



THE ELEPHANT IN THE ROOM IS CANCER. TEA IS THE RELIEF CONVERSATION PROVIDES.

ELEPHANTS AND TEA

JUNE 2019

← Steve Giallourakis,
two-time cancer
survivor



MY NAME IS STEVE
I'M A DRUG
ADDICT

THE STORY OF HOW MY CANCER
LED TO ADDICTION

PLUS

THE FRECKLE
EFFECT

P. 4

HOW I OWNED
CANCER

P. 18

P. 6

I'M IN
REMISSION!

P. 20

KEEP
CALM



ABOUT TRIAGE CANCER

Triage Cancer is 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.

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- Accessing clinical trials
- How to work through treatment or take time off
- Applying for disability insurance
- Estate planning and other important documents
- Managing medical bills, finances, and getting financial help
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Learning to Be a Brother and Not a Coach

Alysse. Phil and Alysse have had their first child, Alana. We both have moved to different parts of Ohio after living together in Lakewood, Ohio.

We sat there throughout the night having our adult beverages, laughing and making fun of each other until it was time for us to head home.

I can honestly say it was one of the happier moments I've seen Steve in a long time. He just started a new job and seem to be in love with it.

WHAT IS THE "NORM"?

On my drive home I began to think and reflect on what Steve has done in the past 10 years.

For context - Steve is now 28 years old and a two-time cancer survivor.

In our society I feel we judge each other based on our accomplishments, career choices, partner choices and whether or not we have kids. Let's not forget having a college degree.

Steve was 18 when he had his BMT and he is still in college, still trying to get a full-time job, not married and doesn't have any kids (that we know about).

Does that mean that Steve is unaccomplished compared to Phil and I, who are both married both with college degrees and Phil has a kid? Absolutely not.

What Steve has gone through by staring death in the face (twice) like other cancer survivors, we forget as the emotional toll it does to an individual and we need to remember that what patients go through is something that most people will never go through until we're old. Like Steve and many others that are still trying to "find the right path" we forget that it's OK just to live life and have fun as normal human being.

Those of us that haven't lived with cancer do not realize what it is like to live in a bubble

or be poked on an hourly basis for tests. We don't know what it is like to have a scan next week to see if the "C" word is back, relapse and be staring death in the face yet again.

10 years is a long time. But 10 years for someone that had a BMT isn't just a long time, it's a second chance at life.

As a brother of a cancer patient and survivor the emotional toll that it takes on us is not the same as that of the actual patient but it's still one that people forget about. Phil and I have finally learned to not get angry at Steve when he does things that aren't of the norm.

But again, what the hell is the norm?

BEING A BROTHER AND NOT A COACH

We need to forget what the norm is or what society thinks a 28-year-old should be doing with their life and be able to accept that there isn't a norm.

As difficult as it is for a brother watching their loved one go through the challenges of living with cancer, we need to be supportive and not try to tell him or her what to do all the time.

Rather than getting upset at them we need to just be there, sit with them, have a drink and learn how to just shut up and be supportive.

I challenge my fellow family members and friends of those fighting cancer to do the same.

This has been one of the hardest things to admit but it is important to just be supportive rather than trying to coach Steve up.

Survivorship is a journey and I hope those reading this month's issue come to understand that just because treatments are over the journey is just getting started.

➔ **NICK GIALLOURAKIS**, PRESIDENT AND CO-FOUNDER OF **ELEPHANTS AND TEA**

BEING A BIG BROTHER and trying not to coach up your little sibling is one of the hardest things to do. Well at least if you have a brother who is smarter than you when it comes to all science and medicine topics. Let's be honest here, if it isn't sports related my little brother probably has me beat. O and he doesn't have a college degree. Does that matter?

FLASHBACK

Where were you on March 27th, 2009? I was having reconstructive elbow surgery and that wasn't the most important part of that day.

My younger brother Steve was having his bone marrow transplant (BMT).

Prior to understanding how the bone marrow was going to be administered to Steve, I thought it was going to be some intense surgery. I was amazed that it was being administered as an IV drip. Technology is amazing.

PRESENT

On Wednesday, March 27th, 2019. Steve, Phil (older brother) and I found ourselves at our friend's bar called Mars Bar in Lakewood, Ohio celebrating with some family and friends Steve's 10th anniversary since his BMT.

The look on all three of our faces said it all; relaxed and happy.

Steve looked at Phil and I and said, "I can't decide if it feels like forever ago or like it happened yesterday."

I couldn't agree more with Steve's statement to us.

We all went on reminiscing about what we all have done in the past three years. I married my wife Camilla and Phil married his wife

JOIN THE CONVERSATION

IF YOU WOULD YOU LIKE TO SUBMIT A STORY TO BE PUBLISHED IN **ELEPHANTS AND TEA**, PLEASE CONTACT NICK@ELEPHANTSANDTEA.COM



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AND
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THE ELEPHANT IN THE ROOM IS CANCER.



10

THE STORY OF HOW MY CANCER LED TO ADDICTION

Conversations

- 1 LEARNING TO BE A BROTHER AND NOT A COACH
- 24 HOW RACE CAN AFFECT YOUR CANCER PROGNOSIS
- 28 MOM'S 6 TIPS: STAYING WELL DURING CANCER TREATMENT

Emotional Support

- 4 THE FRECKLE EFFECT
- 18 HERE IS HOW I OWNED CANCER

Survivorship

- 6 I'M IN REMISSION... NOW WHAT?
- 8 THE SECOND WIND: SURVIVING CANCER
- 17 MOVING CONNECTION ONLINE

Sexuality

- 14 IT USED TO FEEL SO GOOD. NOW IT FEELS SO BAD

Jen's Corner

- 20 KEEP CALM AND CARRY ON: LIVING WITH SCANXIETY
- 22 LIFE IS HARD ENOUGH. FRIENDS CAN MAKE THE JOURNEY SO MUCH BETTER.



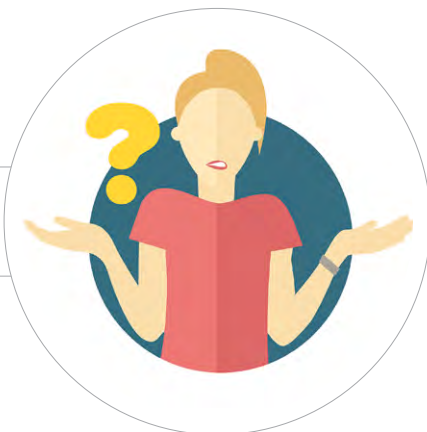
{ What's Online }

CHECK OUT OUR WEBSITE FOR MORE CONTENT.
WE UPDATE NEW STORIES WEEKLY FROM PATIENTS,
SURVIVORS AND CAREGIVERS. SOME OF OUR LATEST
STORIES INCLUDE:

IT IS OK TO ALLOW
YOURSELF TO FEEL
By Urska Kosir



I HAVE NO IDEA
WHAT I AM DOING
by Kirsten Efremov



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The Freckle Effect



Even on days with the worst brain fog, I can easily remember the busy summer morning of June 2015.

While getting ready for work, I noticed a small lump in my left armpit. Believing I was a healthy, 35-year old female with no risk factors for cancer- I assumed that my body was fighting a germ and went about my day. Unfortunately, after multiple tests and a needle biopsy, I received a phone call from my doctor stating, “your biopsy came back positive for cancer”.

I was paralyzed with shock- in absolute disbelief by her words.

Before my diagnosis of cancer, I learned some harsh life lessons. I became a widow. Life is fragile, precious and short. After my husband David’s death I adopted a mantra for myself and young son Caleb: “live in the moment”.

At the time, I really believed that I had learned the life lessons that were meant to transform me. It wasn’t until I was diagnosed with Stage 3 Triple Negative Breast Cancer, that I would fully comprehend the value of living in the moment!

I remember sitting in the breast surgeon’s office on a beautiful sunny day in mid-July. She calmly explained my aggressive, difficult to cure, type of breast

"Instead of viewing these melanin-inspired growths as another side effect of treatment, I chose to look at them as a reminder. ... to 'live in the moment' and truly view them for reflection and gratitude."



cancer and the treatment options. The schedule of my upcoming tests, scans, surgeries and infusions sent me into a tailspin of fear.

The fear of the unknown was quickly replaced with fear for my son. What if I die? Who will teach him the life-lessons that I know... who will support his dreams and quiet his fears? Who will love him unconditionally like only I can? After that appointment, I frantically began Googling my diagnosis, but more importantly my prognosis.

The treatment predictions weren't great, but what other choice did I have?

There was no time to dwell on the fear and anxiety I felt. I quickly assembled my healthcare team to handle this diagnosis and had my port inserted the first week in August and a few days before Caleb's 4th birthday. It was Caleb's excitement over the superhero-themed birthday party that drove me to reassess my mind-set. I was preparing for the ultimate battle – the battle for my life.

I knew then that I was not going to be able to manage working full-time and maintaining home life with the intense treatments, side effects and surgeries on my own. Hence, the love and support from friends and family is what allowed me to trust the proposed treatment plan without hesitation. The opportunity to be Caleb's Mom is what got me out of bed every morning; in spite of the emotions that I was experiencing.

Over the next fifteen months, my body evolved into becoming a fierce, determined warrior. I transformed the energy of fear I felt into purposeful action and was able to successfully complete 16 rounds of infusion chemotherapy, a double mastectomy with lymph removal, 25 rounds of radiation, eight rounds of oral chemotherapy and finally breast reconstruction while working full-time.

Caleb's unwavering support, love and simple childhood excitement is what inspired me to stay focused and moving forward.

The human body is amazing and so resilient! I am astounded by the amount of trauma and abuse it can withstand and still "look healthy". It wasn't until I received my survivor care plan in early 2017 that I finally stopped to take inventory of mind, body and soul. Reflection is a useful tool – without it we miss an easy opportunity for growth.

One of the many changes I noticed in my physical appearance was the amount of freckles that I had compared to that summer morning in June, 2015. Instead of viewing these melanin-inspired growths as another side effect of treatment, I chose to look at them as a re-

minder. Not a reminder in the traditional sense of remembering the terrible experience of cancer treatment. Instead a reminder to "live in the moment" and truly view them for reflection and gratitude. Instead of being angry over the changes my body has gone through, I choose to embrace how remarkable I am.

Gratitude is defined as, "the quality of being thankful; readiness to show appreciation for and to return kindness."

Early on in treatment, I was grateful for the side-effect management tips and tricks I learned and the unsolicited love and support that I received from family and friends. Before diagnosis, gratitude had always been a buzz word during therapy sessions, it wasn't until I was faced with life -and the limited options I could pursue to enjoy it- that I understood how important this appreciation can be to maintain focus.

My therapist has always advocated for a gratitude journal- me being the non-conformist- it took me years to finally start one. Caleb and I started the simple exercise of acknowledging what we are grateful for every day as we are driving home. Caleb's seven-year old perspective of appreciation is the most rewarding part of my day and easily illustrates how amazing and precious our lives are!

As a 38-year old female, I have faced more decisions than most people my age. We can allow our traumas to define us or we can use the traumas to transform us. I get a choice of how to view the new freckle I found this morning.

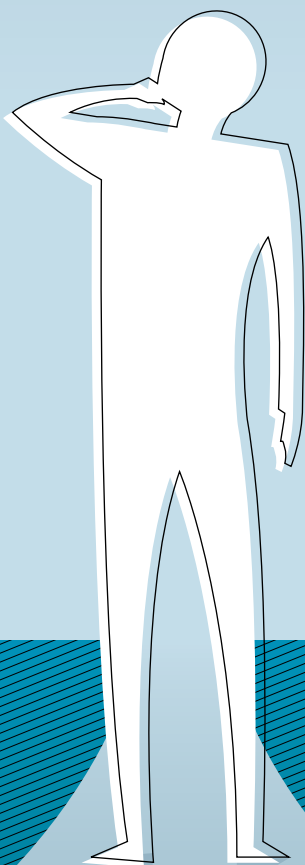
Today, it illustrates to me where I have been but also where I am going- and I am filled with gratitude! Navigating life and the experience of cancer offers one final choice with your survivor care plan. You can either reflect on the journey by thinking about what cancer has taken away or you can be grateful for the valuable lessons and perspectives that it can illuminate.

