



### What's All This?

CancerCon is an annual 3.5-day gathering where attendees' lives are transformed by engaging with hundreds of peers who understand what you're going through.

Wait. Why are you reading a flyer?

Visit CancerCon.org to get the full scoop and learn all about the opportunity to join us in Denver.

Financial aid available.

For more information, email support@cancercon.org or call 212-619-1040 x414

### No judgments. No stigma. Just young adults.



### April 11-14, 2019 Denver, CO

Hyatt Regency Convention Center 650 Fifteenth Street Denver, Colorado 80202

CANCERCON2019

A PROGRAM OF STUPIECANCER ORG

(L-R) Phil, Steve and Nick Giallourakis 13 years ago during Steve's first cancer.



## A Letter from a Brother

My name is Nick Giallourakis. I am not a cancer patient or survivor, but my little brother Steve is a two-time cancer survivor of two different cancers at ages 15 and 18.

I'll dive into Steve's story but needless to say he is the inspiration myself and co-founder Angie (or Mom to Steve, Phil and I) have to start this new magazine for the adolescent and young adult (AYA) cancer community.

Over the past 10+ years Angie and I have been cancer advocates. Angie has been to Washington D.C. several times to lobby for additional funding for research to cure all of the cancers that effect the AYA community. My professional experience has been within the magazine world working for brands to bring together new trends and communities to one central location to gather information.

During our travels and talking with people we have realized there isn't a central location dedicated for the AYA cancer population to bring together not just patients and survivors but the support organizations across the country that do such an amazing job for the AYA community.

Elephants and Tea's goal is to do just that—to be a central location for people to share their stories to inspire each other and find where they can go for help with their struggles battling AYA cancer, either as a patient, survivor or caregiver.

We want to work together for the good of the patient, survivor and their families as we are all one Herd.

We would have never been involved in the cancer world if my brother Steve had never been diagnosed. Spoiler alert I met my wife

because of Steve and his nurses while he was in the hospital on a six week stay but we will save that story for another day.

This is going to be the abbreviated version of Steve's story as there are several stories he will be sharing along the way. But to give you a taste of it and to understand why we are doing what we do here we go...

It has been 13 years since Steve was first diagnosed with his first cancer, osteosarcoma, and 10 years since his second cancer diagnoses of secondary acute myelogenous leukemia (AML) which we found out was a result of his chemotherapy from his first cancer (WTF).

Thankfully, Steve received a bone marrow transplant from a generous random person as no one within our family was a match and has been cancer free for almost nine years now. Hell yes!

But as those of you who are survivors know Steve's battle had just begun.

I'm not trying to down play the fact that Steve has beaten out two cancers, several spinal surgeries, a bone marrow transplant, chemotherapy and radiation. It is a miracle that he has survived and truly is an inspiration to all.

I don't think people really understood how the side effects impacted Steve — like missing out on his high school and college years.

Frankly, I was one of those people.

My brother Phil and I were constantly trying to help Steve get his life together. Maybe it was us being protective older brothers trying to make sure our brother makes it in life. We never stopped to understand or take a deeper dive that Steve and others like him have legitimate struggles. Let's face it, those of us who have never had to fight cancer just don't understand.

Angie encouraged me to attend Stupid Cancer's CancerCon in 2018. I did, and I have never felt more ashamed about how I had been treating Steve.

I'd constantly yell at him for forgetting things or not paying attention or even freaking out when he would wake up in the morning and something wouldn't feel right and his anxiety level would sky rocket.

I kid you not, almost every single survivor I met at CancerCon reminded me of Steve. Anxiety levels off the charts and forgetting things. Chemo brain is for real folks.

Not only is this an introductory letter for *Elephants and Tea* but an older brother apologizing how wrong he was towards little brother. Steve I am sorry and I love you.

We are here to inspire and bring together the AYA community; not just to beat cancer but for life after cancer. We do not want cancer to define you, we want you to define you.

Be heard. Join the Herd.



→ NICK
GIALLOURAKIS,
PRESIDENT AND
CO-FOUNDER OF
ELEPHANTS
AND TEA

JOIN THE CONVERSATION

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

# ELEPHANTS TEA

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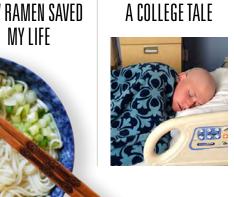


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THE ELEPHANT IN THE ROOM IS CANCER.









