. Some employer plans may carve out deductibles from the plan's out of pocket maximum. They may also have a separate out-of-pocket maximum and/or deductible for prescription drug costs.

Additional Resources

Quick Guide to Health Insurance Basics – *TriageCancer.org/QuickGuide-HealthInsuranceBasics*
Quick Guide to Health Insurance Options –*TriageCancer.org/QuickGuide-HealthInsuranceOptions*
Quick Guide to State Health Insurance Marketplaces – *TriageCancer.org/QuickGuide-Marketplaces*

About the Plans

Option #1			Option #2		
Type of Plan	Plan Type		Type of Plan	Plan Type	
☐ Employer ☐ Marketplace ☐ Other	☐ HMO ☐ PPO ☐ EPO/Other		☐ Employer ☐ Marketplace ☐ Other	☐ HMO ☐ PPO ☐ EPO/Other	
Insurance Company Name:			Insurance Company Name:		
Plan Name:			Plan Name:		
Is my primary care physician in the plan's network?	Are my hospitals and specialists (e.g., oncologist, surgeon, etc.) in the plan's network?	Are the prescription drugs I take covered by the plan?	Is my primary care physician in the plan's network?	Are my hospitals and specialists (e.g., oncologist, surgeon, etc.) in the plan's network?	Are the prescription drugs I take covered by the plan?
☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No ☐ Only Some	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No ☐ Only Some

Plan Costs

Option #1

Monthly Premium	Deductible
$ A	$ B
Co-Insurance (Cost-share)	Out-of-pocket Maximum for an Individual
%	$ C
Out-of-pocket Maximum for a Family	Is there a separate deductible for prescription drugs? If yes, enter amount
$	$ D
Is there a separate out-of-pocket maximum for prescription drugs? If yes, enter amount	Does the plan have out-of-network coverage? If yes, enter percentage
$ E	%

NOTES

Option #2

Monthly Premium	Deductible
$ A	$ B
Co-Insurance (Cost-share)	Out-of-pocket Maximum for an Individual
%	$ C
Out-of-pocket Maximum for a Family	Is there a separate deductible for prescription drugs? If yes, enter amount
$	$ D
Is there a separate out-of-pocket maximum for prescription drugs? If yes, enter amount	Does the plan have out-of-network coverage? If yes, enter percentage
$ E	%

NOTES

Doing the Math

Use these formulas to figure out your total out-of-pocket costs for your health care for the year, assuming health care expenses will reach the out-of-pocket maximum.

1. Does your plan have a separate deductible and/or out-of-pocket maximum for prescription drugs? If yes, use this formula.

Option #1

(__A__ x 12) + __B__ + __C__ + __D__ + __E__ = _____

Option #2

(__A__ x 12) + __B__ + __C__ + __D__ + __E__ = _____

2. Does your plan include deductibles in the out-of-pocket maximum? If no, use this formula.

Option #1

(__A__ x 12) + __B__ + __C__ = _____

Option #2

(__A__ x 12) + __B__ + __C__ = _____

3. Does your plan include deductibles and prescription out-of-pocket costs in the out-of-pocket maximum? If yes, use this formula. *(Note: Plans sold on the State Health Insurance Marketplaces will always use this formula)*

Option #1

(__A__ x 12) + __C__ = _____

Option #2

(__A__ x 12) + __C__ = _____

Disclaimer: This worksheet is intended to provide general guidance on choosing a plan. There may be situations that fall outside of this worksheet. It is provided with the understanding that Triage Cancer is not engaged in rendering any legal or professional services by its publication or distribution. Although this content was reviewed by a professional, it should not be used as a substitute for professional services.

Your Voice, Your Story, Your Way

BY YOLANDA MURPHY

I'm not sure if this is a good or bad thing, but every time I meet someone newly diagnosed with cancer, whether as a young adult or otherwise, I instantly think of how they can share their story. Of course, while they are in the thick of their active treatment or right after surgery isn't really a time that they think of sharing what they are going through, but instead are focused on living and surviving their battle with cancer. Makes sense, right?

In hindsight though, I feel that while going through my journey would have been the "perfect" time to share what I was facing. I wanted others who may face the same journey to have a literal first hand testimony to what it looks and feels like to go through this young adult cancer journey. It, to me, would have been the rawest and most true expression of what was going on in my life.

Here is the truth… No matter when, where, or how you share your story, someone needs to hear it! Your voice, your story, your testimony is the unequivocal proof that there is an "After". Although our journeys may be different, even through the same diagnosis, this is what it can look like to be young, to have cancer, and to be a walking, talking, living, breathing example of what it can look like to survive!

I quickly learned from day one of diagnosis to today as a five-year cancer free survivor that after all I have gone through, big or small, through this YA cancer fight, there will always be someone who needs to hear my side of the story. Even back then I knew that one day others would need to hear, see, and BELIEVE that if I can go through cancer and survive (even thrive during what is now my "After") that they most assuredly could too!

Your story and what you have gone through connects you with others. This helps shape and lead where you are going in your "After." I would have never imagined at the ripe age of 36 that breast cancer was going to be a part of my future. But when I look back to the first time I shared my story, I wouldn't trade the nervousness, imposter syndrome, or fear for the world. I think of those feelings and then think of each person that has told me they have been impacted by something I have said or done in my own fight with cancer. It makes me realize even more that I can't keep what I have gone through to myself but must share to help others and to ensure they know they aren't alone in it.

The different ways that you can tell your story are limitless! From print in the form of a blog, newspaper, or magazine like Elephants and Tea, digitally by way of social media (e.g., Facebook or Instagram), on an online platform such as YouTube, or verbally by speaking publicly, serving, volunteering with organizations or even a podcast! But at the core of it all, essentially you tell it YOUR WAY!

I recently shared my story and chose to style it in a Moth type talk (look up The Moth Podcast; it's amazing!). I was nervous and excited but wasn't sure how others would receive this style of storytelling. I have a blog, a podcast, and have spoken publicly in an array of spaces, but I wasn't sure how this would go over. Despite all of that, I pressed forward and even received a "standing O" at the end. I hope that in me sharing this, you find a little bit of you and how you can share your amazing story too!

SO WHO WAS I?

Picture it, Pittsburgh, February 2016. A 36-year-old black woman just moved into a new apartment, thinking of how this new year will most assuredly be hers to finally get things accomplished that she had been putting off – like getting her master's, paying down debt and finally getting a beau! Yas!!! It was the "Year of Yolanda", and life was ripe with opportunity!

So, who was I? I was a young woman with dreams, hopes and visions for that year and the many to come! I was anticipating a major mental and physical shift for my life and was excitedly expecting the best for my future. For once in my life, I was doing it for me! No longer was I putting other people's needs before my own – physically, mentally or emotionally. Not friends, not roommates, not lovers – JUST FOR ME!! I was going to take over the world!

WHERE WAS I?

But then life happened… One night while in my new apartment laying on a blow-up mattress (ya know, since the new furniture was coming the following week), my hand brazed my chest in an effort to get comfortable, and there it was, the hard misshaped mass that would change the rest of my life.

"What is that?" I thought.

"Am I really feeling that?" I questioned.

"Maybe it's the two glasses of merlot?" I surmised.

But then I quickly thought to myself, "Ya know, it's probably just a cyst or tissue that has changed because I started my cycle recently. Yeah, that's it… I will wait until it ends and check my breast again…"

A week later, it was still there…

So here I am a week later, still with this hard intruder in my breast. I try not to panic! I rationalized further, “Well, you have a gyno appointment coming up so you can have it looked at then!! Yup, that’s what I will do, I’ll wait until then. In the meantime, it’s nothing! It’s probably just a cyst or tissue that has changed. Yeah, that’s it… I will go to my appointment, and it will be nothing…”

Very soon I realized how much that nothing was something!

> *“Since I didn’t know what it looked like to be a young adult and an African American breast cancer survivor, I paved my own way. I wasn’t going to be the emaciated bald pale patient that they portrayed in the movies. I was not going to be laying on my deathbed anytime soon!”*

SO, WHAT WAS IT?

February 8th, 2016, I got the call I was dreading, while at work. I quietly slipped into an unused conference room to receive my diagnosis: Stage IIB Invasive Ductal Carcinoma. The nurse continued to rattle off medical terms I didn’t understand, and schedule appointments for me I didn’t know I needed. At the end of the call, she says, “I’m so sorry, hun.” And hangs up the phone.