I use the "freckle effect" as a reminder of my daily gratitude to be here for not only my son but for ME!

BY ERIKA JANE, SURVIVOR

I'm in Remission... Now What

?



HEY THERE, MY NAME IS MITCH AND I HAVE STAGE IV SOFT-TISSUE CANCER. IT'S A REAL BUMMER. I got diagnosed when I was 20 and if we're gonna be honest with each other, it's put a real damper on the first half of my twenties. All my friends graduated college and went off and got cool jobs and I had to drop out and move in with my mom. She's a sweet lady, but not my ideal roommate. Anyways, I'm not here to talk about the negatives of cancer. Rather, I'm here to talk about the exact opposite: what happens after cancer.

I was diagnosed with terminal stage IV synovial sarcoma and was given a few months to live. I was diagnosed in July of 2015 and was told it was unlikely I would make it to the holidays of that year, so about six months. Ready for a real plot twist? I actually survived past that time. Crazy right? It's true. That's how I'm sitting here, writing this article in the year 2019. But a lot of shit happened between July 2015 and today, including about eight months of remission.

It was pretty dope news when I got my scan results from my oncologist and he told me that after 28 cycles of chemotherapy, 12 weeks of radiation, and one open-heart surgery, I finally had no visible tumors. It was amazing, I figured I was finally going to be able to go off and live my life the way I wanted to again. In a way, I was right.

But in a much bigger way, I was like a 13-year-old dating their cousin: just plain wrong.

You see, you never really stop having cancer. It's like a dark shadow that is always looming behind you, just waiting for the day when it can show back up and ruin your life all over again. Statistically speaking, the odds of your cancer recurring don't really start to dwindle until after five years of having no sign of recurrence. So that's 1,825 days you must spend fearing that today is the day it comes back. And even after that, it is still possible, just less likely. So now that I've introduced some extremely pessimistic stats and concepts like an absolute ass, let's discuss the matter at hand: sur(thr)iving in remission. Like that pun? Surthriving? Just thought of it. Pretty clever.

After my eight months of remission, I was utterly relieved to hear my cancer had returned. Seems odd, but the truth is the waiting is the hardest part. Not knowing whether something is wrong and whether I may be letting my cancer grow uncontested is so much worse than just knowing the enemy at hand and taking steps to resolve it. It is to me, at least. I felt like a bag of popcorn: I had all kinds of tiny seeds in me, and I was spinning around the microwave just waiting and waiting until they all suddenly would start to pop and grow. So if you want to enjoy your remission and not spend it feeling like an anxiety-riddled low calorie snack, I came up with a four step process to achieving that. I call it the SGK method (not as clever as surthriving but whatever. I'm not Mark Twain, leave me alone). It goes as follows:

- 1 START RECOVERING
- 2 GO LIVE
- 3 KEEP YOUR HEAD IN THE CLOUDS
- 4 CONTROL YOUR DESTINY

Let's break it down step by step and get you on the path to living the shit out of your remission.

START RECOVERING

You probably just finished chemo or radiation or surgery or something like that, so you probably feel like a half-full bag of NYC garbage sitting on a sidewalk on a hot summer's day. It's OK, that feeling goes away if you treat yourself right.

At first, treat yourself. Give yourself a nice pat on the ass for surviving treatment and go eat some cupcakes or something. Take naps. Do whatever it is that you haven't been able to do or enjoy while you were in treatment. But once you do those things, you gotta get your head back in the game. If you want to stay healthy, you got to be healthy. Drink lots of water, eat your veggies, exercise, meditate, use essential oils if you're into that kinda thing. Do what you can to make your body a well-oiled machine. I have no idea if this helps prevent cancer, but it can't hurt to try and get your body back into fighting shape so that if/when your cancer does return, you'll be fit as a goddamn fiddle for treatment round two rather than an amorphous blob dragging its lazy ass back into the hospital. It also helps you mentally. When I went into remission, working out gave me the confidence that I was still creating positive change that was helping my fight against cancer, even if it was only in my head.

GO LIVE

You've been given a second chance at life, make the most of it. Get started on this once you've recovered enough and you feel like a human again. If you have stuff on your bucket list that you were waiting for the right time to accomplish, now is that right time. And if you don't have a bucket list, start one. It'll force you to get out there and have cathartic experiences. Don't pigeon-hole yourself to just experiences like vacations or sky diving though.

A bucket list can be things like getting into the habit of reading or picking up knitting or some shit like that. Don't think the only way to live is to go out and spend money on experiences, because if you were anything like me, you're probably broke as a joke cause you just spent the last year fighting cancer instead of earning money. For me, I made it my goal to get the hell out of my mother's house and live with my friends during remission. So I went out, got a better job, and did just that. It wound up being one of the best years of my life living with those guys and it

made me feel like I was making up for the senior year of college I missed out on.

KEEP YOUR HEAD IN THE CLOUDS

It's important to keep your mind clear of negative thoughts or influences. If you let the bad shit in and start fearing what might happen, it can consume you and ruin what time you have. I would recommend getting a therapist if you can. I didn't get one until after my remission had ended and she has done wonders for my mental health. I wish I'd had her earlier to guide me through the negativity that can come with stopping treatment.

Remember that the recovery stage is important for your physical health early, but your mental health should be a focus for the entirety of your remission. I didn't really believe in stuff like meditation, acupuncture, aroma therapy, etc. until I tried it and it really does help. There are even mindfulness apps you can download that have guided sessions for free that can help you to keep a positive, optimistic outlook. If you're not into the whole mindfulness thing cause you think that shit's for hippies, there are other things you can do to keep your

mind occupied like finding a hobby or taking anti-anxiety medications like Ativan (though try not to rely on these, their effects fade over time which means you'll find yourself taking more to achieve the same results over time).

CONTROL YOUR DESTINY

Fear is the one thing that can really ruin your remission like it did for me. What got to me the most was feeling like I didn't have control over my own life. I felt like the dormant cancer inside of me was controlling me, rather than the other way around. I think the key to keeping this fear from ruining your mental health is to find a way to get control. Everyone has different beliefs, which means that everyone will have different ways of gaining that sense of control and feeling like they are the ones driving their future. It's important to look into yourself and find what that action may be for you. Maybe it's meditation,

maybe it's working out, maybe it's eating healthy. Whatever it may be, find that sense of control and keep the fear out.

These are my four steps for enjoying remission, but don't think of these as hard-and-fast rules. Maybe you have a different set of steps for enjoying your remission, and that's fine. Just make sure you find what the process is that will help you to live your life as meaningfully as you can.

After all, life can be pretty fun if you know how to live it.

"If you have stuff on your bucket list that you were waiting for the right time to accomplish, now is that right time. And if you don't have a bucket list, start one."



← **MITCH LORTZ** WAS DIAGNOSED WITH TERMINAL STAGE IV SYNOVIAL SARCOMA AT THE AGE OF 20. HE IS NOW 24 LIVING IN BOSTON, MA WITH HIS FIANCE, SYDNEY AND DOG, MEATLOAF. YOU CAN USUALLY FIND HIM AT MASS GENERAL HOSPITAL BUT HE ALSO SPLITS HIS TIME BETWEEN HIS PROFESSIONAL CAREER IN MARKETING AND MANAGING HIS PERSONAL CANCER BLOG. IN AN ATTEMPT TO USE HUMOR AND A POSITIVE ATTITUDE TO PROMOTE WELLNESS, MITCH HAS BEEN WRITING FOR HIS BLOG [ARE YOU FOR SERIOUS?](#) AND COVERS TOPICS RANGING FROM THE POSITIVE ASPECTS OF CANCER TO DEALING WITH HEMORRHOIDS AND OTHER CHEMO SIDE EFFECTS.



The Second Wind: Surviving Cancer

When I think of the word “survivor”, it doesn’t feel like it applies to me. Although I’ve been in remission for nearly three months, it’s still like, holy shit, I had cancer. I just experienced an epic fight inside of my body to rival the battle scene from the movie 300.

Ring the bell (at Seidman Cancer Center at University Hospital in Cleveland, OH) and receiving the honorable title of survivor should have made me feel incredibly bad-ass. Instead I was left feeling like a Spartan- outnumbered, unarmored and wearing sandals to a fight. Unprepared for victory.

It’s one thing to accept the diagnosis of cancer as a young adult, but it’s a whole different monster accepting what I went through and will continue to experience during my lifetime.

I feel like I have PTSD (post traumatic stress disorder). I worry at every ache or pain- thinking, “What if I’m sick again?”. Thinking about this battle continuing for any longer is distressing, but sometimes it’s hard to fight those negative thoughts.

Being poisoned for the last seven months has left me reeling with a litany of issues. I am struggling to comprehend what the F just happened to me. Nobody told me about this part.

Everyone made it sound like survivorship was all sunshine and rainbows, but it’s been quite the opposite.

Right after chemo was over, I was immediately excited. I was all, “I’m gonna go climb a mountain and skydive like next month, I’ll feel better by then”. Much to my disappoint, I quickly figured out that treatment is a rite of passage into survivorship- but it doesn’t mean that all of a sudden, the battle is over.

When I list all of the things I can physically and mentally do compared to what I can’t do post-chemo, it’s terribly disappointing. I’m still impossibly exhausted, I sleep for 12+ hours every night which can be really depressing.

My right leg is always numb and as a result, I have trouble walking. My body is all out of whack, I’m either sweating profusely or shivering, or both at the same time. I’m still hair-less.

I feel like someone removed my brain, put it in a blender, shaped into a Jell-O mold brain-looking structure and put it back in my skull. I forget things easily, I’m cloudy and foggy, and I’m often emotionally distressed.

I feel like that toddler in the mall that you feel bad for because his parents have him in a monkey backpack with a leash for a tail. Every time he runs away he’s snapped backwards by the tail-leash. Making progress, then back where he started. One step forward, two steps back.

By the way, when I was a toddler, I was that kid in the mall, constantly trying to explore on my own and run away, much to the upset of my parents and mall security...

In the midst of all this darkness and uphill battle that has been cancer and survivorship, I cannot ignore all of the amazing and wonderful things that have happened since I became a survivor instead of a patient.

I’ve tried my best to see the positive side of the negative experiences that I’ve had the past seven months and when I list the negative things that have happened to me versus the positive things, I quickly realize that the good outweighs the bad- by far.

I learned a lot about myself and I feel a sense of self-assurance that I’ve never had before. I learned who was truly there for me- whether it be family, friend, or acquaintance.

My relationship with my father is stronger than ever, and my mother and I are closer than we were before cancer.

I’m much more confident than I was before cancer. I’m 25 years old, I used to have thick, wavy hair. I was blessed with pleasant features, I have big brown eyes, I’m 5’9 and pretty slender, used to have long eyelashes. I always was confident in my appearance, but I never truly appreciated myself.

Hannah hanging out
at CancerCon

Treatment caused me to gain almost thirty pounds, my face was always swollen, I lost all of my hair, and my skin often looked grey or washed-out. Looking like a pudgy, female version of Mr. Clean left me feeling like the ugliest woman in America.

But, feeling this low about my appearance made me appreciate the way I used to look and how I look now so much more. I used to never go anywhere without a hat or wig. I never let anyone other than my medical team, my dad, boyfriend, or roommates see me without something covering my head.

Now it's like, this is my bald-ass head, I look like an alien but I just beat cancer and I'm beautiful and this is just what I look like now... not forever. I have some battle scars, but I am woman, hear me roar. Ya know?