### www.ElephantsAndTea.com

### TEA IS THE RELIEF THE CONVERSATION PROVIDES.



## { 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:





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Angie Giallourakis

#### **President and Co-Founder**

Nick Giallourakis

#### **Design Direction**

CaveDwellerStudio.com

### Graphic Design Consultant

Joey Terry

### Elephants and Tea **Contributors**

Jennifer Anand Amelia Baffa Tess Blasko Mallory Casperson Marloe Esch Steve Giallourakis Samantha Krizo

### **Advertising Inquires**

Nick Giallourakis (440)773-9931 Nick@ElephantsandTea.com

### Offices:

3270 Grenway Road, Shaker Heights, Ohio 44122

Elephants and Tea Magazine is produced by Elephants and Tea, a NGAG, LLC company. Elephants and Tea provides online and print stories to the adolescent and young adult (AYA) cancer community. Cancer is the Elephant in the room, Tea is the relief the conversation provides.



6 NEW YEAR'S

INTENTIONS

THE HERD WEEKLY NEWSLETTER > www.ElephantsandTea.com/subscribe/ Sign up at this link to receive via email the new stories of the week every Friday morning.

SUBSCRIBE TO ELEPHANTS AND TEA MAGAZINE AND THE HERD **NEWSLETTER AT ELEPHANTSANDTEA.COM/SUBSCRIBE** 

# Surviving College After Surviving Cancer



### THREE YEARS AGO I ATTENDED A SESSION CALLED NAV-IGATING COLLEGE AND CANCER AT CANCERCON presented

by Michele Rosenthal, Director, Academic Advising and Learner Success at Northeastern University College of Professional Studies. Michele is an experienced college and cancer coach. I was looking for tips that could help me in my college journey, but was shocked to find that I was already doing everything the Michele recommended! Here are the five people most important to your success in college:

### OFFICE OF ACCESSIBILITY (OA)

First, let me take a moment and brag on what an absolutely incredible OA the University of Akron has!! Granted, my dad dragged me in the first time I ever went there, but from then on they are like my ever-ready back-up troops, just waiting for me to use! The people there are always extremely kind, and go out of their way to help me.

But, back on track. I had no idea what an OA could do. So in case you have no idea, let me tell you!

First, there is a disability specialist. He or she is your go-to point person. I send my specialist all my latest doctor letters and information, which she keeps on file. When I'm sick, I just let her know I'm in the hospital, or whatever the situation, then she informs all my professors. This really saves a lot of time and hassle for me when I'm not well. Any questions/problems/issues are all worked through with her!

Accommodations: So my disability specialist helped me sort out my accommodations. It was deemed that I needed 50% extra time on tests, because of my neuropathy and chemo brain. Because of my neuropathy, I've also been able to type instead of hand write tests with heavy writing portions. I've also utilized the switching classrooms accommodation, so I didn't have to walk as far between classes. Another useful one for me was the alternative textbook format. Textbooks can be quite heavy! The OA has most of the college textbooks on file in PDFs, that they can send you to use, so you don't have to lug a textbook around. If they don't

have it on file, they'll scan your book for you! There are so many different accommodations offered — these are just the main ones I've used!

Don't be ashamed or embarrassed to utilize these. It was really hard for me to accept that I needed the extra test time and the help, but it has really helped me through school.

### **DEAN'S OFFICE**

Make yourself known to your dean! For me, this was the Dean of the Honors College, and eventually the Dean of Engineering. As big and scary as some deans can seem, they are all there trying to promote the welfare and success of their students. Just stop by, explain your situation, and let hem know that you are trying your best in college!

My relationship with Dean Mugler of Honors really helped me when I relapsed. He put all my scholarship on hold while I was out of school, and send the various student groups to visit me! His office also sent me a beautiful card every week. The engineering Dean's office was also a huge help in getting me into classes I needed, because I was off schedule with the rest of my class.

One of the biggest helps from all the Dean's Offices has been the emotional support they've provided. I received numerous cards from them when I was in school, and they helped me obtain many scholarships as well. Just this last semester, I had to have a CT for some things, and received so many encouraging emails and words of support as I waited for the scan results. Being surrounded by people who care about you, and are looking out for you — I can't begin to explain how much that helps me.

#### **PROFESSORS**

Let your professor know your situation. I've heard both sides of this argument, but my advice is to tell them right at the beginning. This doesn't mean you're going to get special treatment — believe me, I haven't! What it does do is help them understand when you need to miss a class, or reschedule a test. I always wait till the second class (to make sure I'm still going to take the class, and also everyone wants to talk to the professor the first class) then I give them a letter from my doctor (to be spoken about later) and explain my 50% time accommodation. I'll then touch base with them before a test, as some like me to take the test in their office, others with the class and then finish the test in their office, and some in the OA.