“What the hell just happened?” is what I thought while I sat in the dark, unoccupied room, just waiting for someone to burst in to acknowledge that they have the room for the next hour. What do I do next? Where do I go? Who do I tell? Does this mean I am going to die? So many questions were swirling around in my head. In the fog of receiving my diagnosis, I did what felt natural – I walked back to my desk and went back to work. It literally took me days, almost a week before I even told anyone. I needed to contemplate what this really meant for my life.

What did a 36-year-old with breast cancer look like? I had never seen that before!

What did it look like in the African American community to actually openly talk about “the C Word?” To be honest, I didn’t know. It was too taboo to even talk about!

How do I tell my parents that I have breast cancer? I mean, my dad just had surgery the previous December to remove what was found that October to be prostate cancer! Let’s not even mention once my dad was back on his feet in January on HIS FIRST DAY BACK TO WORK, he fell, tore some ligaments and had to have emergency knee surgery! I didn’t want to add stress to them after all of that! WHEW!!

So many questions that I didn’t have the answers to. I felt like I had no control over what was about to take place in my life, and that did not sit well with me.

So where was I? I was a newly diagnosed young woman, not married, no kids, and desperately needed to take control of my own narrative. I had to pull up my bootstraps and face this head on. It would shape how I battled during and after this tumultuous journey I was about to embark on!

So, I chose to fight! This disease was not going to win!

WHERE AM I NOW?

Since I didn’t know what it looked like to be a young adult and an African American breast cancer survivor, I paved my own way. I wasn’t going to be the emaciated bald pale patient that they portrayed in the movies. I was not going to be laying on my deathbed anytime soon!

I was going to overcome this hurdle in life, much like others I have faced and conquered! I leaned on my faith to push me through the dark times – surgery in March, chemo from April to July, and radiation from August to October – and I was going to come out victorious!

AND I DID JUST THAT!! My tribe rallied around me throughout my journey, and we all pushed to defeat breast cancer one treatment at a time! I walked in rooms and told people my story and how I would overcome. I spoke after active treatment about how this was just the beginning and I had been given another chance!

I attended conferences and advocacy trainings, all to build a network of those who, like me, didn’t see themselves represented where they received care. I created spaces such as a blog and podcast so that myself and other African American breast cancer and young adult cancer survivors could talk about our exceptional journeys and share how we have made it to where we are today.

I became for others what I needed when I didn’t have a “Me” in sight!

Life has a way of knocking you down and making you either face reality or run from it. I faced it head on! Who am I now? A 42-year-old five-year breast cancer survivor pushing the needle in every room I walk in for those of us who feel they have no voice!

And yes, I am that voice, and I WILL BE HEARD!!! ●

A Q&A WITH WENDY AND CARLO, THE HOSTS OF THE CANCER PATIENT PODCAST

BY JENNIFER ANAND

If you had a chance to explore my Q&A with the mysterious Cancer Patient: Behind the Emoji a few months ago on Elephants and Tea (https://elephantsandtea.com/patients/the-cancer-patient-behind-the-emoji/), welcome back to another episode of The Cancer Patient. Today, we speak to Carlo and Wendy, the hosts of The Cancer Patient Podcast, and friends of the elusive The Cancer Patient. Wendy and Carlo will be the closing keynote at this years Gabfest.

Jen: Tell me, who are you??

Carlo: I'm a two-time survivor of non-Hodgkin's lymphoma. I've been in remission for five years, and ever since my second diagnosis, I've been heavily involved with local support groups. I've joined various AYA orgs, such as Send It and First Descents. I've met a lot of AYA cancer people along the way, and my advocacy work just started growing from there. I help create content for various social media cancer pages out there. I've written 2-3 articles in the past, and I'm a co-host with Wendy for the TCP podcast. Not sure why I was chosen for that, but here we are! I'm also an RN and have experience in clinical research and work as a traveling nurse.

Wendy: I'm an oncology social worker and a program manager at M.D. Anderson. I've worked in oncology for 15 years and have a passion for AYAs, so I'm really glad to be able to work specifically with this population. I do the podcast mostly because they asked me to, and because I love what TCP represents.

Jen: Why are you involved in this podcast?

Wendy: It connects people through sharing all kinds of stories and perspectives, which is important because AYAs often feel isolated and alone. The voicemails are from real people with real experiences. I also love that it's a safe space for people to share the hard stuff. It's like an elevated version of the TCP Instagram page.

Jen: I'm sure we've all seen a meme or read some stories from the TCP Instagram page. Why a podcast?

Carlo: I see the podcast as an extension of the TCP Instagram page. If you follow it, in addition to the memes, there are some really in-depth discussions in the story feed which are all submitted via DM from followers. We discuss heavy, lighthearted, and funny topics – from pooping your pants to infertility to deaths in the community – with the goal of highlighting and amplifying voices from the community. The challenge is that the story feed only lasts for 24 hrs, so we wanted to create something that would last.

It was clear that a podcast was the way to go, so a group of us got together and brainstormed ideas. The first AYA support group I went to was facilitated by Wendy, so we go way back. And for me, it was a no-brainer – if we're going to do this podcast, I need Wendy in on this. Not just as a facilitator, but because she has a personal passion for the AYA community.

Wendy: Yeah, I think you can throw in a lot of different people who would be great, but having someone with a mental health background and oncology experience is crucial. The podcast weaves in and out of some difficult and uncomfortable conversations, so you just have to have someone with the skills to effectively explore, facilitate, and validate. I think that the combination of my practical knowledge of oncology/healthcare and my involvement in AYA organizations and my oncology social work experience is what makes me a good fit. Along with the good rapport Carlo and I already had together!

Carlo: Aside from my work creating content for social media, and my full-time job as a nurse, I have my own personal experiences within the cancer world. Wendy knows how difficult it was for me to navigate insurance, infertility, financial issues, and pretty much all the usual things AYAs go through. I'm open about my experience, and I try to combine that with sharing experiences from others I've heard along the way. I've seen firsthand the impact of cancer on mental health, so I'm a huge advocate for mental health, therapy, and getting support through all of that. I believe in trying to see the cancer not just as something physical, but also mental.

Wendy: Carlo is a great person to host this podcast because he has had so many different experiences. Treatment both inside and outside the USA, relapse, big hospitals, small hospitals – all kinds of experiences, connections, and support groups. Experiencing cancer as a patient, and also providing care as a nurse. I think that broad range of experiences is what makes him so relatable, and gives him such a unique perspective that so many others are able to relate to.

Jen: So how did you get started with the voicemails?

Carlo: At first, the idea of doing a podcast was really daunting. Voicemails were less intimidating, so we used cancer confessions as a trial. Something the TCP Instagram page could use, and then something we could incorporate into the podcast. Send It Foundation reached out and said that they would be interested in sponsoring the podcast, so that's really what finally got us moving forward. There are already a ton of podcasts about cancer, and they're all good, I just wanted to do something different. The idea of just me and Wendy talking wasn't interesting to me or to the team. We really wanted to do something that had more meaning. Since we already had the Instagram platform with a decent number of followers, we wanted to use the voicemails and make a support group in a podcast form. So, there's a topic. People talk about it. The facilitator gives advice and helps navigate the conversation into something productive. And that's basically the goal of the podcast!

Wendy: Carlo has always loved the voicemails. Even after we started the podcast, he'd listen to an episode and then come back to the group saying – we need to incorporate more. So that's what we're doing!

Carlo: We want to give the TCP community and cancer patients everywhere a voice. And not the watered-down, filtered, or edited version of it. We wanted to talk about the real stuff. Some of the topics are really intense and heavy, but sometimes we need to hear that too.

Jen: Tell me more about hosting guests on your podcast?

Carlo: We are working on ideas for guest hosts, but for the most part we want to keep the podcast focused on sharing voices and stories from within the community. If we do have guests it'll be for special topics outside of our areas of expertise – like oncofertility or oncodermatology.

Wendy: As much as I love the concept of guest speakers, an educational podcast is so different from a support group type podcast. We want

> *"We want people to feel like they are hearing from each other and talking to each other, not being talked to"*
> – Wendy

people to feel like they are hearing from each other and talking to each other, not being talked to – if that makes sense. I do think that some topics will be better led by an expert in the field, but there are a ton of podcasts out there that do the education part well, so generally speaking there's no need to duplicate it on TCP podcast.