I was given a second chance at life that most people don't often get. I learned what I want and what I don't want. I learned to not compromise on things that are important to me. I learned to stop apologizing for being myself and to stop apologizing for being honest. I have new goals and new aspirations that I fully intend to fulfill.

Being a survivor of cancer isn't all about remission and clean scan results or checking boxes. You can read all of the blogs and pamphlets, you could have the best medical team and support system in the universe, you could be in my position and have a curable cancer.

But beating cancer and reaching remission is like quitting smoking or losing weight. Unless you change your mentality and lifestyle, you'll struggle- before, during, and after treatment.

Surviving is about acceptance- of the disease, and of yourself. Trust me, I learned the hard way.

People often say, "I'm so sorry for you" or "How do you deal?". My response? Cancer is the best thing that ever happened to me.

Don't get me wrong- it scared the living shit out of me. But it taught me more than I could have ever learned in my natural existence... it taught me how to live a whole-some and full life full of love, happiness, and security.

And for that, I will forever be grateful.

➡ HANNAH STARKEY, SURVIVOR



MY NAIM



STEVE

I'M A DRUG ADDICT

HOW MY
CANCER
LED TO
ADDICTION



WHAT IS YOUR STRONGEST

strongest. The type of memory that creeps your mind when you're alone. The type and you feel as if you can hear the actual get loose and be heard.

For me it was a day that I had 5mg morphine pushed straight into my heart. The morphine injected into Steven's body mediport in order to rapidly relieve him of recall anything other than how it made that every cell in my body was feeling pure I remember. This is my strongest memory.

This is what crawls back into my mind when it's quiet. It is my memory that I feel scratching at the inside of my head begging to be remembered. This memory has affected me more than I would have ever cared to admit, until now.

My name is Steven Giallourakis and I am a drug addict.

I was 16 years old the first time I realized that I was a drug addict. I obviously didn't admit this to myself until couple of years later. I don't recall the exact day, but my father was asleep on his leather chair. My mom had already gone to bed and I didn't feel well.

I felt very alone and very sad.

Two months earlier I had just finished my treatment for my first cancer. It was a 10-month journey filled with two spine surgeries,

MEMORY?

I mean your to the front of when it's quiet memory trying to

(milligrams) of (Editor's Note: was through his severe pain). I don't me feel: a sensation ecstasy. That is all



In my early twenties my drug use was at its most rampant. I had just finished treatment for my second cancer. I was suffering immense amounts of pain due to my Graft Versus Host Disease (GVHD). For those of you whom are unfamiliar with GVHD let me explain. When someone has a bone marrow transplant, the immune cells that grow might not be used to your body. When they are not used to your body, they are essentially many dogs in a new house. It's not that they don't want to be there, they just aren't used to the house. So, the dog pisses, shits and nibbles on everything. Now imagine the dogs are your immune cells and the house is your body. That is GVHD.

Because of my pain, I was being prescribed essentially any drug I wanted. I was being prescribed monthly doses of Percocet. I was essentially stoned for an entire year. I was taking 2.5mg/325mg Oxycodone HCl, acetaminophen (Percocet) every 4 to 6 hours...for a whole year. Let me tell you, it was one of the favorite years of my life, but it was also one of my most lonely years. Living alone I had no one around to really see what I was up to. When I wasn't throwing parties in my apartment I was stoned. All I wanted was to not feel the way I did. My body was crying out for relief and my mind was simply trying to cope with the physical and emotional anguish I was experiencing.

I felt so alone. I was unable to put to words what I was feeling. It was during this year that I first thought of taking my own life.

I never imagined I would even contemplate suicide but let me tell you, the sweet repose of death seemed very alluring. I never actually planned anything, but the thought would reside in my mind from time to time. This type of drug use and emotional struggle would continue for the next couple of years.

It wasn't until I was 23 years old that someone finally spoke up about my drug use. I was dating a very nice girl. She had also been through some things in her life that allowed her an intimate look at drug addiction. She had someone very close to her have problems with drugs. So, when she was dating me she picked up on the signs of my drug use very quickly. It was this first time my drug use would end a relationship for me. She told me that I was on my way to being out of control and that she couldn't watch or be with someone else that has these issues. I don't recall being too receptive. Truthfully though she might be able to tell you more accurately what happened because I was probably stoned when we talked.

During this time, I was also struggling with school. My brain was having a hard time handling the type of stress that school throws at you. Halfway through every semester the same thing would happen to me. My stress would build, and I would take drugs to cope. I didn't know how to handle real life and because of that I struggled in school. My grades reflected this trend. If I finished a class, I got a good grade.

countless chemotherapy treatments and five weeks of radiation. During those 10-months I developed a fondness for my pain medication. I didn't have that much pain that night, but I was sad and feeling alone.

Morphine can be a lonely person's best friend. It's like a warm blanket that encompasses every inch of your body. Unfortunately, that night I misplaced my morphine pills. I first looked in my bin of drugs to see if I left them in there. Then I searched my bathroom and my brother's room and then my parents' bathroom. I found myself back in my room tearing it apart. My heart was pounding through my chest. I thought to myself, "where in the hell did I put them?". I turned my room inside out trying to find them.

Then I looked in the mirror and saw what I looked like. I looked like a mad man. I was panting and sweating. My hands wouldn't stop shaking. What was happening to me? Why was I doing this? I decided to lay down. I tried to calm myself. I shut my eyes, but the silence was deafening. All I could hear were my own thoughts. As if my insides were crying out for a sweet release from this internal pain. After hours of feeling like this I managed to fall asleep.

That night would be marked as the beginning of my abusive romance with opioids.

This romance would last the next 10 years. The effects of my addiction echoed throughout my life during that time. It affected everything from my schooling to my relationships.



National Suicide Prevention Lifeline • 1-800-273-8255
<http://suicidepreventionlifeline.org/>

Substance Abuse and Mental Health Services Administration • 1-800-662-HELP (4357)
<https://www.samhsa.gov/find-help/national-helpline>

However, I rarely finished a class. I usually ended up with a “W” for withdrawing during the semester.

After having this happen so many times, I was suspended from school. I had been struggling to get through school ever since my second cancer. That was six years at this point from my first cancer. Six years of staying in the exact same fucking place. Six years of watching the world pass me by. It was in that moment that I felt more lost than ever, and yet in this moment someone would emerge to help me.

I reconnected with someone I had known since I was a young boy. We spent the next two years talking and spending a few wonderful moments together. She would become the greatest love of my life. It was only with her by my side that I was able to step back from school and reevaluate my life.

During this first two years of our relationship I still struggled mightily with my addiction. She would take the brunt of my addiction for those two years. I would forget so many things we talked about. I would forget I needed to pick her up from places or take her places. The worst is I would take my meds just before bed so I could enjoy the high at a quiet time of night. Unfortunately, I wouldn't sleep and then I would miss taking her to work.

Over the course of those two years she helped me understand my addiction in order to tame it. However, as we all know, one can't change unless one wants too. I didn't want to. I remember thinking “I have my addiction under control”. I did not have my addiction under control. It wasn't until a specific incident occurred that made me really want to change.

In February of 2016, I went to my palliative care doctor. I live in Ohio and just three months prior medical marijuana had become legal. I came into my doctor's office to inquire about the new law and what it meant for people like me. The appointment did not go the way I thought it would. After inquiring about medical marijuana my doctor gave me a rather unexpected response. He told me that there was no evidence to suggest that marijuana would help. Also, that my best bet was to try and pick up some pot from some bum on a street corner...yes my doctor said that to me.

Before I even had a chance to be outraged, his Fellow handed me three one-month prescriptions for my favorite opioid Nucynta. I hadn't asked for any drugs, I just was asking about medical marijuana! In fact, an already prepared prescription for Nucynta was waiting for me prior to the appointment. In that moment I felt so betrayed. I felt like the doctor did not have my best interest in mind. I tore up the prescription and told him that he was the reason why we had an opioid epidemic in our country. I left his office that day swearing I would never go back. More importantly I thought to myself, I will never take another opioid ever again.

Since that day in my doctor's office, I have not touched an opioid. The struggle to stay sober has been much more difficult then I ever could have imagined. I have gone through withdrawal before. I have had those terrible night sweats and I have had days where there is nothing, I can do to satiate that craving: Where every second of my body is burning from the inside out and all I want is the sweet release from this agony.

PHYSICAL DEATH ASIDE, I
FIND THERE IS NO WORSE
THING THAN LOOKING
IN THE MIRROR AND
REALIZING HOW MUCH
YOU ARE WASTING.
WHEN YOU REALIZE HOW
MUCH TIME AND MONEY
YOU HAVE THROWN
AWAY BECAUSE OF THIS.

I am now in an entirely different battle to stay sober. The first year was by far the worst. I hadn't really talked to my doctors about what I was trying to do. I did not have the support that I initially needed to succeed. Thankfully my fiancé at the time, was incredibly supportive. I would have nights where I would begin to ruminate. One way to calm down for me was to play chess. My fiancé knew how much I loved to play chess with her and she would grab the board. She would play with me no matter how late it was. If it wasn't for her, I wouldn't have made it through that first year.

I am not out of the woods yet when it comes to my addiction. I may not take opioids anymore, but I do feel that my addiction crops up in other ways. Sometimes I feel as if my addiction is more like a parasite than anything else. Every time I think I have it under control it evolves. I find myself using a little bit too much marijuana at times. I also tend to get some of the most incredible cravings for certain foods and at times it can be truly debilitating.

Simple tasks can become so hard to do. I have days where I just freeze. My mind becomes stuck in the mud and I will begin to pace back and forth...slightly convulsing. I feel as if I am having a battle with myself. I have to yell and convince my inner self that we are stronger then this. That I am stronger then this illness and that I am not a piece of shit.

Physical death aside, I find there is no worse thing than looking in the mirror and realizing how much you are wasting. When you realize how much time and money you have thrown away because of this. When you look at yourself and realize that nothing will change all the lies you have told. If you are lucky,

you won't end up in a place like this alone. I pray that you are as lucky as I am.

here is a reason I can tell this story: I asked for help. This is not something I did on my own. I had love and support from my family and friends. I had a fiancé who pushed me to go back to my psychiatrist. At the end of that first year I started seeing a psychologist and psychiatrist regularly. What I began to realize was that my addiction was tied directly to my depression.

I began to learn more about my depression and my addiction. I began to see a pattern in my cravings and I dare say that my depression is the cause of my drug addiction. When I am feeling good and not depressed, I don't have cravings. If I miss a dose of my anti-depressants like a jackass, I get cravings.

The reality of all of this is that my addiction will never fully go away and neither will my depression. I can however manage my depression which in return will keep my addiction at bay. This has and will continue to take hard work. I have to keep seeing my doctors and need to keep taking my medication. This type of treatment is working for me.

I can't say that it will work for you but if you have an addiction and/or depression talk to people that you know and love you. It is okay to ask for help. It doesn't mean you're weak. Asking for help actuality it means you are strong.

➡ STEVE GIALLOURAKIS, SURVIVOR



WARNING
MATURE
CONTENT

USED TO FEEL

So Good

THE VULVOVAGINAL BLUES

BY MARLOE ESCH, BSN, RN, OCN

NOW IT FEELS

SO BAD!

Ok, so maybe I'm not the greatest lyricist, but there's a good chance you know what I'm talking about. Symptoms like vaginal and vulvar (external genital) dryness, along with itching, burning, and irritation are common after cancer. I call these the Vulvovaginal Blues, and experiencing them can put a serious damper on sexual trysts with your honey. But even if you've noticed that your lady-bits don't respond exactly as they used to, that doesn't mean that you are broken or doomed to life of putting up with disappointing, uncomfortable sex.

WHAT'S CANCER GOTTO DO WITH IT?