One of my professors stopped me after class and asked me in depth about my cancer. I was on high-dose steroids in her class, and it helped her understand why I was fidgety, had trouble concentrating, and sometimes didn't make it to class. Another professor suggested I take an incomplete in the class — this just meant I could take the final later

than the rest of the class, which allowed me more time to study, and also resulted in me being less stressed!

**DOCTORS AND YOUR MEDICAL STAFF** You already know they're your best friends. Use them. My social worker wrote me a doctor letter that I give to all my professors. It has a really brief medical history, and also outlines that they (the doctors) recommend that I stay hydrated and eat during the day, and also may need to rest through the day. It lets the professors know that I'm not making this up!

Also, if you are ever admitted to the hospital, or have appointments, get a doctors letter and give it to your professors. Good communication builds your credibility, while also showing that you're still dealing with stuff medically!

YOU

You know who you used to be pre-cancer. Don't let yourself get in your way. It was/is so easy to get discouraged in college. It's really tough for kids who haven't had cancer! You will be busy and stressed and tired. You'll also be trying so hard not to get the cold that's going around the dorms. And trying to get enough sleep. While still being as involved in normal college living. It's a really tough balance. You may have to readjust your grade expectations. You may have to learn where all the elevators on campus are. You may have to ask your friends to carry your books. Or take notes for you when you don't make it to class.

Learn about the new you. And don't hate that new person. That was my biggest mistake. I tried to be the pre-cancer me, with all the grades, and activities and the put-together life. And I got so discouraged when I failed miserably. But that's not who I am. I am the post-cancer Jennifer. Chemo brain is real. Classes are extremely hard. The cold weather means I'm going to have an exhausting cough till April.

Find what works for you. I found my brain couldn't process a three hour long final. I finally learned to ask professors if I could split the final, and they all agreed. And my grades went up a bit. I found that I need to be involved with people, to help me balance my academics. And I needed to have a highly organized schedule because I didn't have the strength to pull all-nighters or the memory to do my assignments on time!

Give yourself some credit. Honestly, that's been my biggest struggle. I was always afraid giving myself credit meant being a proud peacock. It doesn't. It means you have overcome impossible odds, and are still pushing through. It's been nine very hard and long semesters thus far and now I only have one left. I've finally learned to be proud in what I've accomplished, since I'm going to graduate in four months.

Lastly, find your people. This summer I watched Grey's Anatomy, and my favorite phrase from that is "You're my person". Find your person. Find the one that you can call and cry with, or call and celebrate with. That will pray for you, and support you, and encourage you. The ones that will tease you and make fun of the way you talk. And will include you in their lunches. And will ask if you're doing OK.

Because you absolutely cannot do college on your own.

**⇒** JENNIFER ANAND, SURVIVOR

These tips originally ran on LacunaLoft.org For more young adult resources check out Lacuna Loft!

### ON A BUDGET WITH CANCER



Let's get real people. Cancer is expensive! Have no fear though...there is still a way to enjoy life and spend less money while doing so. Here are 9 tips for being on a budget while dealing with cancer...

### **10** DON'T GO ANYWHERE YOU LIKE TO SPEND MONEY.

For me, this means not going to Target. I don't know how it happens but I typically spent about \$40...regardless of what I intended to buy there in the first place.

### 2 PACK A LUNCH AND/ OR SNACK.

Eating out is so expensive. Spend a few extra minutes each night, or each morning, making your lunch and packing an extra afternoon snack. All of a sudden that \$8 lunch just turned into a healthy, and just what you wanted anyway, \$3 packed lunch.

### **3 SKIP THE** EXPENSIVE COFFEE.

You know that chain coffee shop that you just can't escape and who charges you out the wazoo for your favorite, creamy coffee drink? Yea, me too! Get yourself some coffee at your favorite coffee shop (yes, they will sell you coffee beans!) and brew it yourself at home! Need those syrups and creamers? No problem! The grocery store sells those too for a fraction of the cost of going to the coffee shop.

### **4** SKIP THE EXPENSIVE NAILS.

Just like the coffee, you can do your own nails at home!

### **6** GO TO MUSEUMS AND EXHIBITIONS WHEN THEY HAVE A FREE ENTRY DAY/ AFTERNOON.

While this takes a bit of internet searching and/or calling to the museum in question, many museums offer a free afternoon, evening, or entire day once a month! Such a great way to get out of the house AND not have to spend money!