Carlo: I can't say it enough – our goal is highlighting patient voices! Every cancer patient has a story to tell, and that's why we are keeping the voicemails anonymous. It keeps everyone on a level playing field. No matter how many followers, or how influential that person is on social media, every single community member has a chance to share.

Jen: Tell us about the format of the podcast?

Wendy: We usually do a brief intro/hello, mention the topic at hand, listen to voicemails, chat about them for a little while, listen to more voicemails, chat about them, and then at some point we wrap up. In between all of that, we insert segments like word of the day (where we define a word or concept like cancer muggle, PCHP, toxic positivity, etc), a sponsor testimonial, or just a funny story.

Carlo: We are trying to create more segments, including one we're currently working in called Cancer Muggle Clapback. Stay tuned.

Jen: Tell me about your favorite topic so far?

Carlo: Scanxiety. That was very validating to me, and to a lot of people.

Wendy: Survivorship. I got so many sweet messages about it, and I think it is a topic that just isn't delved into enough. Cancer isn't linear, and just because treatment might be over doesn't mean the struggle is over. Sometimes that's when the struggle is just beginning, and there needs to be more conversation about that.

Carlo: We actually made survivorship into a series because we got an overwhelming number of voicemails. Usually, we receive 10-15 voicemails on a given topic, but we got almost 60 on survivorship! Slowly but surely, we are cancelling the narrative that cancer is over when treatment is finished.

> *"Every cancer patient has a story to tell, and that's why we are keeping the voicemails anonymous. It keeps everyone on a level playing field. No matter how many followers, or how influential that person is on social media, every single community member has a chance to share."* – Carlo

Jen: Any future topics you are excited about?

Carlo: This is dark, but I'm excited for survivor's guilt. I don't think survivor's guilt is talked about a lot, and even for myself, it's hard to talk about. I'm curious to hear the perspectives from the community. I'm looking forward to taking a deeper dive and hearing Wendy's perspective.

Wendy: There's just so many! This probably sounds terrible, but the hard ones are the ones I look forward to the most. Survivor's guilt is a big one. There's so much related to that as well, like advanced care planning, legacy work, and talking about the people we've lost. At some point, I really want to explore the concept of death ideation as well.

Jen: As a cancer survivor myself, there is always an emotional weight I feel with all things cancer related. How do you deal with that weight while actively talking about these important cancer topics?

Carlo: I'm not going to pretend that taking deep dives into cancer and all that is an easy thing to do. When I say heavy, it is heavy. I feel that heaviness personally, because I also went through those experiences. It may be heavy. It may be difficult. But I always keep in mind that talking about my story and experiences will help other people, and that is worth it. That's why I'm doing this podcast. Because it CAN help people. I've been helped a lot: financially, emotionally, mentally. So many helped me back on my feet. It's impossible for me to pay them all back, but I can start by paying it forward. This is what I'm doing to pay it forward.

Wendy: Everyone who works or lives in the cancer space feels a heaviness at times. The heaviness may look or feel different, but it's there. Things that hurt your heart, things that are hard to talk about, things that you hate to talk about. So the advice I give patients is the advice I give myself. Give yourself a break and do the things that fill your tank (or give you more spoons, or whatever your preferred analogy is). I take walks, binge watch TV, and/or vent to people who I know can carry the weight of my feelings (including my therapist).

Carlo: One of the most fortunate things of working with Wendy is she calls my shit out. "You need to back out. Disconnect."

Wendy: Always with love.

Jen: What can we expect from you both at Gabfest?

Carlo: A live support group/live podcast! We don't have a specific topic, so we'll see what the audience wants to talk about and go from there. That's how the podcast goes, and that's how we want to do our session.

Wendy: Totally agree.

Jen: Any final words for anyone debating whether to attend Gabfest?

Carlo: If you tune into our session, there will be an unexpected surprise! ●

Speaker Bios

Vijay Anand

Originally from Chennai, India Vijay came to Case Western in Jan '92 for Graduate work in Biomedical Engineering and stayed put in Cleveland since then. He spent 18 years at EY, and recently moved to MRI Software as the VP of Artificial Intelligence. He loves cooking and volunteering with Civil Air Patrol - inspiring young minds to pursue STEM and Cyber. God, family and country are his priorities.

Amelia Baffa, APRN, PMHNP-BC

Amelia Baffa is a Psychiatric Mental Health Nurse Practitioner (PMHNP-BC); she is board certified by the American Nurses Credentialing Center and is dual boarded in both adult and pediatric psychiatry. She was awarded the University Hospital Trustee Award for Nursing Excellence and the Red Cross Community Hero Award, in 2015. She received her master's degree in nursing from Walden University and her bachelor's degree from Akron University with a Post-Masters Certificate in PMHNP. After graduation she participated in one of the first Psychiatric APRN Fellowships in the United States, the Integrative Community Psychiatric APRN Fellowship, at Portage Path Behavioral Health Center in Akron, Ohio. She sees adults ages 12 to 64 and she specializes in anxiety disorders, bipolar disorders, depressive disorder, post-traumatic stress disorder (PTSD), schizophrenia, women's mental health issues, pregnancy and mental health, and post-partum depression.

Mary Clare Bietila

Educator, Writer & Patient Advocate. Mary Clare is a Chicago based consultant on the patient experience for health centered organizations. Her advocacy is informed by her experience as a leukemia and stem cell transplant survivor living with multiple treatment based chronic illnesses. Before cancer she worked in education and loves leading writing workshops and crafty projects with patients and her daughter's Girl Scout troop. On Sundays you will find her in the bell tower ringing the bell for First Unitarian.

Sage Bolte PhD, LCSW, CST

Sage Bolte is Chief Philanthropy Officer and President of the Inova Health Foundation. She joined Inova 15 years ago as an oncology counselor and most recently served as Executive Director of Life with Cancer and Patient Experience for the Inova Schar Cancer Institute. She is known nationally for her work in sexual health and cancer and is respected as a leader in the field of oncology social work. Sage received her bachelor's degree in both psychology and social work at Hope College, in Holland, Michigan, and later continued her studies at the University of Michigan, where she received her master's degree in social work. She received the American Cancer Society's Doctoral Training Grant in 2008 and obtained her Ph.D. in social work from The National School of Social Services at the Catholic University of America in 2010.

Monica Bryant, Esq.

Monica Fawzy Bryant is a cancer rights attorney, speaker, and author. She is dedicated to improving access to quality information on the practical, insurance, and financial issues surrounding a cancer diagnosis. Monica is the co-founder and Chief Operating Officer for Triage Cancer, a national nonprofit organization that provides education on the practical and legal issues that may impact individuals diagnosed with cancer and their caregivers, through events, materials, and resources. Throughout her career, Monica has provided over one thousand educational seminars, written articles and blogs, and appeared on television, radio, and podcast shows discussing healthcare related legal issues. Previously, she worked as Midwest Regional Director for a national disability rights organization, Legislative Counsel for U.S. Congresswoman Linda T. Sanchez and Law Clerk for U.S. Senator Dianne Feinstein. During her time in Congress, she focused on health, justice, civil rights, and women's issues. Monica is an Adjunct Law Professor at University of Illinois at Chicago School of Law, teaching a class on Cancer Rights. She lives in Chicago with her husband, two children, and fur baby, Paisley.

Jay Carter

Jay is a cancer survivor, an avid outdoorsman, and a software engineer. After being diagnosed with Chronic Myeloid Leukemia in 2011 and enduring a stem cell transplant, he experienced the negative physical and mental impact cancer can have on one's life. He found healing not only in the outdoors, but also in the connections he made with other survivors. When not on an adventure in nature, you can find him behind a computer screen working on ways to combine tech and fitness in a way that is beneficial to the cancer community.

Diana Cejas, MD, MPH

Diana M. Cejas, MD, MPH is a pediatric neurologist in Chapel Hill, North Carolina. She obtained her medical degree at Howard University in Washington, DC in 2010. She completed pediatric residency training in the Tulane University – Oschner Health Systems Pediatric Residency Program in New Orleans, Louisiana. She obtained a Masters of Public Health in Maternal and Child Health at the George Washington University in Washington, DC prior to moving on to her pediatric neurology training at the University of Chicago in Chicago, Illinois. She is board certified in both General Pediatrics and Neurology with Special Qualification in Child Neurology.