Healthy blood vessels, nerves, and hormones all play a role in the genital changes that happen during sexual arousal. Unfortunately, certain cancer treatments can disrupt any part of this complex process. For example, pelvic surgery or radiation can alter the blood or nerve supply to your genitals, or cause tissue damage and scar formation. This can change how stretchy or flexible your vagina is and decrease the tissue's ability to naturally lubricate when you get excited.

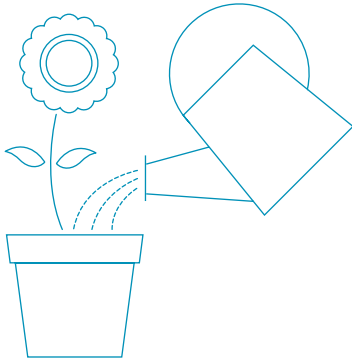
Treatments can also have an impact on the hormone estrogen, which plays a big role in both maintaining a normal vaginal environment and promoting blood flow and lubrication with sexual excitement. If your ovaries are removed by surgery or damaged with chemotherapy or radiation, estrogen levels drop. Radiation or surgery to the area of your brain that regulates how your ovaries function can also lead to low estrogen. And endocrine therapy (also called hormone therapy) can alter how estrogen works in your body or stop estrogen production altogether.

DISCLAIMER

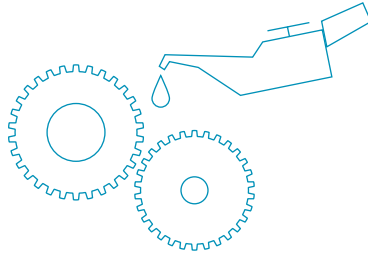
This information is not a substitute for medical care. Always inform your healthcare team of any concerning symptoms you are experiencing, and consult with your provider before initiating new treatments, therapies, or health routines.

SO, WHAT'S A GIRL TO DO?

Consider this: What if we were as diligent about our genital health as we are about our oral hygiene? I'm serious! If we brush and floss daily in the name of preventing cavities and gingivitis, surely we can adopt some simple strategies to help alleviate the Vulvovaginal Blues. In the words of stellar sex therapist Sallie Foley, our vulvovaginal maintenance mantra should be to "Moisturize, Lubricate, Stretch!"

**Vaginal Moisturizers...
For Maintenance**

Vaginal moisturizers are non-hormonal, over-the-counter (OTC) products that are designed to maintain day-to-day vaginal comfort. They absorb into the vaginal wall and help the cells lining your vagina hold moisture. It's kind of like... hand lotion, but for your vagina (note: don't *actually* use hand or body lotion — these can easily irritate sensitive genital tissue!). Moisturizers come in a tampon-like applicator or as a vaginal suppository, and should be applied regularly, up to 2-5 times weekly. Look for ones that contain vitamin E or hyaluronic acid, such as Hyalo-GYN. Other brands include Replens and K-Y Liquibeads. Ask your provider for recommendations.

**Personal Lubricants... For Lovin'**

These are non-hormonal, OTC products intended for use during any type of sexual activity or touch (not just penetration) to reduce friction and promote comfort. The trick is to apply lube liberally to the vulva, vagina, and your partner prior to sexual play. Lubes can be water-based, silicone-based, or oil-based. Water-based lubes are easy to wash off and non-staining, and they are compatible with latex condoms and safe for silicone sex toys. Silicone-based lubes are long-lasting and compatible with latex condoms, but cannot be used with silicone sex toys.

Water- or silicone-based lubricants are generally recommended over oil-based lubes (such as petroleum jelly, mineral or baby oil, and natural oils like olive, coconut, avocado, and peanut) for a few reasons. For one thing, oil-based lubricants are not compatible with latex condoms. Additionally, they may trap bacteria and increase risk of vaginal infection. Some oils can also be irritating to mucosal tissue (olive oil), or may disrupt healthy vaginal bacteria (coconut oil).

Consider avoiding lubes with glycerin, which can be drying and may increase the risk of yeast infections. Glycerin also increases lube osmolality (yes, I said lube osmolality – flashback to 7th grade science!), which cause tissue damage. You may also want to avoid certain preservatives, like chlorhexidine, which can disturb the

balance of healthy vaginal bacteria. For this same reason, the pH level of a lube is important, too. Other potential irritants include dyes, scents, flavors, or lubes marketed as "sensation enhancing." (Seriously, you guys; that warm tingly feeling is from capsaicin — an extract from *hot chili peppers*!) A general rule of thumb is the more unnecessary additives, the more likely it is to be irritating to genital tissues.

Confused yet? I get it — shopping for lube can be intimidating if you don't know exactly what you're looking for. The bottom line is that there are many options when it comes to lube, and not all of them are created equal. More details about personal lubricants can be found in two great resources from Dr. Lynn Wang, and at A Woman's Touch.

The consultants at your local sexual health shop are also a wealth of information and would be happy to help you sort through the Land-o'-Lubes. Or you can also order online, if you prefer. Either way, I'd recommend starting with several samples and trying them out. Tell your partner it's all in the name of research!

**Stimulation and Stretch**

Do you stretch in the mornings after getting out of bed, or as a part of your regular exercise routine? Feels good, right? Stretching our muscles can be invigorating, improve flexibility, and

CONTINUED ➔

**TALK
WITH YOUR
PROVIDER...**

...if attempting penetration is painful. Ask for a physical exam, which can help determine whether there is something other than simply lack of lubrication that may be cause for concern.

...before starting a routine with vaginal moisturizers or a new lubricant, even if they are OTC. It's also a good idea to check for sensitivities or allergies by testing a sample on the skin of your inner arm before applying to your genitals

...if the OTC things you've tried aren't working

...if you think you may have an infection, vaginal mucositis, muscle spasms, or genital GVHD

...if you have any other questions about your sexual health



➔ **MARLOE ESCH, BSN, RN, OCN, AND YOUNG ADULT CANCER SURVIVOR, GRADUATED FROM THE UNIVERSITY OF WISCONSIN-MADISON SCHOOL OF NURSING (GO BADGERS!) IN 2008. AN ENTHUSIASTIC SUPPORTER OF SEXUAL HEALTH AND WELLNESS, SHE HAS HAD THE OPPORTUNITY TO SPEND TIME IN HER COMMUNITY EDUCATING— BOTH SURVIVORS AND HEALTHCARE PROFESSIONALS ON THE TOPIC OF CANCER AND SEXUALITY, INCLUDING PRESENTING FOR THE YOUNG SURVIVAL COALITION, THE ONCOLOGY NURSING SOCIETY WISCONSIN CAPITOL CHAPTER, AND PLANNED PARENTHOOD OF WI. SHE HOLDS A CERTIFICATE FROM THE SEXUAL HEALTH CERTIFICATE PROGRAM THROUGH THE UNIVERSITY OF MICHIGAN, TRAINING IN BOTH SEXUALITY EDUCATION AND SEXUALITY COUNSELING, AND HAS MADE IT HER MISSION TO BRING SEX INTO THE SURVIVORSHIP SPOTLIGHT.**

prevent against injury. Well, as it turns out, a regular stretching routine can also benefit our genital health. Gentle stretch and massage of vulvovaginal tissues promotes blood flow and improves natural lubrication, vaginal flexibility, and sensation. Also, in the way that stretching before a run can loosen up our muscles and joints, a gentle stretching routine prior to engaging in sexual activity can improve comfort. Check out the The Vaginal Renewal Program, developed by the sex-perts at A Woman's Touch, for a how-to guide.

ISN'T THERE A PRESCRIPTION FOR THIS?

In general, OTC vaginal moisturizers and personal lubricants can be super helpful in managing bothersome symptoms of vaginal dryness after certain cancer treatments, and both the National Comprehensive Cancer Network (NCCN) and the American Society of Clinical Oncology (ASCO) recommend trying these first. But for women who continue to have symptoms, it is worth asking your provider about prescription options.

Low-dose vaginal estrogen or DHEA (another type of hormone) are two types of prescription treatments for vulvovaginal symptoms. Because there is limited research addressing whether or not topical hormonal treatments are safe for women with estrogen-dependent cancers, both the NCCN and ASCO guidelines stress the importance of discussing the risks and benefits with your provider. Both safety and quality-of-life are important to take into consideration — be your own advocate!

BEYOND THE BLUES

Discomfort with penetration is a common sexual complaint for young women who've been through treatments for cancer, and it's often related to symptoms of vulvovaginal dryness. But there are other possible reasons for pain with sex that should also be taken into consideration.



- **Did You Remember to Preheat?** It's funny because it's true! Women tend to require more time to warm up than our male counterparts, and sometimes we survivors just take a little longer to feel good-and-ready. Try building interest and anticipation with kisses, snuggles, touch and massage on the couch for a while before moving things to the bedroom. Or heck, use your new stimulation and stretch routine (see above) as your own private sexy-start-up.
- **Muscle Memory.** Pelvic floor muscles can tighten around the vaginal entrance in response to touch or anticipation, making penetration difficult or painful. Physical therapists who specialize in treatment of the pelvic floor muscles can help women learn how to consciously relax these muscles and decrease discomfort.
- **Does Your Vagina Need a Sick Day?** Bacterial vaginosis (BV), yeast infections, urinary tract infections (UTIs), and certain sexually transmitted infections (STIs) can cause pain or burning with intercourse. Detection and treatment are key to improving symptoms.
- **Maybe it's Mucositis.** Providers are pretty good at warning us about oral mucositis — that raw, painful inflammation and ulceration that can happen inside our mouths with certain chemotherapies.

But ALL of our mucous membranes can actually be affected in this way, including our vaginal lining. If you are concerned that this may be an issue, talk with your provider about your symptoms. Avoid penetrative activities during this time to allow for healing and decrease risk for infection, and don't introduce any moisturizers or lubricants to the area without first getting your provider's OK.

- **Got GVHD?** If you have had an allogeneic bone marrow or stem cell transplant, vulvovaginal symptoms could be related to Graft-versus-host disease, which can affect genital tissues. Ask your provider if this is a possibility.

A COUPLE OF FINAL THOUGHTS

If you have a partner, he or she might also be a little confused about some of the changes to your sex life or how your body responds to touch. Remind your partner that just because your body's response has changed after cancer doesn't mean that how you feel about them has changed!

Also, remember that there's a lot more to sexual satisfaction and enjoyment than just our genital response. Sex can be hard to talk about, but good communication and a willingness to be creative are crucial to overcoming any obstacles you might face. Your sex life is worth the effort!

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When I was diagnosed with cancer, I was 24, my mother had just died, and I lived in the middle of the cornfields. I lived in a big college town in otherwise urban America, where the corn festival was a local tradition, and college football took over the fall landscape. I'd never heard of Hodgkin's Lymphoma before, I didn't know I was considered a 'young adult' cancer survivor, and I had no idea why my life was refusing to fit back into its pre-cancer mold.

"Maybe," I thought, "once treatments are done, I'll be good to go. Back to the grindstone." Maybe.

So I waited, as one does, all the way through treatments and then through that 6-week period of time afterwards when I was scanned yet again and was finally labeled NED (No evidence of disease). One big fat waiting game.

But a day went by after my label of NED and I didn't feel back to my old self. Then a week, and then a month, and then the whole summer. Old Mallory would have spent Wednesday night out salsa dancing and would have had an early start in the lab on Thursday morning. Maybe Thursday night, she'd stay up late, getting some results ready for the lab

lacking any other local way to meet other young adults facing cancer, I started a blog to find them. Over the next year I had hundreds of conversations with survivors from all over the world. When I skyped one evening with my very first cancer friend, a woman from Australia, we talked for several hours about cancer and life and scars and fatigue and everything in between. I'd never felt more seen in my new body, as this new person, as I did in front of this stranger from across the world.

My story is not unique in its isolation, in its unfamiliarity with how to deal with cancer. Young adult cancer survivors are an under-researched, under-cared for patient population and they are not surviving cancer in the same rates as those diagnosed at a younger or older age. Young adults can often go an entire treatment regime without meeting another person their age who has also faced cancer and this isolation has been shown to impact quality of life and overall wellbeing.