### 6 CARRY A **BOTTLE OF WATER.**

Buying a water (or soda) while you are out and about can cost you an arm and a leg...and let's not even get into the waste that plastic bottles leave in our landfills. Instead, carry around a water bottle wherever you go. You'll stay well hydrated and your money will stay safely in your wallet. I seriously carry a bottle of water everywhere I go...I am particularly partial to this bottle and this bottle.

### 🕜 HAVE POTLUCK **DINNERS WITH** FRIENDS INSTEAD OF EATING OUT.

This is a great way of engaging your social network while also eating well. Having each person bring a food item helps to spread out the cost of the evening while remaining far cheaper than going to a restaurant.

### 8 WHILE TRAVELING. EAT NON-US FOOD.

Have you ever noticed that the best, cheap food in a city tends to be found in non-US restaurants? Instead of going to that steak house, try the Ethiopian place down the street. Instead of that milk shake and fries, try the Korean restaurant with its diverse menu at great prices. You will broaden your culinary horizons at the same time as enjoying a great meal.

### 9 SEE A MORNING OR AFTERNOON MOVIE.

Mornings and afternoons are the best time to see movies. Not only are the tickets less expensive then, but the theater is also guaranteed to be less crowded!

**►** MALLORY CASPERSON, CEO, LACUNA LOFT, SURVIVOR

## How Ramen Saved My Life



WHAT DO YOU RECALL FROM YOUR CHILDHOOD? What memories stick in your mind? Is it playing with your friends? Is it birthdays or family vacations? For me, there is truly one thing that sticks in my mind. My mom's Avgolemono soup. For those of you who aren't Greek, or unfamiliar with Greek cooking, it is Chicken and Egg Lemon soup. Ever since I was a little kid, I remember my mom making it. I don't recall her making it for special occasions, but it was something very special to me. I was a very picky eater growing up. I am pretty sure my diet consisted of hard salami, slices of American cheese, Goldfish, and my mother's homemade pasta sauce.

In case you don't know, that is not a balanced and healthy diet. My poor mother, try as she might, really struggled to get me to eat other foods. It was by no means her fault. I do recall always liking one dish, it was her Avgolemono soup. I could also tell my family really

enjoyed it too. Whenever we were eating it there was just silence. This was quite a feat for our family, between my brothers and I, our house was never quiet. So, for there to have been utter silence, there must have been something incredible going on. It was my mom's Avgolemono soup.

It wasn't until after being diagnosed with my first cancer that my taste for food really expanded. I would watch hours of the Food Network and the Travel Channel. At the time I was never quite sure why I watched these channels. All I was doing was torturing myself. Most times I couldn't eat or drink and all I wanted to do was throw up. Yet there I was watching the Food Network and the Travel Channel.

Later I would realize that it was because I wanted to escape. I wanted to see a world I had never known and might never get to know. I would lay in my bed wanting to visit these places and try these foods. There was one show that stood out and it was Anthony Bourdain's: No Reservations. Bourdain would travel to these incredible places that I never thought of visiting. He would eat food with strangers and be completely happy doing so. Whenever he would travel to countries in Asia one could usually bet he would find an incredible tasty bowl of noodles. In Vietnam he found the Lunch Lady. This incredible woman makes these ethereal broths that attract people from all over Ho Chi Minh City. It appeared that everyone eating her soup was happy, as if the problems of the day had just vanished. It reminded me of being a little kid again and eating my mom's soup. I saw on their faces what I felt as a child. I needed to find that feeling again. It would take me 12 years, but I would reach my goal.



VEGETABLE
MAC & CHEESE
BY ALLY ZEITZ,
DREXEL FOOD LAB



Make with whole-wheat pasta and cancer-fighting cruciferous veggies and it becomes an inexpensive, healthy meal that will help patients keep their weight up, and keep the kids happy. Whether for a single serving or a family meal, you can prep the pasta ahead of time and if you are tired, you can use frozen vegetables instead of fresh to speed up this deliciously healthy treat. This recipe can be found online at cookforyourlife.org

The act of cooking brings me peace and tranquility."