Speaker Bios

Aerial Donovan		Aerial Donovan is the Chief Program Officer at Cactus Cancer Society, formerly Lacuna Loft. Her passion is helping the young adult cancer community discover resources and encouraging them to engage with each other. Her knowledge and expertise in community building and organizing + executing digital events has helped Cactus Cancer Society's programming flourish. Prior to Cactus Cancer Society, she was VP of Programs at GRYT Health and volunteered with organizations such as Stupid Cancer, Imerman's Angels, and previously with Cactus Cancer Society.
Marloe Esch, BSN, RN, OCN, CSC		Marloe Esch, RN, BSN, Oncology Certified Nurse (OCN), and young adult cancer survivor, graduated from the University of Wisconsin – Madison School of Nursing (go Badgers!) in 2008. She enjoys educating both survivors and healthcare professionals on the topic of cancer and sexuality, and has presented for the Young Survival Coalition, the Oncology Nursing Society, and Planned Parenthood of WI, among others. She holds a certificate from the Sexual Health Certificate Program through the University of Michigan and is currently pursuing her Doctor of Nursing Practice (DNP) at the University of Wisconsin – Milwaukee. An enthusiastic supporter of sexual health and wellness, Marloe is making it her mission to bring sex into the survivorship spotlight.
Angie Giallourakis, PhD		Angie Giallourakis, Ph.D., Co-Fouder of Elephants and Tea and President of the Board of Directors for The the Steven G. Cancer Foundation, is a former rehabilitation counselor, college professor, researcher, turned cancer advocate and mother to a four-time cancer survivor. Over the past eleven years she has sought to learn about the best ways to survive cancer treatment. As a result of this research she has become a trained IREST yoga nidra meditation teacher, integrative nutrition health coach, integrative oncology navigator and yoga4cancer teacher.
Nick Giallourakis		Nick Giallourakis is the Executive Director of the Steven G. Cancer Foundation (SGCF). Elephants and Tea is a nonprofit media brand, part of SGCF, with the mission to help adolescent and young adult (AYA) cancer patients, survivors and caregivers know they are not alone in facing cancer. Elephants and Tea's unique storytelling ability is built from Nick's expertise in developing community and content - which includes engaging audiences with digital events and media.
Wendy Griffith, LCSW, OCSW-C		Wendy Griffith is a Licensed Clinical Social Worker and program manager of MD Anderson Cancer Center's AYA Program. She facilitates has over 14 years of health care experience that includes clinical work with patients/caregivers and macro-level work involving project development/management and quality improvement. In her spare time, she co-hosts The Cancer Patient podcast and is a Wellness Guide with Project Koru.
Elisabet Harms DNP, RN, CMSRN, CNEcl		Liz is an acute care nurse in Denver, Colorado. She actively teaches pre-licensure nursing students for several Denver area universities. In 2011, she was diagnosed with colon cancer. After treatment she was impassioned to improve the socialization, concerns, and support of young adult cancer survivors. She has volunteered with several young adult cancer organizations and currently serves as the co-Executive Vice President of The Colon Club, an organization which seeks out new ways to raise awareness, educate, and support colorectal survivors and families.
Stephen Heaviside		Stephen Heaviside is a musician, writer and AYA cancer advocate. He resides in Orange County, California and loves dolphins, true crime documentaries and good coffee. You can follow him on Instagram/Twitter @heavysighed and on Facebook. His music is available on Spotify and Apple Music.
Cary Kim		Cary Kim is the Director of Survivor Relations for Handful, an activewear company based in Portland, Oregon, with a mission to support the 1 in 8 women (12.5%) who will face breast cancer in their lifetime. This year, she celebrates 15 years since her diagnosis with late stage 3 disease and believes that an active lifestyle is an essential part of long-term survivorship.
Carlo Lopez, RN		Carlo Lopez is currently in remission as a two time lymphoma survivor and had a bone marrow transplant in February 2016. Carlo is a registered nurse, AYA cancer advocate, content creator for various cancer support platforms, and host of The Cancer Patient Podcast. You can find episodes for The Cancer Patient Podcast by visiting https://senditfoundation.org/resources/podcast/.

Speaker Bios

SEE PAGES 12-14 FOR FULL AGENDA

Amanda Marsh

Amanda Marsh is a 16-year survivor of Non-Hodgkin's primary mediastinal diffuse large B-cell lymphoma, having received her first job offer and diagnosis the same day. When life threw the cancer curveball and all her post-college plans went out the window, she decided to join the 1,000 in 100 Project to inspire her to achieve new personal goals after treatment was finished. A writer and editor by trade, she lives in New York's Hudson Valley with her husband, preschool daughter, and toddler son in a Victorian house that always needs something fixed. In her little spare time, she enjoys crafting, reading, New York Times crossword puzzles, puns, and getting easily distracted by sparkly things.

Sharla Moore, MPH

Sharla Moore, MPH is the Manager of Clinical Research Programs for the Women's Cancers Program at City of Hope. In this position, Sharla is working to bring together laboratory scientists and expert physicians in a strategic integrated program that will bring treatments to the women who need them. The mission of the program is to improve our understanding of the risks for developing breast and gynecologic cancer, to develop novel strategies for treatment and prevention, and improve the quality of life of our survivors. Sharla became a widow and single mom to two boys, all at the age of 39. At 29 years old, her husband was graduating from law school and she were pregnant with their first child – then he was diagnosed with cancer. Eric died 10 years later, in 2014, and having to tell the two boys their dad wasn't coming home from the hospital was the hardest thing she's ever done. Every day since then, it's about being their parent and trying to make their life as normal as possible. She hopes to be there for other caregivers like her – supporting each other at all the different stages of cancer. Sharla earned a Bachelor of Arts from University of California, Riverside and a Masters of Public Health from University of California, Los Angeles.

Yolanda Murphy

Yolanda J. Murphy - Speaker/Advocate/Survivor - Yolanda J. Murphy was born and raised in Pittsburgh, PA. She graduated from Trinity Christian High School and went on to obtain her BS in Business Management from Carlow University. For several years, Yolanda worked for a healthcare company and until 2016 was living a "normal" simple life. At the age of 36, things drastically changed. Yolanda was diagnosed with Stage 2 Invasive Ductal Carcinoma (IDC) of the left breast. She underwent four rounds of chemotherapy and thirty radiation treatments. As a young African American woman, she thought this could never happen to her and more frightening was the inability to find the necessary resources to help her navigate her now new normal.

Kara Noskoff

Kara Noskoff, Hospital Programs and Services Manager, Teen Cancer America. After working with the adolescent and young adult (AYA) oncology population as a Child Life Specialist, Kara developed a passion to improving AYA cancer care. With a focus on community building, she helped develop monthly programming, retreats, and events that provided support and education. Kara later joined Teen Cancer America to support healthcare professionals working specifically with AYA oncology patients and survivors to develop comprehensive AYA programs and services. Through providing consultation, resources and opportunities for collaboration, the TCA team is working to enhance the culture change at each institution with hope to ultimately impact the national picture for AYA cancer care.

Tara O'Donoghue

Tara O'Donoghue is a yoga teacher (500 RYT) and trauma informed (TIYT) Yoga Therapist who specializes in yoga for cancer and grief support. She started Lov Yoga after caregiving for and eventually losing a loved one to cancer. Her mission is to help others experience mindfulness, balance, and transformation in life through the healing practices of yoga, breathwork, meditation and self reflection. www.lov.yoga

Lisa Orr

Lisa is a 34 year old Stage 2b Triple Negative Breast Cancer Survivor (diagnosed in January 2019). She is a proud wife and mother of two boys, ages 6 and 4, and lives just north of Boston, Massachusetts. Lisa is a member of the Patient Advisory Committee for Elephants and Tea and has had her writing published in the magazine five times. She is passionate about her role in helping to run writing workshops with Elephants and Tea. In these workshops, the magazine partners with AYA cancer programs at hospitals around the country to aid patients, survivors, and caregivers learn how writing can be used as a healing tool. In her free time she enjoys cooking and baking, she cannot wait to get back to traveling, and enjoys spending time with her family and friends.