Offering survivorship care, going beyond the clinical walls, beyond the cure and helping these young adults thrive after cancer is vital. Survival is insufficient. Young adults require connection to one another, peers to validate their concerns, and a safe place to process what has happened. And most importantly, they need these things delivered in an easily accessible, age-appropriate way.

MOVING CONNECTION

meeting on Friday morning. She'd wake up early on Friday to make sure she had time to iron her shirt, have some coffee and breakfast, and grab the keys for the meeting room from an admin. Saturday, she'd go for a long run and then make a big batch of pancakes with a friend. Old Mallory was fun and witty and had no need for sleep. Sleep could happen after that late night in the lab, that evening spent salsa dance, that get together with a group of girls and a few bottles of wine.

A year went by of this waiting. Waiting to feel normal and back to my old self. I was frustrated and mad and had trouble accepting this new person who needed sleep and boundaries and at least an hour's warning before heading out for an activity. She was higher maintenance, quick to suggest an evening in, and frightened of everything. Who was this imposter who had taken over my body? My friends tried to understand, but with nothing in their health repertoire even close to cancer, there were things they just couldn't connect with. I tried to find support but there wasn't any nearby. The local cancer hospital hosted no support group for anyone under 40 dealing with cancer and the cancer support organizations in abundance around the country did not have a location near me.

Finally, I gave in. I left graduate school, I started therapy, and I tried so hard to love this new person. I Googled and found the phrase 'young adult cancer' and learned that my issues were unique to my age group but not to my individual person...there were 70,000 other young adults diagnosed the same year I was. More importantly,

ONLINE

Meeting other young adults who have faced cancer in-person is ideal but what if that isn't possible? What about those young adult cancer survivors who are isolated, inpatient in the hospital following a bone marrow transplant? What about those young adult cancer survivors living rurally and potentially hundreds of miles from the nearest cancer center?

What about those young adult cancer survivors treated at a hospital where there is no recognition of young adult and therefore no age-appropriate resources? In these situations, and countless others, in order to remove financial, geographic, and medical barriers to survivorship care, offering supportive programming online is imperative. In these situations, online communities can offer that much needed connection to someone who understands what a survivor is facing.

It is not enough to just survive cancer. Through an online community and online programs, young adult cancer survivors can connect with one another, validate one another's concerns, and thereby reclaim their post-cancer lives alongside those who understand. They can regain control over their lives post-cancer and thrive. This is the right of every young adult cancer survivor and online communities and programs can make this a reality.

➔ MALLORY CASPERSON, SURVIVOR, CEO OF LACUNA LOFT.

Here is How I Owned Cancer

December 7th 2017, that's the date that the tumor was found in my femur. One of several upcoming dates in the months to come filled with experiences I never imagined I would have to endure. Including January 30th 2018, the day I was diagnosed with osteosarcoma.

For the next nine months I would take three different types of chemo, and would be dealing with appointments, surgeries, scans, x-rays, MRI's, different doctors, blood transfusions, traumatic situations, side effects, depression, anxiety, loneliness, fear, pain, needles, various medications, a foggy memory, allergic reactions, emergency room visits, and hospital stays.

I also experienced many days and long nights filled with sickness, weakness, and dependence. A whole new unfamiliar version of life awaited me. I even had a reconstructive leg surgery midway through treatments.

So now I have metal rods and magnets in my leg. At the time I didn't think I would be able to survive it but now I have beaten it! It's not over until it's over! No matter what type of cancer others may have, they themselves will attest to dealing with such issues and more. So, it is important to know how to cope with this lifestyle and how to add a positive twist on the entire situation.

When facing this disease expect to undergo some really dark times. There is no way that I would have survived this experience if my supporters and I didn't remain positive and strong as often as we did. I came to the realization that I had cancer and I was going to have to face it no matter what.

So, I might as well make it as pleasant as possible. Being positive may not be an easy thing to do all the time but it will have such

a great impact if mastered. It is okay to fall, just remember to keep getting back up. Staying positive does not mean that you have to be happy all the time. It means that even on hard days you know that there are better ones coming!

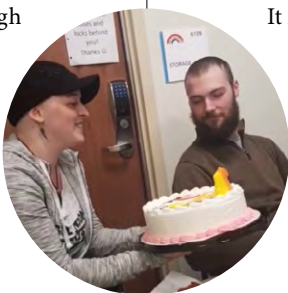
Stay in touch... join our Email Newsletter I would like to share five strategies I used to help give me a sense of control, piece of mind, and helped reign in my anxiety and depression as much as possible.

SOCIAL GATHERINGS

It is essential to take time for yourself and wanting alone time is completely acceptable and understandable. However, some situations call for some reinforcement. Social gatherings can be extremely helpful when dealing with this disease; the more support the better.

When I was diagnosed with cancer I planned a wig extravaganza. That way I could prepare for chemo, and hospital life. It was a great experience because I got to ease into my new-found lifestyle. I also wasn't alone. I was surrounded by people who loved and cared about me. At the party I received many gifts to help me through my journey. Including various wigs, headscarves, hats, bags, and needed items for extended hospital stays during chemotherapy.

It truly lifted my spirits and gave me a sense of control over what I was being forced to deal with. It felt nice to feel somewhat prepared for what was to follow.



Then, when I was informed that my hair would fall out and could as soon as the second chemo, I decided to have a shave party! I booked an event at a hair salon I had been a customer at since I was a young girl. A few close friends and family members gathered with me that day. Some of them even shaved their heads as well. I was the last one to go. It was truly one of the hardest things I had to do. Head shaving party

I shut my eyes and tried to meditate my mind away from what was happening and when I opened my eyes not only was I bald, but many around me were as well. It was nice to not feel like the odd ball out. I also looked better with the hairstyle then I initially thought I would. We all donated our hair to Wigs for Kids; doing something like that for others having to deal with this horrible illness really made me feel good. The owner of Wigs for Kids even made me a wig that resembled my hair drastically. It was a major life event that I was able to reinvent into a positive light.

Lastly, the AYA (adolescents and young adults) social support group (at Rainbows Babies and Children's in Cleveland, OH) really helped me out during this journey. I still attend meetings and have made lifelong friends. The meetings can be really great. Talking with others who have dealt with cancer is really helpful. It's better than I expected!

DECORATING

It can be overwhelming when being introduced to new appliances (wheelchair and crutches) used in your everyday life. New places can also present an overwhelming or uncomfortable factor.

For example, I would spend countless days in the hospital and it would eventually lead to me feeling very trapped, lonely, isolated, and anxious. It was also scary to be a part of a place I had not been before. The medical life intimidated me.

So, I decided to bring a little piece of my known life along with me. I would fill my entire wheelchair with sentimental items. From my clothes, to bedding, lamps, pictures, posters, lights, decorations, accessories, and anything else that gave me a reminder of my life and some of the things that made me happy.

I was first put on crutches when the tumor was found. It was hard to walk with such a large item and made moving around a little more difficult. People stare and sometimes think I needed a lot more assistance than I usually would.



So, I decided I would give them a different reason to stare.

I decorated my crutches with the color purple and even added a pink bag on one to use as a purse. The other side has a pillow pet which adds more comfort to my arm, then I was upgraded to a walker. When I got the walker, my grandmother was able to decorate it with cheetah print duct tape for me! It always gains a lot of positive attention and compliments. I used the same animal print pattern on my wheelchair. Leopard Skin Walker

Personalizing my items made me feel better about having to use them. It made them feel more familiar.

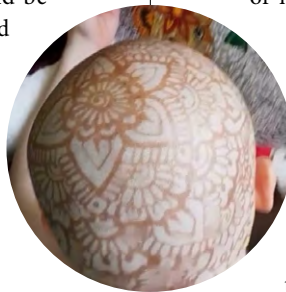
DRESS UP

On the days I was feeling good and actually had energy I would dress up. When I say dress up I don't mean put on a ball gown. I mean put effort in what is chosen, flash your personality and your style.

I loved matching my jewelry with my outfits, and also wearing different wigs, headscarves, and hats. It made me feel beautiful and reminded me to love myself. I got to revamp my outfits and try things I hadn't been given the chance too before. I also got so good at doing different styles when wearing my head wraps or wigs.

During the summer it would be too hot to wear wigs on my head so I wore sunhats. Once I got a mandala henna design instead which is a temporary tattoo. It was so unique!

This helped to restore some of my confidence and made me feel more comfortable.



HOLIDAYS

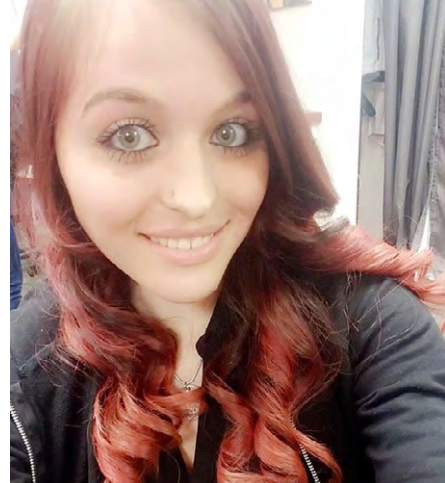
It can be hard having to spend holidays in the hospital, being away from family traditions and missing out on events. However, they can still be celebrated.

I would decorate my room for each holiday I stayed there. I also made crafts, and signs that related to the current holiday coming up. When I was admitted during Easter I brought my grandmothers breakfast casserole that she only made for breakfast that day every year. My mom and I had it together in the hospital. It was still just as delicious!

Then I was admitted on Halloween. So, I decided to ironically dress up as a nurse and I handed out candy to the actual nurses that were working that night. It's important to be thankful for the little things. It may not happen exactly as expected but it was nice trying different ways to celebrate.

I was in the hospital on my boyfriend's birthday as well. So, I invited a few of our friends and family to come to the hospital and we had a small gathering in the playroom where we shared in pizza, ice cream cake, and laughs. I couldn't go to the party, but I brought the party to me. cake for birthday

I had to learn how to adapt to my surround-



ings and utilize my options. Even if they weren't as good as my first choice, I did everything in my power to continue to enjoy life.

RELEASE

I think it is important to remember, but don't linger in all of the bad times. If there is a time or moment that gives you PTSD or truly messes with you emotionally I suggest releasing it. Any way you can.

During treatment I would release a little bit by writing in a journal but after treatment I decorated another journal that was for writing one positive thing that happened to me each day. It really helps to keep me centered, and keeps my mind straight.

On February 28th 2018, I had my port placement surgery and my very first chemo. It was the worst chemo I had and it resonated with me. So, on February 29th 2019 I went to a park and released sunflowers because it's the flower for bone cancer.

Try creating your own way of releasing. That way you can try to keep your emotions in check as much as possible. It is also a way to do something good on that day to replace the bad.

Getting diagnosed and dealing with all the things that come with cancer can make it hard to find the positives and good when you have to deal with so much hardcore bad.

But there are ways!

These are just some ways that helped the entire experience be more pleasant than thought to be possible for me.

Cancer is no longer a death sentence. No matter how much time each of us have left, try to enjoy the ride to the best of your ability.

Fight the good fight! Don't give up! Instead of feeling owned by cancer try owning the cancer instead!

➡ CHAMPAIGNE CORFEE, SURVIVOR

Keep Calm and Carry On

LIVING WITH SCANXIETY



I gained a pound and a half!!! I never in my life thought I'd celebrate gaining weight. I've always been on the well-endowed side of life and have always been trying to lose weight. I was anticipating just shedding pounds on chemo, but then I learned about steroids... The only time I felt like I was effortlessly losing weight was right before I was diagnosed, and that, as I found out, was due to cancer!

So when I was slowly dropping weight, over the holidays no less, without being on a regimented diet or exercise program, I panicked. Ever shed pound didn't spark the joy that it typically would, it filled my heart with dread.