Two years ago, my mother and I were in Washington D.C for the Childhood Cancer Walk on the Mall. For one of our meals I insisted that we go to Momofuku, one of Dave Chengs' restaurants. The only seats were at the bar. I started up a conversation with the bartender. I asked him many questions as I was very interested in the restaurant. It wasn't until we were ready to leave when I realized ramen wasn't on the menu, so I asked the bartender. He told me that it was a special and that he had already mentioned that to me. I realized that due to my exhaustion and sadness from the day's events I didn't hear the specials. I was so mad at myself. I have been watching and reading about Dave Cheng since I was first diagnosed. I dreamed of trying the true ramen! I immediately told my mom that we had to come back again tomorrow. Thankfully she loved the food as well, so it was not hard to convince her.

The next night we sat in the exact same seat, and knew exactly what to order, the Tonkotsu(pork) style ramen. I felt like a little kid on Christmas. I was sitting on the edge of my seat waiting for the food to arrive. It finally arrived. The most incredible looking bowl of noodles. I put my face over the still steaming bowl of noodles and just inhaled. The smell was incredible. I didn't care how hot it was. I took up my chopsticks and went for it. The noodles and the broth were so hot, but I kept eating them. The noodles were perfectly chewy. The broth was utterly ethereal. I don't even recall what was in the broth other then the noodles. It tasted so good, and in that moment, I was transported back to my childhood. Here I was, sitting next to my mom, just like a child all over again. That moment was truly perfect. We spent the rest of the night talking about the soup and what it tasted like and how it made us feel. One of the favorite moments of my life. When I returned home, I was determined to first make that broth, most importantly to never lose how I felt that night.

I have been alive for just over 28 years. For most of my life I have never felt like I fit in.



I have always felt weird and a little bit of an outcast. It was never my friends' fault. I could not have asked for better friends in my life. They have stuck by my side through thick and thin and have always been there for me. Even with all the love my friends and family gave me I still felt like I was on the outside looking in. This feeling has only been exasperated my severe depression and anxiety.

Then I started to make Ramen.

I remember the first time I made a batch. I watched the broth simmer for 14 hours. I remember watching the broth change from this clear liquid to this substance that looked like a world unto its own. The bubbles of chicken and pork fat that would mix and separate between the surfacing bubbles had me totally enamored. The rhythmic gurgling of the bubbles and the aroma that wafted over me were transformative.

I felt at peace. It was as if my depression and anxiety had vanished, like I had taken a magic pill.

This feeling would only be matched by the first time I served some to my best friend

Gabby. She looked just like those people sitting at the plastic tables in Ho Chi Minh City eating the Lunch Lady's soup. The stress of their day appeared to disappear. In this moment I felt happy, to see something I made give someone I cared about such joy, just warmed my heart and for a moment nothing could touch me.

For the last two years I have tried to make a batch of ramen every week. For me, it has become the most important thing I can do for my mental health. The act of cooking brings me peace and tranquility. On my bad days a bowl of it takes away my pain and frustration. Watching my friends and family enjoy soup fills my heart with love.

There are so many things we can't control in life. Things that cause us pain and suffering, sadness and despair. If I can help transport myself or my loved ones, to a place that helps us forget our problems, even if just for a moment, I will do so.

For me happiness is at the bottom of a bowl, but it's a bowl of ramen.

⇒ STEVE GIALLOURAKIS, SURVIVOR

🖛 Cook 1/2 pound whole wheat pasta until al-dente. 🖛 Make the béchamel sauce: Melt 4 tablespoons butter over medium heat in a small saucepan. Stir in 1/4 cup all-purpose flour until it is smooth. Cook until it starts to brown slightly. This is a roux. Slowly add 2 cups warm milk, soy milk or stock while constantly stirring to avoid lumps. Cook stirring until the sauce thickens, and begins to bubble. Add 1/2 teaspoon salt and Pepper, to taste, and 1/2 teaspoon freshly grated nutmeg and 2 teaspoons grated Parmesan (optional). If the sauce is too thick, gradually stir in extra liquid, a little at a time, until the desired consistency is reached. It's ready to use. 🗕 Heat 1/2 tablespoon olive oil In a sauté pan over medium high flame. - Add 1/2 small cauliflower, chopped and sauté until the cauliflower is soft, about 10 minutes. Add 1 1/2 cups spinach to the cauliflower and cook until the spinach is wilted, about 2-3 minutes. Season with salt and pepper. 🛏 In a large bowl mix together béchamel sauce, cooked pasta, cauliflower, and spinach. Place in a greased casserole dish and top with 1 cup mozzarella

cheese, shredded. Bake in a preheated 350 degree oven for about 20 minutes or until the cheese on top is golden brown.