Ellen Polamero, LCSW

Ellen is a therapist in private practice with over a decade working specifically with cancer patients and their loved ones. Before going into private practice, Ellen worked at City of Hope (an NCI Designated Cancer Center) with both inpatients, outpatients and their families through every stage of treatment and survivorship. She has focused on caregivers, and specifically spouses/partners, since the beginning of her time at City of Hope. Ellen has written articles and been an invited speaker at multiple national conferences addressing the mental health impact of cancer on patients and caregivers.

Jean Rowe, LCSW, OSW-C, CJT

Jean is guest faculty of several programs for Cactus Cancer Society. Her background includes 16 years in the oncology space primarily working with young adults affected by breast cancer. Jean's original programs include themes around reclaiming intimacy after cancer, addressing burnout and compassion fatigue, journal drop-ins to temper the triggers of everyday life and coping through the holidays. Grounded in all of them is the importance of self-care. She is honored to work with Cactus Cancer Society and all whom they serve. You can connect with Jean at linkedin.com/in/jean-rowe-2448119/ or at jean@cactuscancer.org.

Stephanie Scoletti, MSW

Stephanie Scoletti is Executive Director & Founder of Young Adult Survivors United, the health and wellness community for young adult cancer survivors aged 18-39 when diagnosed. YASU's comprehensive model provides emotional and mental health, social, and financial support that enhances young adults' quality of life. Stephanie's advocacy focuses on prevention, increased awareness, and most effective ways to support this unique cancer population. Dedicated to her hometown, she was a 2019 Pittsburgh Magazine "40 under 40" honoree and 2018 KDKA Radio "Hometown Hero" awardee. Stephanie is a member of the Southwest PA Cancer & Environment Network, a UPMC Hillman Cancer Center Community Advisory Board Member, and an active advocacy representative for the American Cancer Society's Cancer Action Network. She is a Patient Advisory Council member for the Elephants and Tea Magazine and Patient Expert Council member for Servier Pharmaceuticals. Stephanie admires community partnerships and any opportunity to embark on new adventures with her husband, Matt. In her spare time, you can find her running, biking, or creating new plant-based meals.

Brandie Sellers, MS, LPC, NCC

Counselor. Speaker. Teacher. Brandie practices counseling via telehealth in Texas. She specializes in sexuality, trauma/EMDR, and cancer. Brandie graduated with an MS in Counseling from SMU. In addition to counseling, Brandie has been teaching yoga, meditation, & Ayurveda since 2005, and is a Certified Yoga Teacher at the 500-hour level. A two-time breast cancer survivor, Brandie has written for cancerwise.org and speaks to cancer survivors, counselors, and other professionals about cancer survivorship. Brandie is crazy about her three children, traveling, and living an artful life with big adventures.

Pat Taylor

Pat (Patricia) Taylor is a producer, writer, director, performer and educator whose credits include documentary films, television specials, plays, musicals, short stories, music videos and major tourist attractions. She has spent more than two decades as an advocate for young adults living with cancer, as well as their parents/caregivers, through two documentary films (Sara's Story and Chasing Rainbows: Young Adults Living With Cancer), countless appearances on conference panels and working groups, and as a section editor for Cancer Knowledge Network and blogger at The Huffington Post. Now semi-retired, Pat is glad to have occasional opportunities like Gabfest to reconnect with the YA cancer community! http://www.chasingrainbows.ca/

David Victorson, PhD

David Victorson is licensed clinical psychologist and professor of medical social sciences at Northwestern University where he conducts research focusing on improving quality of life and wellbeing for people affected by cancer, especially young adults. He is also a co-founder and director of True North Treks, a national nonprofit dedicated to helping young adults and caregivers affected by cancer to "find direction through connection" through connecting with nature, peers, and mindful awareness practices.

Rachel Walker

Rachel was diagnosed in 2019 at the age of 36 with triple negative breast cancer. She has worked as an industrial engineer for the last 18 years in various industries. Her hobbies include camping, biking, rollerblading, hiking, kayaking, and yoga. Diet, exercise, and mental health have been a large part of her life for the last 15 years, which have been beneficial in her survivorship.

Beau Whitman

A recent cancer survivor and a personal trainer in NYC for the past 5 years specializing in foundational training. His drive and enthusiasm comes from being a competitive gymnast, division one track athlete, and college coach. You can find Beau on Instagram @beau.whitman.

The Who's Who of Sexual Health in Survivorship

BUILDING A SEXUAL WELLNESS RECOVERY TEAM

BY MARLOE ESCH, BSN, RN, OCN, CSC

Changes in sex, intimacy, and relationships are common after cancer. But if you are experiencing an issue, it can feel pretty lonely and you may not know who to ask for help. Your primary care or oncology care teams are always a good place to start. After all, sexuality is just another aspect of survivorship care (and health in general), and most clinicians are happy to have these conversations (although you might have to be the one to bring it up!).

Sometimes, though, problems are best addressed by a professional with sexual health-related expertise. If this is the case, your primary care or oncology care team may offer a referral to one or more appropriate specialists, depending on your specific concern. Let's take a look at some of the different players that can contribute to your sexual wellness recovery team of experts.

SPECIALTY MEDICAL CARE

Doctors, advanced practice providers such as nurse practitioners (NPs) and physician assistants (PAs), and nurses can work in specialized areas of medicine that address different aspects of sexual health, including endocrinology, reproductive system specialties, and urology.

- **Endocrinology**
  Endocrinology is the branch of medicine that deals with diagnosing and treating endocrine system disorders. Glandular endocrine organs throughout our bodies secrete chemical messengers (hormones) that regulate a multitude of different body processes, including reproduction and sexual functioning. For example, parts of our brain (the hypothalamus and pituitary gland) make hormones that tell our ovaries or testes to produce estrogen and testosterone, which play a role in various aspects of sexuality. Cancer treatments can disrupt this process and alter levels of these sex hormones, which may affect sexual desire, physical arousal, and fertility.

  Alterations in the function of other endocrine glands can also impact sexual functioning. For example, hypothyroidism and adrenal insufficiency in survivors can contribute to problems with sleep, fatigue, and lack of energy, which may indirectly affect sexual desire and function. Endocrinology specialists can assess for and help manage many of these issues.

- **Gynecology and Andrology**
  These are specialties that focus on diagnosing and treating problems of the reproductive system. Gynecologists are experts in medical care for people with female reproductive organs and physiology, and commonly care for women throughout their lifespan. The lesser-known specialty of andrology is concerned with medical care for people with male anatomy and physiology. Andrology is sometimes considered a specialty of urology (see below).

  Soapbox alert: These sex-specific specialties raise an important debate about what being male or female actually means, which requires a bit of reflection. Adhering to the conventional idea of biological sex as a male/female binary can be problematic, because it's actually not accurate. Check out the discussion titled "Sex is a Spectrum, Silly!" to learn why.

- **Urology**
  Providers who specialize in urology focus on the medical and surgical care for urinary system disease and dysfunction. Because of the anatomical proximity of the urinary tract to the reproductive organs and genitalia, symptoms or problems can be related. Urologists often deal with male sexual health concerns, and urogynecologists combine female reproductive and urinary tract care.

PHARMACISTS

With all of the medications that may have been part of your cancer treatment and symptom management plan, it's possible that you already have a great relationship with your pharmacist! Pharmacists are experts in medication use, drug interactions, and side effects. Don't be afraid to ask if a new medication could impact your sexual function or be responsible for symptoms you might have developed since starting it. Sexual side effects can occur with some medications, and your pharmacist is a good resource for determining if this is a possible cause for your concerns. They may also be able to help you talk with your provider about alternative options. You can also ask questions about over-the-counter (OTC) medications and supplements.

PELVIC FLOOR PHYSICAL THERAPY

This specialty area of physical therapy focuses on the rehabilitation and health of your pelvic floor muscles, which are important for sexual function and response. Some of the challenges that a pelvic

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Cancer to 5K provides a community of support for cancer survivors through a free 12-week training program. Take your life back from cancer…one mile at a time.

4K for Cancer

4K for cancer is a cross-country bike ride or run where young adult participants make their way across the country raising hope and awareness for young adult cancer.

410.964.0202 ulmanfoundation.org info@ulmanfoundation.org floor PT can work with you to address include sexual pain , orgasm or ejaculation issues, and problems with incontinence (loss of control of bowel or bladder function). These professionals are often a critical piece of the sexual wellness rehabilitation puzzle after cancer!