When I saw that pound and a half, it was my reassurance that the cancer wasn't back.

When I relapsed, I was sleeping all day, every Saturday. Growing up, if I took a nap it meant it would take a long time for me to fall asleep at night. But this was different- I could sleep all day and still fall right asleep at night. And then I found the reason- the cancer was back. But still- I sleep two Saturdays in a row, and while my body feels better, my brain is a tragic mess.

I'm sure you have your own triggers. On and off I have bad back pain- must be a bone cancer. A series of headaches has got to be a brain tumor. Walking up a flight of stairs and

becoming breathless, and the cancer is back in my lungs. I consider myself a reasonably intelligent person, with unfortunate Googling skills. I think of myself as a logical person, 98% of the time. But that 2%- that's the killer. Fear can immobilize us. Anxiety can overwhelm us. And uncertainty can break us. The smallest abnormality in my body hurtles me towards the worst-case scenario.

I've heard the term "scanxiety" quite a bit. And it is so real. That uncertainty of what is going to happen at this next PET, CT, or even an ultrasound can be so overwhelming. I've found I get crabby and super on-edge in the week leading up and right after it. I forget even

the simplest tasks. I make a conscious effort to not think or worry about what will happen, but my subconscious can think of nothing else.

After my first cancer, I had the typical 3-month scans. And they found the cancer had returned. After my second cancer, they found a suspicious lump on my new three-month scan. And my heart seemed to stop.

It didn't seem possible that I could get cancer for a third time in less than 18 months. After a major surgery and removing my thymus, it turned out not to be cancer. But the worry was still there.

They say your chances to survive increase drastically after five years. March 18th last month marked six years post-transplant. And I think my worry has gone down by 6%. I'm not stupid. I know I'm at a greatly increased risk of secondary cancers due to my radiation. I don't know what will happen. Even though none of us know the future, it doesn't always make the future any easier!

This last year I had a few liver/abdominal ultrasounds. There was a suspicious finding... how every good horrible cancer story begins. My wonderful survivor oncologist decided to track it with a new ultrasound every few months, just to make sure it didn't grow or spread. She is incredible about researching the radiology report and presenting me with the findings and course of action promptly, and I trust her greatly.

I had an ultrasound in early August. Routine, same old ultrasound as I'd had a few times since January. Get the warm jelly, fall asleep as the tech pushes on your stomach, roll to your side when she tells you, sleep again as she goes to make sure the doc got all the pictures he wanted... Then this young, newer doc walked into the room. He announced that he wanted to do the ultrasound again, this time with contrast, because "there's a new spot on your liver".

As rational as I typically am, there is no logic left in my head the week of any imaging. The slightest cough, a twinge of bone pain, and a breathless walk around the neighborhood all turn into signs that the cancer is back and attacking me. So a "new spot" is instantly a big bad horrible thing. My nerves and chemo-shot veins didn't help the tech put an IV in, but after 4 tries we had one.

I finished the ultrasound, and the head doc came in and reviewed everything. He didn't seem too concerned and sent me on my way. My oncologist was on vacation that week, so

I didn't hear from her for a week and a half. I had my entire soon-to-be-shortened life planned out by the time she called. I thought through how I would keep on working, what treatments I would or wouldn't be willing to go through, if I would move back in with my parents, and so much more. Perfectly normal thoughts for any 24-year old, right?

The young doctor hadn't reviewed his notes (and spoken out of turn) and this second spot was apparently always there and nothing to worry about. And my life could return to normal.

But during that limbo period, I realized how deep the fear runs in me. I'm not afraid of dying- I have full confidence in where I am going. But there's so much to think about that I shouldn't have to think about. My anxiety manifests itself in anger, short-temper, and extreme emotions. I can cry if a dog looks at me. When I return to the land of the living, I always get super mad at myself for being so irrational.

Recently, I was talking to another 20-something-engineer-cancer-girlfriend. A smart, logical, mature person. And she had some blood tests in regard to her cancer that had happened the day before. She shared how anxious and on-edge she had been all week! She echoed my irrationality sentiments and said how just waiting for those test results was hanging over her head.

As sorry as I was to hear her pain, it made me really glad to hear I wasn't alone! I wish I could give you some advice on how to eliminate the anxiety, fear and gut-wrenching emotions that come with scans and tests and waiting for results, but I can't. I can't even promise it gets better, because the reality is it doesn't. But I want to leave you with two thoughts on this subject.

KEEP CALM AND CARRY ON

Don't jump to the worst-case scenario until you have the facts. Preaching to the choir with that statement, but it is something I try to consciously remind myself of. Maybe it's just a clump of dead cells or an inexperienced doctor blabbing when he shouldn't. Maybe it is cancer, but don't stress unnecessarily until you have to.

Friends can be great here. I had a bad cough that I saw the doctor for while in college. My original cancer was in my lungs, so they are greatly damaged. The doctor said there were some issues, and that there were further

reviews and tests needed. My friends knew about the appointment, and that was the first thing they asked me about when I got back to the computer lab. I was dealing with the same cancer-is-back fears and tried to avoid them, but they wouldn't drop it.

When I told them the uncertain verdict, they were quick to comfort me, and told me not to stress until I knew for sure. They were the voices of reason and logic and steadiness that I needed when I wasn't myself. Find yourself a friend who will be the brain you need when your's overloaded.

LIVE EACH DAY AS IF IT IS YOUR LAST...AND SOMEDAY YOU'LL BE RIGHT.

Cancer or not, none of us is guaranteed to-morrow. As cliché as it may be, live life to the fullest. Be bold. Make decisions that are courageous and do the unexpected. Don't be wild and stupid, but remember that you faced cancer, you should enjoy all life has to offer.

And if you pack your non-scan-worrying days with life, you'll have some amazing memories to look back on when you're not sure if you'll live to make any new ones.



➔ **JENNIFER ANAND** WAS DIAGNOSED WITH HODGKIN'S LYMPHOMA IN JANUARY 2012, FOLLOWED BY CHEMOTHERAPY AND RADIATION TREATMENTS FOR EIGHT MONTHS. JENNIFER IS NOW A SURVIVOR AND JUST CELEBRATED HER FIVE YEAR ANNIVERSARY THIS YEAR AS CANCER FREE. EVERY WEEK ONLINE AND IN OUR QUARTERLY MAGAZINE JENNIFER ANAND WILL BE PROVIDING HER REAL STORY AND EXPERIENCES TO HELP INSPIRE PATIENTS AND SURVIVORS. WE CALL THIS JEN'S CORNER.

Life is hard enough. Friends can make the journey so much better.



Friends can make the journey so much better. Over the last few years, I've had a number of good-hearted friends who knew I had cancer ask me how they can help/support other cancer peeps that have come into their lives, so I've compiled a list:

GIFT CARDS

- **Restaurants**- give the family a break from cooking! And the opportunity for a night out. The staff at our local gym gave my family a Subway gift card. Nothing fancy, but an incredible blessing as it gave us many healthy, tasty, and quick meals on the go.
- **Shopping**- especially for the cancer kid. I did an extraordinary amount of clothes shopping. The worse I felt about how I looked, the more money I spent on things to make me look good. I know that's not a great idea, but frankly it did help me. With the incredible advent of online shopping, there's so much people can buy!
- **Media**- you are stuck in four bland walls for



an undetermined length of time. Netflix, Amazon Prime, iTunes, Google- all great gift cards to allow the cancer kid an outlet through music or movies.

DINNER

Food is always helpful. A professor who was part of my string ensemble brought dinner for my family. She's a self-proclaimed non-cook but wanted to help out. She bought some chicken strips, bottled pasta sauce and pasta, loaf of bread and pesto, and a cake. All of it was ready-made from the grocery store. But the fact that she thought about us and wanted to show her love through a meal- still one of our most fondly remembered meals. No way she's

getting a Michelin star, but she's first rate in our hearts. Buy a frozen lasagna and some side dishes or order some pizza or buy a box of cinnamon rolls. It's not about the fanciness, it's about the fact that you took the time to think about and bring some food.

HOUSEKEEPING



Let's re-circle to that low-energy thing. Pay for a housekeeper, or just go over and clean! Something as simple as running a vacuum, which you may not think twice about, can be a herculean task for someone in treatment. Also, with cancer it becomes even more important to have a clean environment, so help them out!

GAMES

The design team I was part of in school arranged to come to my house (since I couldn't go anywhere). They bought me a board game and came over and played



for a few hours. The security of my own house allowed me to dictate how involved I could be. And when I retired to the couch, they kept playing with my siblings!

MOVIES

A few clubs from the Honors College at Akron also wanted to visit. They brought a giant stack of DVDs they had checked out of the library, as well as a bag of popcorn and some movie candy boxes for an in-home movie night!

CHILDCARE

I'm listing this from a sibling point of view. I know they often get left behind and are certainly not in the focus. Our neighbors took my siblings out to swim and dinner on a few occasions, and also had them over, even if it was as simple as baking some cake together! If your friends have kids, offer to take them out to the park, or a movie, or a museum to give them a chance to get out of the house and the cancer peep some quiet/alone time. Another option would be to watch the kids at their house- play a game or make cookies together to entertain them!

ASK

Ask how you can help them. I blew-up like a balloon from the steroids, and also felt incredibly uncomfortable from my clothes rubbing against my sensitive skin. April asked what I needed, then went to the thrift store and bought me a whole new wardrobe in way bigger sizes than I typically wore. She bought baggy, loose fitting, but still nice looking clothes for me. These clothes helped me be comfortable at the hospital, and not have to wear the hospital gowns.

VISIT

But not if you have a cold or don't feel well. In that case, stay as far away as possible!



CARE

My friend Leah and her brother Caleb visited me in the hospital. Unfortunately, due to crazy hospital scheduling and stuff, I ended up in an MRI for most of their visit, and then just slept for the rest of their visit. They drove an hour to see me. They were both in college, in engineering, so I know they didn't have free time galore, if any. Leah knew me only a little bit, and Caleb barely knew me at all.



But they came. That meant the world (and still does) to me. I felt horrible for sleeping the entire visit after all the trouble they took to visit. And then- a few weeks later, Leah called to see if she could visit-again. After the last time, I was shocked that she would still offer to make that long drive, on the chance I would sleep a second visit away! We compromised with a Skype visit. She set up her laptop in her kitchen, as she made lemon bars. I love baking, so we had a wonderful time talking as she baked!

Leah's friendship and kindness helped me realize there is no excuse to not reaching out and being there for cancer peeps. She was a college student, with limited time and finances. Yet, she was willing to give up most of her Saturday to drive far away and spend her gas money on me- a girl she wasn't super close with (at the time!) and had nothing to offer her back. Thank you, Leah.

There's a Facebook post I see often. It says "In a world where you can be anything, be kind." If we all took just a few minutes a day to think of others and be kind to them, our world would be a better place.

➔ JENNIFER ANAND, SURVIVOR



WARM THINGS

Cancer gives you low blood oxygen, which can make you very cold.

- Hats are great to help keep bald heads warm, while also being a fashion statement. Dear April crocheted me a beautiful Tiffany blue flapper hat. I loved it!! She saw how much I wore it, and made me a second, brown hat. She put a large button on it, then crocheted flowers and bows in different colors that I could attach on and customize the hat! Having such stylish and gorgeous hats really helped boost my self-image. A coworker of my dad's bought me one of those animal hats, because she said everyone in her daughter's school was wearing them. I felt pretty hip and also warm in that hat!
- Scarves- someone gifted me a large, warm, bandana style scarf. It came in handy to wrap around my bald head, but also kept me warm when I used it as a blanket.
- Blankets. A church in Georgia sent me a gorgeous pink quilt. I took many naps underneath that blanket!
- Socks- feet get cold.
- Booties- hospital floors are gross. Slippers and the like are awesome, to make sure my feet don't have to touch the gross and cold floor.
- Hand warmers. I'm from Ohio, which can get decently cold! Combine that with chemo cold, and you're in for a frigid day. The little hunting hand and foot warming packs are great to provide a boost of warmth to a cold cancer soul.