PSYCHOSOCIAL CARE

- **Sexuality Counseling**

  Sexuality counseling is a problem-specific, solution-focused approach to addressing sexual challenges that may arise as a result of changes in health, illness, aging, or other life circumstances. Counseling aims to improve sexual wellness and function through assessment, education, strategic goal-setting, and incorporating specific suggestions into your plan of care. Professionals providing counseling will work with you to identify your needs and priorities, and to implement practical strategies to achieve desired outcomes.

  Any of the professionals listed above may provide sexuality counseling as part of their care, within their scope of practice and role responsibilities. Clinicians often integrate different sexuality counseling techniques into health visits like pelvic floor PT consultations, nursing education sessions, treatment follow-up appointments, or survivorship clinic encounters. They may also offer one-on-one counseling sessions that focus on addressing a specific sexual issue. Examples of topics that sexual counseling can address include contraception and safer sex practices, partner communication, intimacy, sexual pleasure, practical guidance for adapting to physical changes, and more.

- **Sex Therapy**

  Sometimes sexual challenges can be pretty complex. They may coincide with struggles such as anxiety or depression, substance abuse, significant conflict in your relationships, or sexual trauma and violence. Sometimes, treatments for cancer can trigger post-traumatic stress symptoms, significant grief over cancer-related losses, or negative changes in body image or self-concept. If these experiences resonate with you, or if you have tried sexuality counseling but have not seen an improvement, you may be best served by working with a licensed mental health professional. Sex therapists are licensed therapists with specialized training in treating sexual issues, and all of the complicated components that can contribute to them.

  Clinicians may choose to become certified in sexuality education, counseling, or therapy through a professional organization (such as AASECT). Certification requires additional training in sexual health competencies and skills beyond what is needed for their professional role.

YOUR PARTNER AND YOU!

Partners can also be a valuable part of your sexual wellness recovery team. If you are currently partnered, enlist their help and support! Because of their unique perspective, partners make great advocates and allies when discussing sexual concerns with professionals, and can be actively involved in problem-solving and implementing any plans of action to help you get your sex life back on track.

And last but not least, you! As the expert of your own body, your health care team counts on you to share with them what your experiences, concerns, and priorities are, and what you most need from them to achieve a state of health and well-being.

For tips and tricks on communicating about sex (with both partners and providers), check out a past article from *Elephants and Tea* titled “Speaking of Sex: Be H.E.A.R.D.!”

BOTTOM LINE

There are lots of people available to help answer questions and provide guidance regarding sexual concerns. A team approach is helpful, since different professionals will bring unique skills and expertise to the table. Some cancer centers offer multidisciplinary sexual health services as a part of their survivorship or quality-of-life clinics. If that’s not the case where you get your care, ask your provider to help you build your own! ●

Bibliography/Resources:

American Association of Sexuality Educators, Counselors, and Therapists (AASECT). (n.d.). *Certification overview.* Retrieved on September 24, 2021, from https://www.aasect.org/aasect-certification

American Medical Association (AMA). (2021). *Specialty guide.* FREIDA. https://freida.ama-assn.org/specialty

Fausto-Sterling, A. (2018, October 25). *Why sex is not binary.* The New York Times. https://www.nytimes.com/2018/10/25/opinion/sex-biology-binary.html

National Comprehensive Cancer Network (NCCN). (2021). *Survivorship* [Version 3.2021]. NCCN Clinical Practice Guidelines in Oncology. https://www.nccn.org/professionals/physician_gls/pdf/survivorship.pdf

SEX IS A SPECTRUM, SILLY!

Contrary to popular belief, determining a person’s sex is not as easy as checking “male” or “female” on a form. Biological sex is actually a complex interplay between several factors, including an individual’s chromosomes, hormonal makeup, internal reproductive organs and external genitalia, and other secondary sexual characteristics (like breast development or body hair patterns, for example). All of these components exist on a continuum and, taken together, determine where on the spectrum of biological sex a person lands.

Ignoring the natural diversity and variation of biological sex (and gender) can alienate individuals whose bodies and identities do not fit into these inadequate *either/or* categories (whether they identify as intersex, transgender, agender, genderfluid, nonbinary, or others). Finding a provider knowledgeable about and welcoming of diverse bodies and identities can be a difficult and frustrating experience. For help locating a provider, visit these following resources:

- GLMA (Gay and Lesbian Medical Association) Provider Directory - http://www.glma.org
- Healthline - https://www.healthline.com/health/mental-health/find-lgbtq-ally-health-provider
- LGBT Cancer Network Provider Database - https://cancer-network.org/providerdatabases/
- WPATH (World Professional Association for Transgender Health) Provider Search - https://www.wpath.org/provider/search

Curious to learn more? Check out Amanda Montañez’s visual representation of the sex spectrum in her article for *Scientific American*. Also, for some artsy exploration on the subject, check out Heather Edwards, a pelvic floor PT and AASECT certified sexuality counselor who creatively celebrates and elevates the beautiful diversity of human bodies as the author/illustrator of several volumes of *Coloring Books for the Crotch Enthusiast*. Box of crayons encouraged!

Looking Back as a Caregiver

BY SHARLA MOORE, MPH

People say that hindsight is 20/20. I think that it's true, but sometimes it can also be painful. At 39 years old, I became a widow. Before that, I was a wife, a mom, and a cancer researcher. Before my husband died, I was his caregiver for about ten years of our marriage. During that time, he graduated law school, started a new career, we had two boys, I earned my master's degree, and when he got so sick he couldn't continue his career, I started a new one. When he wasn't able to work anymore, I went back to work – working in cancer research during the day, and then being a caregiver at night for my husband (and kids). Honestly, I don't remember everything from that time. I remember some really great times, and I also remember some really hard times. I remember being tired and frustrated a lot. I was not the perfect mother or wife or caregiver – but I did the best I could. Looking back, would I have done some things differently? Absolutely. I didn't always have the most patience or energy when I needed it. I loved my husband, and I loved my kids, and I loved my job. I was trying to keep a lot of balls in the air and feeling like I wasn't doing anything well. When people asked how I was doing, I would always respond that I was fine. People offered to help, but they didn't know what to specifically offer, and I didn't know what to ask for. I didn't have the energy to ask for specific things, but I should have. I think it would have helped. My ego told me I needed to do it myself, but looking back, I needed help.

My experience as a caregiver taught me a lot of things – it's a mixed bag of what to do and what not to do. I think I can boil it all down to a few pieces of advice. First, you (as the caregiver) need to ask for help. Be specific. If you need someone to take your kids to the movies so you can have two hours to yourself, then ask for it. If you need someone to wash your car, then ask for it. My next piece of advice is for those who are offering help. When someone is sick (or passes away), people are there to help, but then they move on. Check in on your friend or family member six months later and see what they need. I'm sure your friend could still use some help. Check in on them a year later to see if they are still struggling. It does get better, but sometimes it doesn't end. Be there for people – it really helps.

About a year after my husband died, my son was playing on a hockey team, and one of the dads passed away unexpectedly. The mom was around my age, and there were also two kids left behind. I didn't realize it then, but being there for them, helping through the process, helping them make decisions, going through paperwork, was so helpful and cathartic for me. Even though I didn't know it at the time, I had learned a lot and was the perfect person to be there with her and for her. Not only did it help her (I think), but it really helped me. It felt like giving back and still helped me through the grief process.

I'm still grieving. I don't know if I will ever be done. I miss my husband and my kids miss their dad. But we are surviving. We talk about him often and laugh remembering some of his funny stories. I try to volunteer when I can and be there for others who need me. Does it make it all better? No, but it does help. ●

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The Caregiver Toolkit: 101

BECOMING A CAREGIVER

BY AMELIA BAFFA, APRN, PMHNP-BC AND WHITNEY HADLEY, MA, LMSW

According to Johns Hopkins, "A caregiver is a person who tends to the needs or the concerns of a person with short or long-term limitations due to illness, injury, or disability." Oftentimes, in the AYA cancer community, this can be a family member, friend, or loved one. One particularly unique and complicated relationship is that of a young adult cancer patient and a parent caregiver. Oftentimes, the caregiver wonders what role he or she will play in the care of their child. Does my son or daughter want me to get involved? If so, how much or how little? Or maybe they just want advice or want someone to listen. How do I ask and how do I know?