How Race Can Affect Your Cancer Prognosis



Cancer is color blind. It affects adolescents and young adults (AYA) of all races and ethnic groups. Yet young patients in some groups tend to do worse than others.

The obvious question is “why?” And the answer is that we simply don’t know.

What we do know is that African-American adolescents and young adults are less likely to get cancer than whites of the same age—but more likely to die of the disease.

We also know that this difference, or disparity, is unfair, and there is no better time to call attention to it than during Black History Month.

WHAT THE DATA TELL US

At first glance, the news looks good for young African-Americans. For most childhood cancers, the rate of new cases, or incidence, is lower among blacks than whites. The reasons for this are unclear. Incidence rates may be related to genetics or biology, but without additional research we can’t be sure.

Dig a little deeper, and things change.

Five-year survival rates for the most common childhood cancers are considerably worse for blacks than whites. Only 73 percent of black children are likely to live five years after being diagnosed with cancer, compared with 81 percent of white children. Depending on the type of cancer, black children and young adults are 38 to 95 percent more likely to die than white patients of the same age.

Again, why?

Researchers at the University of Minnesota wondered if social factors—such as income, health insurance coverage, and education—might play a role. The answer turned out to be “yes.” In fact, the researchers found that these social factors reduced survival rates for black children and young adults by:

- 49 percent for those with neuroblastoma
- 44 percent for those with acute lymphoblastic leukemia
- 34 percent for those with non-Hodgkin’s lymphoma
- 28 percent for those with acute myeloid leukemia

The social factors all have something in common. One way or another, they make it harder for black patients to get the care and information that could help them live longer. In other words, the issue is access—or, more accurately, the lack of it.

THE LINK BETWEEN ACCESS AND SURVIVAL

Black children and young adults, especially those who live in rural areas, are less likely to have access to healthcare services, to high-quality healthcare and, especially, to innovative treatments and clinical trials.

Some families don’t have adequate health insurance—or any insurance at all—to help pay for incredibly expensive cancer treatments. Even those with insurance may not be

able to afford the other costs that come with cancer care. Examples include co-payments for covered treatments; gas or taxi or bus fare to get patients to their appointments; day care or babysitting expenses for younger brothers and sisters; and the cost of taking time off from work.

Many families that struggle with expenses haven't had the same educational opportunities as those with higher incomes. This lack of opportunity compounds the problem because lower education levels are linked to lower survival rates. Why? Once again, researchers are not sure.

Certainly, it's not because those with lower levels of education don't care about their disease or have less desire to live. Some researchers suggest looking at the doctor-patient relationship. Is it possible that doctors and nurses do not fully explain the risks, side effects, and benefits of all treatment options to patients of lower education levels? Do healthcare providers take the time to ask all patients—regardless of education level—about what they wish to do to fight their disease?

WHAT YOU CAN DO RIGHT NOW

Improving access will not be easy. It requires major changes to policies, practices, and ways of thinking. But it is the best way to address racial disparities in cancer care and treatment of other potentially life-threatening diseases. Organizations like Clinical Research Pathways, which seeks to increase access to new medicines, are working on long-term solutions.

But what can be done now for today's cancer patients and survivors?

One of the most important things you can do is to reach out—to your doctors and other healthcare providers, support groups, and other resources. That's not easy, especially when every aspect of your life is being taken over by this dreadful disease. Keep reminding yourself that, by asking questions, you will get access to better treatments that could increase your chance of a better health outcome. If you can't do the outreach yourself, ask a friend or family member to help.

Every visit with your doctor is an opportunity to get answers to your questions. If your

doctor is too busy, ask a nurse or another member of your healthcare team. Most hospitals and many medical practices have people on staff whose job is to help you and your family get through your cancer experience. Don't be shy about taking advantage of these services.

Access to care often depends, in part, on where you live. Cancer treatment is complicated so, if possible, it's better to get care at a hospital or medical center that specializes in cancer or treating children. Forty-two states have a National Cancer Institute (NCI)-funded cancer center that provides the newest, most innovative treatments for cancer patients, including children and young adults. In addition, there are more than 220 children's hospitals in the U.S. For adolescents and young adults, one of these hospitals might be the best option.

Medical care alone is not enough. Ask your doctor or another member of your healthcare team to help you find a support group or put you in touch with other cancer patients. There also are lots of resources that young cancer patients can tap online. The NCI, American Cancer Society, Life with Cancer, Cancer.Net, and CancerCare all have information about cancers that affect adolescents and young adults (AYA). A Google search of words like "children and cancer," "cancer resources" and "AYA cancers" will turn up additional helpful websites. E-newsletters, like *The Weekly Herd* from Elephants and Tea, can be a wonderful source of support.

THE CRITICAL ROLE OF CLINICAL TRIALS—AND CLINICAL RESEARCH PATHWAYS

Clinical trials for childhood cancers play an important role in improving treatments. We've had major successes in treating childhood cancers, in part because so many young patients participate in trials. As many as 50 percent of children and young adults with cancer will enroll in a clinical trial. Most of these patients will be white.

Less than 5 percent of black patients of all ages participate in clinical trials. As a result, when new drugs are introduced, no one knows how well they work with African-Americans—or what side effects they will have—because

blacks weren't included in the testing process.

That's where Clinical Research Pathways comes in. We have partnered with Morehouse School of Medicine (MSM) in Atlanta, Georgia, (a historically black medical school) to increase the number of minority patients who sign up for clinical trials. If we succeed in Atlanta, we will expand our project so that, eventually, we will increase minority participation in clinical trials across the U.S.

Our project draws on what we've learned from research on how to make patients more comfortable with clinical trials. For example, we know that talking with a trusted physician—about the risks and benefits of a trial, how long the trial will take, and whether there will be extra tests and costs involved—makes a big difference in what patients and their families decide. We also know that many African-American patients are more likely to choose and trust African-American physicians, and that we need more minority physicians to conduct clinical trials.

MSM has one of the largest networks of minority physicians and an excellent reputation as a trusted healthcare provider. It makes sense for Clinical Research Pathways and MSM to partner to recruit minority physicians and train them to run clinical trials. These physicians will then be in the best position to talk with their minority patients about clinical trials and options for care.

We believe this approach will increase minority participation in clinical trials. It will help make sure that more minority patients are aware of clinical trials, have discussed their options and, with help from a trusted physician, have decided whether a trial is the right choice. Those who do take part in a trial will have the opportunity to try new medicines and realize the benefits they might provide. At the same time, minority patients will help us learn how well new medicines work for African-Americans and whether they are at risk for different side effects. That information will help lead to better medicines, higher-quality healthcare and, ideally, improved health and well-being for minority patients.

➡ MARJORIE A. SPEERS, PH.D.



➡ MARJORIE A. SPEERS, PH.D., IS THE EXECUTIVE DIRECTOR OF CLINICAL RESEARCH PATHWAYS, A NONPROFIT ORGANIZATION THAT WORKS TO IMPROVE HEALTH AND WELL-BEING FOR ALL BY CREATING PATHWAYS TO NEW MEDICINES AND TREATMENTS.



ASCP Patient Champions - www.ascp.org/patients

The ASCP Patient Champions program empowers patients, caregivers and advocates through education and awareness about diagnostics, lab tests, and follow-up care through the real-life stories of patients, our Patient Champions.



Bee You Wigs - <https://www.beeyouwigs.com/>

Bee You Wigs philosophy is simple. Here, you can create your own kind of beautiful. Pastel colored, pixie, mermaid, whatever hairstyle you've ever wanted we can make it specialized to you. Each and every wig is made by hand. If you have Alopecia, going through cancer treatments, thinning or are just wanting a new look. Whatever the reason, if you can think it, we can create it. For every ten wigs purchased we will be giving away a custom wig to someone in need.



BMT InfoNet - <https://www.bmtinfonet.org/>

Blood & Marrow Transplant Information Network (BMT InfoNet) is a leading advocacy organization for bone marrow, stem cell and cord blood transplant patients. Founded in 1990, BMT InfoNet has pioneered a vast array of services to help transplant patients make critical decisions throughout their transplant journey.



CancerCare® - https://www.cancercare.org/tagged/young_adults

Founded in 1944, CancerCare is the leading national organization providing free, professional support services and information to help people manage the emotional, practical and financial challenges of cancer. Our comprehensive services include counseling and support groups over the phone, online and in-person, educational workshops, publications and financial and co-payment assistance. All CancerCare services are provided by oncology social workers and world-leading cancer experts.



Cancer Warrior Alliance - <http://cwa.life/>

Our mission is to deliver cancer support resource information to the cancer community by building relationships with and providing resource information to clinics, hospitals and those affected by cancer.



COALITION AGAINST CHILDHOOD CANCER

CAC2 - <https://cac2.org/>

Coalition Against Childhood Cancer (CAC2) effectively advances a variety of childhood cancer causes by unifying the childhood cancer community through broad-based coordinated action and collaboration that leverages the strengths and expertise of its individual members and minimizes duplication of effort.



Cook for Your LIFE - cookforyourlife.org

TEACHING HEALTHY COOKING TO PEOPLE TOUCHED BY CANCER. The American Institute of Cancer Research estimates that more than 1/3 of the most common cancers could be prevented through healthier eating and lifestyles. Since 2007, Cook for your LIFE has provided in-person and online healthy cooking classes in English and in Spanish free of charge. Our mission is to teach the wider cancer community of patients, caregivers and survivors how to live better, healthier lives through providing 101 education about healthy food, and by teaching the basic cooking skills needed to succeed in improving diet for better overall health outcomes. We really do teach healthy cooking to people touched by cancer.



Dear Jack Foundation - <https://www.dearjack-foundation.org/>

The Dear Jack Foundation provides impactful programming that directly benefits adolescents and young adults diagnosed with cancer in order to improve quality of life and create positive health outcomes from treatment to survivorship for patients and their families.



Epic Experience - <https://www.epicexperience.org/>

Cancer Survivorship is more than follow-up appointments, blood tests, and scans; it's about living life to the fullest beyond cancer. Epic Experience empowers adult cancer survivors to do just that through free week-long adventures in the Colorado Rockies. Our Mission - Epic Experience empowers adult cancer survivors and thrivers to live beyond cancer.



First Descents - firstdescents.org

First Descents provides free life-changing outdoor adventures for young adults (ages 18-39) impacted by cancer. First Descents' goal is to bring the healing power of adventure to young adults living with and surviving cancer. Through destination week-long programs and local multi and single-day programs, First Descents empowers participants to adventure beyond their diagnosis, defy their cancer, and connect with others doing the same.



Gilda's Club - <http://www.gildasclubmadison.org/>

Gilda's Club provides a broad range of services to support those living with cancer. Members include adults and children; those who have a diagnosis of cancer, their loved ones, friends, and co-workers; survivors of cancer and family survivors.



GRYT - <https://grythealth.com/>

GRYT Health is an award-winning, mobile app-based social community founded by cancer survivors and caregivers who wanted to create a more human approach to helping people live on their own terms. Through the GRYT app, we've created a platform for people affected by cancer to connect to others with similar experiences, and to tailored information that helps our users become more aware of options specific to their needs or diagnosis – empowering them to make choices that are right for them.



Handful - <https://handful.com/>

Handful is owned by women, powered by women, and united by a passion for encouraging all women to grab life by the handful. Handful's year round charitable giving is focused on the 12.5% of women (the 1 in 8) who will be diagnosed with breast cancer in the US each year.



Imerman Angels - <https://imermanangels.org/>

Sometimes the best therapy is just talking to someone who's been there. Imerman Angels connects cancer fighters, survivors, caregivers, and those with cancer predisposition with "Mentor Angels" – volunteers who share the same, or similar, experiences. Mentor Angels provide a chance to ask personal questions and receive support from a peer who has been down the same road. The service is absolutely free and available for those touched by any cancer, at any age, living anywhere in the world!



JL Barker - <https://www.jlbarker.org/>

JoAnna Barker is a 20- something who defeated cancer and wrote a book about it. You'll laugh, you'll cry, and then you'll find multiple references to books and movies that she some how related to cancer. Don't be fooled, if you don't have cancer you'll still love this book. It's a great read for people with cancer, people who love people with cancer, and people who just want to know how to relate. We hope you enjoy this reading journey. Trust us, it's not what you'll expect!



Lacuna Loft - lacunaloft.org

Lacuna Loft is a nonprofit organization providing online support programs to young adult cancer survivors and caregivers. The only organization offering diverse online programs regardless of diagnosis and regardless of where they live, Lacuna Loft is changing the way that age-appropriate support is provided to young adults facing cancer. Survival is insufficient and we are here to make sure that survivorship support is available, accessible, and specifically designed for young adults facing cancer.



M Powerment - cancerdudes.org

Our mission is empowering men to thrive after cancer. With a scarcity of resources geared specifically to men's unique needs, M Powerment was created to provide education and resources in order for men to successfully move past their cancer experience.



The Steven G AYA Cancer Research Fund - fightconquercure.org

The Steven G. AYA Cancer Research Fund is a non-profit organization. Our purpose is to raise awareness about AYA cancer and the need for research to find better ways to treat and cure our young people! Throughout the year we distribute Be Calm & Stay Strong Wellness Bags to YA (young adult) cancer patients in Ohio as well as smoothie days at Rainbow Babies and Childrens Hospital in Cleveland, OH. The Smoothie Day Program provides a nutritious snack and a healthy break from the world of cancer.



Project Angel Heart - <https://www.projectangelheart.org/>

Project Angel Heart was founded in 1991 to address a major challenge for Coloradans who are ill: getting the nutrition they need to get stronger, heal, and remain at home. Many are too sick to get to the grocery store or unable to cook for themselves. Others find they have to choose whether to buy food or medication to make ends meet.



Project Koru - <https://www.projectkoru.org/>

Project Koru enriches lives through community and the outdoors as a way to move forward after cancer. The Koru spiral is shaped like an unfurling fern frond. It symbolizes new life, growth, strength, and peace - the very channels of energy we aim to inspire for survivors at our camps. We envision a world of empowered young adult cancer survivors.



Sephora Stands - https://www.sephorastands.com/classes_for_confidence/

We stand with those facing major life transitions. Discover techniques and products that address the visible effects of cancer treatments in a fun, hands-on beauty class. Get skincare tips tailored to your needs, then get matched with Color IQ and receive step-by-step instructions for a radiant complexion, natural looking brows and defined eyes.



Soccer for the Future - <https://www.soccerfor-thefuture.com/>

Soccer for the Future is a nonprofit that provides soccer programming for pediatric cancer survivors, patients, and their siblings and we use the game of soccer to teach short term goal setting skills. Create a safe place for kids experiencing cancer to gain the confidence and skills to play soccer and succeed in their goal setting endeavors.



Stupid Cancer - stupidcancer.org

Stupid Cancer a 501(c)3 nonprofit organization, is the leader in young adult cancer advocacy, research, and support. We create shared experiences by producing life-changing live events and digital content that end isolation, build community, provide education, and foster meaningful relationships that last a lifetime. Our mission is to empower, support, and improve health outcomes for the young adult cancer community.



Teen Cancer America - <https://teencanceramerica.org/>

Formed by legendary rockers Roger Daltrey and Pete Townshend of the Who, Teen Cancer America's (TCA) mission is to improve the experience, outcomes, and survival of teens and young adults with cancer by providing facilities and programs designed especially for them in hospitals throughout the USA. Through Teen Cancer America, we can HEAL, SUPPORT, and TRANSFORM lives. Together, we can EMPOWER THE FUTURE!



The Dragonfly Angel Society - <http://www.dragonflyangelsociety.com>

We are a mother daughter team also known as the caregiver and survivor duo. Our story begins with a breast cancer diagnosis back in 2010. Finding amazing resources and meeting other survivors and caregivers showered light on the journey. The struggle to find survivorship and caregiver resources was almost more difficult than going through cancer treatment. From books, to websites, nutrition links, organizations, events and so much more, survivors can now find the details all in one place - The Dragonfly Angel Society.



Triage Cancer - <https://triagecancer.org/>

Triage Cancer is 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. A cancer diagnosis can be a life altering event, not only for the individual diagnosed, but also for an individual's family, friends, caregivers, and community of support. Triage Cancer helps people move beyond diagnosis.



True North Treks - truenorthtreks.org

At True North Treks, we help teens & young adults with cancer find direction through connection after the very dis-connecting experience cancer can bring. We fulfill our mission through implementing unique and supportive healthcare programs and services that are not available anywhere else. With a little help and guidance from the STARS, we do this through Skills Training, Advocacy, Resources and Support.



Ulman Foundation - <https://ulmanfoundation.org/>

The Ulman Foundation has been nothing but supportive to me during my cancer journey. From providing key information, to visiting me during my chemotherapy treatments, they showed me that I am not alone in this fight to end cancer." - Lena, Hodgkin's Lymphoma Survivor. The Ulman Foundation is dedicated to changing lives by creating a community of support for young adults, and their loved ones, impacted by cancer.



Willpower Girl — Mette de Fine Licht - willpowergirl.com

Teenage cancer survivor, author, blogger and speaker Mette de Fine Licht has written 10 books, including the memoir, *Willpower Girl — A Teenager's Trek Through Cancer*. The book is a rare insight into a teenage cancer patient's mind with all the fear, doubt and longing for a normal teenage life.

yoga4cancer

yoga4cancer - y4c.com

yoga4cancer (y4c) is a specialized yoga methodology that is tailored to address the specific physical and emotional needs left by the cancer & its treatments. This unique evidence-based approach is not just gentle or restorative yoga but focuses on how to stimulate the immune system through movement, improve flexibility & strength along with reduced anxiety and boost overall well-being.

Mom's 6 Tips: Staying Well During Cancer Treatment

WE KNOW THAT A CANCER DIAGNOSIS IS INCREDIBLY STRESSFUL AND FRIGHTENING. A person's emotions are usually over the top – and yet, we know that in order to survive this horrible ordeal the patient needs physical and emotional nourishment while in treatment.

People who undergo cancer treatment need to feel as good as possible. Chemotherapy and radiation messes with one's energy level, bodily functions, and emotions. Radiation can alter the composition of the skin by causing a burning sensation and/or swelling. Surgery means some part of the body was cut into – not pleasant to think about, but a reality.

In order to remain strong enough to endure treatments individuals should seriously consider maintaining a healthy diet, do some type of physical exercise, and get emotional support.

I am not suggesting you start a new diet or a new exercise program. But I do recommend you consider the following suggestions:

EATING HEALTHY FOOD

Talk to your doctor and medical team about any dietary limitations before you add any new foods or supplements to your diet.

- Eat plenty of vegetables and fruit.
- Drink easily digestible beverages.
- Check out "Cook For Your Life's" recipes on-line. Ann provides a whole host of suggestions that address problems you might be experiencing during treatment.
- Eat Good Food!

EAT FRUITS AND VEGETABLES

Fruits and vegetables should be first on the grocery list.

- What fruit and vegetables do you like?
- Smoothies are refreshing and easy way get nutrients - like fruits and vegetables - into the body - and give you energy!!
- Stock up on your favorite yogurt (fresh or frozen), frozen or fresh fruit, and your favorite juice or milk.
- Get a blender. Ask your friends and family to pitch in and buy one for you.
- Or better yet, visit Vitamix.com and learn about how you can receive a free refurbished machine through your hospital.

GET SOME EXERCISE.

ALWAYS CHECK WITH YOUR DOCTOR BEFORE DOING ANY EXERCISE!!!

- Move around if you can.
- Walk - Stretch - Dance - Try Yoga
- Move about in a way that feeds your soul
- Some resources: yoga4cancer.org and nih.gov/health/yoga/introduction.htm

MIND-BODY RELAXATION

Mind-Body meditation can help you learn to relax in order to reduce stress and anxiety. A mind-body meditation often includes the following steps:

- Establishing a relaxed state of mind by finding a comfortable position, and an intention or a purpose for the meditation such as "I am relaxed and will sleep soundly."



- Do body sensing through a step by step process where using your senses to explore physical feelings and become relaxed.
- Practice deep breathing techniques and experience relaxation.
- Research has shown that mind-body meditation can reduce physical and emotional stress and promote a better night's sleep.
- Resources: <https://nccih.nih.gov/health/meditation/overview.htm>, <https://www.irest.org/irest-research>

EMOTIONAL SUPPORT

- Getting emotional support means different things to different people. For some people it means spending quality time with friends and family who listen and are supportive.
- If you feel that friends and family are not helping – and you have concerns – consider talking with your doctor or nurse about getting a counselor, psychologist, or clergy person to help.
- Sometimes talking with an objective person outside your friends or family circle can provide relief.

CONCLUDING THOUGHTS

Managing and completing cancer treatment is a test of emotional, spiritual, and physical endurance. The examples presented here are suggestions to consider as a means to improve one's quality of life. And, a good quality of life can help with survivorship. These suggestions are based upon research. But as mentioned above it is vital that you communicate with your oncologist and medical team.

Don't be afraid to ask for help! You have a right to learn about the best ways to behave and feel during cancer treatment.



← **ANGIE GIALLOURAKIS, PH.D.**, CEO AND CO-FOUNDER OF ELEPHANTS AND TEA, IS A FORMER REHABILITATION COUNSELOR, COLLEGE PROFESSOR, RESEARCHER, TURNED CANCER ADVOCATE AND MOTHER TO A TWO TIME CANCER SURVIVOR. OVER THE PAST TEN YEARS SHE HAS SOUGHT TO LEARN ABOUT THE BEST WAYS TO SURVIVE CANCER TREATMENT. AS A RESULT OF THIS RESEARCH SHE HAS BECOME TRAINED IN IREST YOGA NIDRA MEDIATION, INTEGRATIVE NUTRITION HEALTH COACH, INTEGRATIVE ONCOLOGY NAVIGATOR AND YOGA4CANCER TEACHER.



BE CALM & STAY STRONG WELLNESS KIT

by Steven G. AYA Cancer Research Fund

HELP US LET AYA CANCER PATIENTS KNOW WE CARE!

Sponsor A Wellness Kit

Cost:

\$125 per Kit

To Purchase:

Email: angie@fightconquercure.com

Visit our website:

www.fightconquercure.org/donation

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and your name(s)*

What's in the Kit?

For Daily Life:

One Large Canvas Bag, Amazon Gift Card (\$50) iTunes Gift Card (\$10), Medicine Box (Twice a Day), Hand Cream, Tissues, Hand Sanitizer, Pen and Paper, Reading Materials, Coloring Book and Pencils

For Wellness Sake:

Exercise Band, Ginger and Lemon Drop Candies, Lip Balm, Nutritional Information from the AICR (American Institute of Cancer Research)

For Relaxation & Contemplation:

Eye Pillow, Wireless Sound Speaker, Ear Plugs, Ear Buds, Votive Candle, Essential Oil and Diffuser

Beauty Basics:

Thrive™ Causemetics

I just wanted to send a note of thanks for the incredible care package! ... I was blown away by this kind gesture and also by the practicality of the thoughtfully placed items.

—AYA Cancer Patient M

I am forever grateful for the amazing bag of goodies.

—AYA Cancer Patient A

Thank you so much for the awesome care package you sent me. It was very generous of you.

—AYA Cancer Patient R



Thank you to our generous sponsors:



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Cancer under 45?

Life moves quickly...

Attend our programs + connect with other
young adult cancer survivors + caregivers
from wherever you are.

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LacunaLoft.org/hello