Sounds to me like we are talking about boundaries. There are family boundaries that have been established and there are organizational boundaries. When a young adult is diagnosed with cancer, the medical team will default to speaking with the patient directly. Sometimes, a parent caregiver can feel excluded from this conversation, or a young adult cancer patient can feel overwhelmed without parental guidance. Having a discussion with your young adult child to ask them what they need and want in these instances is crucial. Establishing an advance directive is imperative to understand and honor your child's wishes. This includes communicating to the medical team whether or not your child would

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like you to make decisions on their behalf if they are unable to do so.

Another important discussion to have with your young adult child is one about finances and insurance. This subject can be difficult because often young adults are trying to establish independence and are uncomfortable asking for help. Having a discussion to help identify expectations for how to pay for any treatment but also other living expenses and long-standing debt like student loans is another necessary step. Triage Cancer is a great online resource; they offer virtual webinars to assist in understanding the financial aspects of cancer. It may be helpful to inquire as soon as possible about financial counseling availability at your son or daughter's treatment facility to help with this conversation.

If you are working, at the earliest opportunity, reach out to your Human Resources department to inquire about benefits and necessary steps to help safeguard your job while you are caring for your child. Similarly, if your child is working, it is important for them to also reach out to their Human Resources department to communicate any changes to their ability to work during this time. Cancer and Careers is a helpful non-profit that offers information about how to broach these conversations and other resources on their website.

We know this sounds like a lot on top of caring for your most important person. However, if you leave these things to chance, you can risk the following: having the medical team make decisions for your child that you or child may not have wished, financial toxicity (high medical debt, defaulting on student loans, loss of a good credit score), leaving potential benefits that you are entitled to on the table, and potential loss of employment.

TAKING CARE OF YOURSELF

Enough of that, let's talk about you. You already know this, but being a caregiver for your young adult child can be challenging. We've all heard the flight attendants remind us to "always put your oxygen mask on before helping your neighbor," but when faced with a child with cancer, this can be hard to remember and even harder to do. As hard as it is, taking care of yourself is extremely important right now. Take some time to create a tool kit of ways you can take care of yourself when you need to recharge. ●

TOOLS FOR YOUR CAREGIVING TOOLKIT

Ten ideas to take care of yourself to get you started:

1. Ask questions! Find the resources you need to educate yourself on diagnosis, treatment, side effects, and what to expect for your loved one. Ask for help understanding or gathering this information. The more you understand about the disease and treatment, the better you will be able to understand and potentially anticipate any challenges as they arise.
2. Ask for and accept help. This can be hard for many caregivers. In the moment, it's easier to turn down help. Take time to reflect on ways that friends and family can help. Are there prescriptions that regularly need to be picked up? Can someone pick up a grocery order for you? Would it be helpful to have a few meals prepared for you each week? Does the lawn need mowing? If you have a list ahead of time of small tasks that would help you, the next time someone asks, it will be easier to provide a specific way they can help you.
3. Identify a small group of friends and family members that you can talk to. Who can you reach out to when you need to vent? Who can you call when you need help with the laundry? And who can you call when you need to laugh and talk about things not related to caregiving?
4. Keep up with your own doctor visits. While it can be easy to reschedule your own appointments and keep pushing them back, it's important to continue to take care of your own health so you can be your best when caring for your loved one.
5. Eat! Be sure that you are eating enough and eating well. Keep yourself hydrated.
6. Move! If you're in the hospital, take a lap up and down the halls. Walk to the cafeteria or step outside for a few minutes of fresh air. If you're at home, take a short walk down the street and back. You can have your phone on you in case your loved one needs something, but take the time to move your body and get some fresh air.
7. Identify the sources of your stress and write them down. Find a professional that you can talk to about these stressors – a counselor, clergy member, or your own medical team.
8. Tap into prayer, meditation, yoga, music, deep breathing, and art.
9. Write! Find a notebook or journal and write your fears, frustrations, to-do lists, and things you are grateful for. Get your thoughts down on paper.
10. Find peers who get what you are going through. Many hospitals offer caregiver support groups, and there are also many available through nonprofits. Connecting with other caregivers can help you feel less alone.

References:

https://www.hopkinsmedicine.org/about/community_health/johns-hopkins-bayview/services/called_to_care/what_is_a_caregiver.html
https://triagecancer.org/
https://www.cancerandcareers.org/en

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BY JEAN ROWE, LCSW, OSW-C, CJT

Once Upon A Time, I became an oncology social worker. When I entered that lane, I was already a writer and kept a journal. During my internship in the last year of graduate school, I was allowed to sit in on a cancer survivors' writing group that took place monthly. It was a creative, rich process where an intimate group gathered and shared. I remember thinking "I want to do this, too." Once in the field, I took a continuing education course about journal writing being a therapeutic tool with Kay Adams. From there, my path led me to become a Certified Journal Therapist through the Therapeutic Writing Institute.

In the midst of that, I started a cancer expressive writing group for all cancer survivors, and that is some of the most fun and meaningful work I've gotten to do yet. There were members of varying ages, genders, diagnoses and stages. It brought together an unlikely gathering of people who found their way with one another and to whom each became fiercely loyal. During that same period of time, I crafted, delivered and evaluated a variety of workshops on specific subjects connected to but not solely related to cancer's collateral impact. I continue to do so, particularly and wonderfully in partnership with Cactus Cancer Society.

Over time, a course evolved the theme (and sometimes the title) of which centered on "healing the healer" for healthcare providers, specifically nurses and social workers. This came out of my own experience with incorporating better boundaries around work and self-care (including while at work). I learned to actually leave my desk for lunch, to take walks around the beautiful neighborhoods surrounding the buildings where I worked and to leave work at work. This included acknowledging that the work would still be there in the morning. What this program for healthcare providers gave permission to was choosing ourselves first, what we often hear on and off of an airplane about putting on our oxygen masks first. You might or might not be surprised at the level of reluctance with which this is met when it comes time to put it into action. My experience in delivering and facilitating this work over the last 10 years continues to remind me that *self-care is a revolutionary act.*

Healthcare providers are really good at helping people. Among the list of roles served, we are problem-solvers, back patters, cheerleaders and space holders. This is all in the plus column. We are being of service which is, in large part, one of the biggest reasons we do what we do.

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Healthcare providers, like everyone else, can run out of steam and be vulnerable to compassion fatigue, to secondary traumatic stress, to burnout and to moral injury. Yet, societal norms (greatly impacted by the desire for immediate response) remain faithful to working late hours, answering calls and emails well past quitting time and worrying about the consequences if we choose differently.

The result over time will take a painful toll. In workshops, I hear things like "I stop what I am doing whenever I get an email from my boss, and then I never seem to finish anything on time." I then unpack that. Does your boss expect an immediate response every time? Was there urgency to the email you received? What would happen if you finished what you started? In that particular scenario, the participant paled at the idea of not answering right away. I encouraged her to treat it like a social experiment. She did, and here's what happened: she was able to complete assignments from start to finish; she was still able to answer her manager's emails in a timely fashion; and, most importantly, she felt better about it.

Here is where the oxygen mask comes in. In the healthcare provider workshops, we arrive at this (what initially is a very scary thing to consider) question: what would happen if you went home at 5:00? What would happen if you chose not to check work email after that time? What would happen if you chose to remove work email from your phone? See? *Revolutionary. This is Your Life Calling* is an invitation. We can keep moving at 90 miles an hour frazzled and depleted but for what reason? No tombstone will celebrate "worked late every night and never got enough sleep." Don't you want to reclaim your time? Don't your boundaries deserve recalibration? YES. I hope that is your answer.

Now, self-care can absolutely look like what my friend, Carissa, calls a "bed party." This involves pajamas, a device for watching your favorite show(s), your phone for texting with those you love, being under the covers on purpose, snacks within reach, and your favorite beverage. This also may be in the camp of what SARK means when she says "build a fort with blankets." It could also be as simple as a one minute meditation at your desk or placing a hand over your heart as suggested by Tara Brach telling yourself "Dear One, it's all right." Or how about moving into child's pose right there next to your desk? I encourage you not to underestimate the power of a small shift in self-care.

Then write about it. For five minutes. What happened? In your thoughts? In your body? How do you feel?

The goal is not to do something "right" or be seduced by perfection or comparison. I find myself saying often these days that real change is manifested in baby steps rather than a grand gesture. Start now. Start somewhere. Try. Failure is not even a part of the process. There is no one right way to do it. Your way of doing it is right for you.

Here is what past healthcare providers either agreed or strongly agreed about:

1. They could identify ways to nurture self-care through expressive writing;
2. They could describe journal techniques useful for stress management; and
3. They could list reasons why expressive writing supports the healing process.

Come join me and learn a simple tool for yourself. You are worth it, and these steps are ones that have always been options. As Glinda said while waving her wand towards Dorothy's shoes in "The Wizard of Oz," you've had the power all along. ●

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TO CARE ADEQUATELY

BY DIANA M. CEJAS, MD, MPH

I thought that we could be better than this. I knew it in my heart. I had learned, when I was small, how to care for things. The flowers blooming in our yard. The turtle that I'd found on the edge of the woods. A stray kitten that had climbed into Mama's car. Even when it hissed and spat and scratched my sister's ankles. "You have to be gentle," my mama said, and I was. I didn't trample the flowers and fed the turtle apples from the tree down by the road. I let it go and settled it on a rock in the sun. The kitten tamed itself soon enough.

I learned that when things are scared, they can hurt you. That sometimes they mean it, but not as often as you'd think. That sometimes they're scared because they are hurt too. I held onto that lesson through my youth. Through arguments, relationships, past people who had been broken and meant to cut me on their teeth. Into adulthood, then medical school.

I knew what it was to be alive. Had been with a calf as it took its first breath. Had been with my cousin after he took his last. I wanted to help people. To make them feel as good as they could for as long as they could. To figure out how to disentangle arteries and nerves and follow them like a path, to find the pathology when I got to the end, to wave it away with my hands. My professors warned me to be gentle. If you went too fast, your scalpel would tear through the muscle. I spent hours in the lab, picking flesh and fat and fascia, dissecting slowly, trying to get it right. My attendings directed me to be gentle. How to hold the needle, the reflex hammer, the endotracheal tube. How to move them just so. How to get it just right.

And so I thought that everything was just this way. Though we see people at their worst, carve their bodies up with knives, poison them to prolong their lives, I thought that we knew how to care. That we knew that delicate things come with teeth. I thought, if nothing else, that we could fake it.

I know how it feels to say the worst thing that person has ever heard.

I know how it feels to hear the worst thing that I have ever heard.

I remember his face when he said it. I remember how it felt when he said it. The cold plastic seat holding me up. The way my wound itched and ached. The look on his face like he had already gone. Like I stood between him and his coffee.

I think I know now how the kitten felt. I think I know now how to bear my teeth.

THE EXCUSE FOR EVERYTHING

BY DIANA M. CEJAS, MD, MPH

My occupational therapist swore to me that no one would ever know. If I exercised everyday, squeezed the putty between my fingers – first the yellow, then the green, then the blue – if I lifted my shoulder three different ways, ten times apiece, five times a day – if I dragged my hand across cotton, metal, sandpaper, and glass, then maybe, one day, I'd be able to feel it. I have good motor function, she said. It's just clumsy. A little slow. "We can work on that," she said. My movements would never be graceful.

I tried to teach myself to play the violin when I was twelve. My grandfather's guitar at twenty-two. Each sits silently in my living room. I have dragged my fingers over each fret, the gut, the nylon, the steel, and still. I feel pressure, static, pain, nothing. Still. My arm looks good, my physical therapist said. If I hold it just this way. My movements would never be graceful, she said, but no one will ever know.

My neurologist said that the pain in my shoulder was because of the tension in my muscles because of the signals that weren't getting through the rind of scar tissue in my brain. Said that physical therapy would help, that shots would help, that patches would help, that pills would help, that I looked so good when I lied and rated my pain a "3." No one would know all this happened to you, she said. It was fine to have a "3" a year after a stroke. Nerves take a long time to heal. A "3" that is a "5" or a "7" in reality is a pain that can hide when it wants to.

My doctors are impressed with my recovery. No one would ever know, they say. I drag my hand across polyester and wool, feel pinpricks, feel numbness, feel the pain in my shoulder. It is a "7" today. A "9" yesterday. I smile and rate it a "4". No one would ever know, they say. But I know. I know. I do. ●

Editor's Note: The above are two reflection pieces written by Diana M. Cejas, MD, MPH, on the importance of caring adequately and being a healthcare professional in the cancer community. Please join Dr. Cejas during YA Cancer Gabfest as she leads an interactive panel discussion on Burnout as a Cancer Professional.

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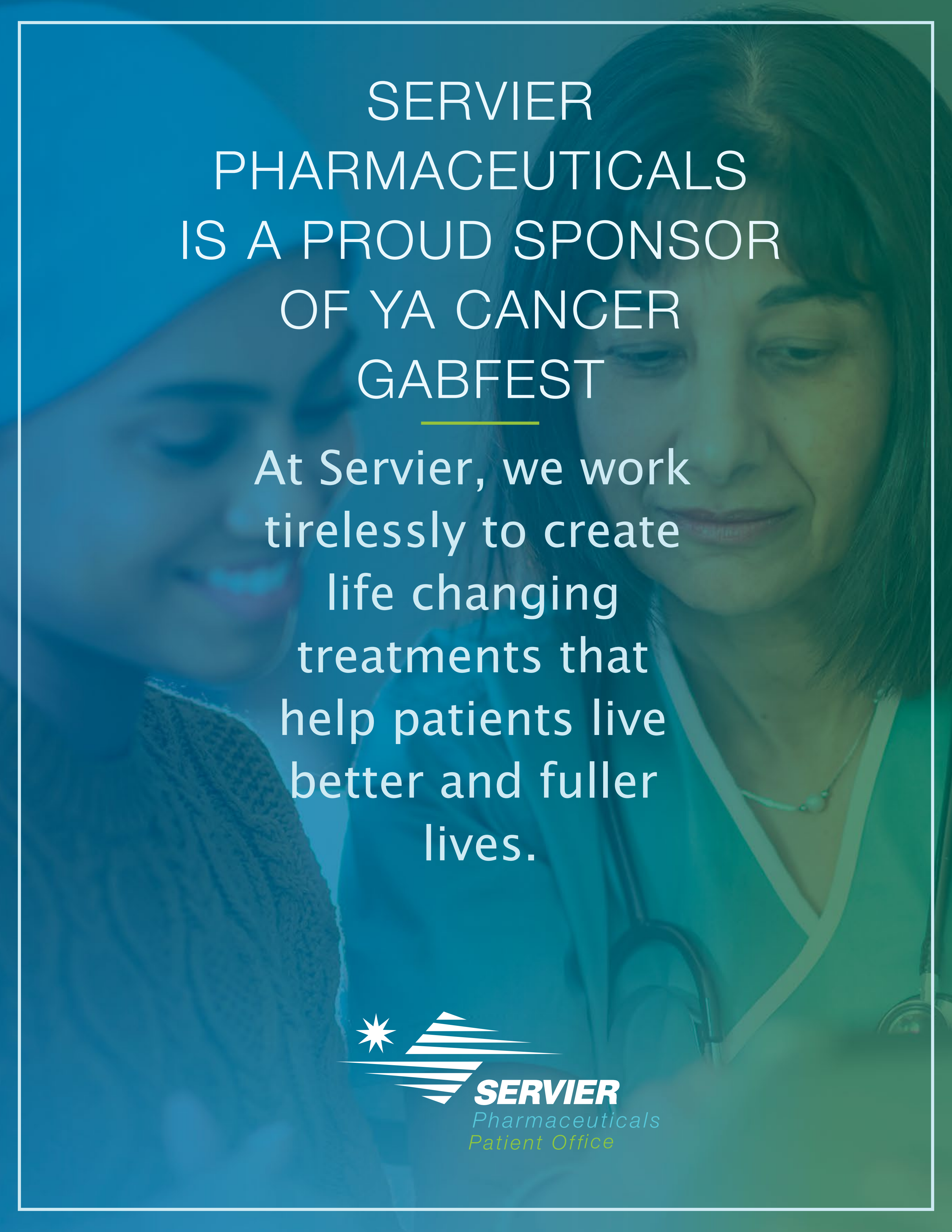

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