about y4c

Cancer and its related treatments can have debilitating physical and emotional side effects. Fear, anger, fatique, muscular pain and fragile bones are just a few commonly experienced side effects, yoga4cancer (y4c) is a specialized yoga methodology designed to address the unique needs of cancer survivors, y4c is not restorative yoga. It is not gentle yoga. Rather, y4c focuses on wellness, flexibility and strength by using movement to target the immune system, reduce anxiety and boost overall well-being.

y4c was developed nearly two decades ago by Tari Prinster - a cancer survivor and master yoga teacher. In developing this program, Tari consulted with medical experts to ensure its safety and practicality. To date, thousands of experienced yoga teachers have completed y4c training, enabling thousands upon thousands of cancer survivors to feel more empowered, rooted and whole.

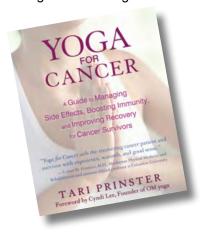
- **y4c offers:** Classes, private sessions and retreats for those with cancer.
  - Certification for experienced yoga teachers in the **y4c** instructional method with a total of 45 credits are recognized by Yoga Alliance and IAYT. This training is offered as intensives and a blended curriculum of online and live learning.
  - A directory of y4c trained teachers.

### join the community

It takes a village to drive sustainable change. y4c is committed to creating a vast network of learning, exchange, trainings and y4c classes in order to assist the growing number of cancer survivors. To learn more about classes and teacher trainings visit **V4c.com**.

### the book

In Yoga for Cancer, Tari shares her personal and professional experience using yoga to manage the challenges of cancer and its treatment:



- Includes 53 yoga poses and 20 sequences that use movement and breathing to reduce and manage treatment side effects.
- · Reveals how current research supports the physical and psychological benefits of yoga to aid recovery and reduce risk of recurrence.
- Is an easy-to-follow illustrated guide for cancer patients and survivors to take an active role in their recovery and long-term health.

Available in bookstores or buy online at y4c.com



"It seems like everyone knows yoga is good for you. At first glance, the idea of yoga for cancer patients undergoing treatment or in survivorship seems a logical step to manage anxiety, gain strength, increase flexibility and create feelings of well-being! Those should be the goals and 'job' of every cancer patient and survivor. Right? Along with keeping their immune system strong to avoid a recurrence. Based on evidence and research all these good things can happen with yoga. However, just like cancer, not all yoga is the same. There are hundreds of yoga styles, philosophies and variations. Seeking specific yoga benefits to aid cancer recovery, what kind of yoga should a cancer patient and survivor choose?

Answer: yoga4cancer (y4c)

### the yoga+cancer story

### the cancer story

Today, more people survive cancer, thanks to medical advancements and diagnostic tools. While this is wonderful news, it has also created a growing population of survivors living with the often debilitating side effects of cancer surgeries and treatment.

### the facts are:

- 1 in 4 Americans will experience cancer in their lifetime. Most will survive but will face long term side effects.
- 13.7 million Americans are living with cancer today. Sadly, that number will grow 24%by 2022 to 18 million.
- The American Cancer Society (ACS) states that 150 minutes of moderate weekly exercise, like yoga, may reduce the risk of cancer or recurrence. Complementary Alternative Medical facilities (CAM) offer and an ever-growing number of doctors recommend yoga for cancer patients and survivors.

### The question is:

Where can these cancer survivors find the support and strength to reclaim their lives? The answer is: in **y4c** classes everywhere.

### the y4c story

The y4c mission is to be that place where all survivors can reclaim their lives. We know our y4c classes help hundreds of survivors build strength, hope and community. Many, like Andria, Veronica, Virginia, Margret. Grace, Janet and Lisa already turn to yoga.

Because **y4c**'s goal is to improve lives of low-income and under-served cancer survivors, classes are free. We know scholarships help prepare yoga teachers meet survivor needs and create healing experiences based on knowledge and evidence along with compassion. We believe survivors should not just survive, they should thrive using the transformative power of yoga.

Classes and scholarships are funded by donations.

\_\_\_\_\_

yoga4cancer | Box 1235 | Stowe | Vermont | 05672 www.y4c.com

### **Survivor Stories**

yoga4cancer classes have been an emotional and physical bridge to my recovery. I started my yoga with the group before my chemo. This kind of support cannot be found in a "regular" yoga class. – Andrea

I may have to deal with cancer, but yoga helps keep my mind, body and soul healthy and strong. – Veronica

After I finished treatments, I felt beaten down, lost. Cancer seemed to take me away from me. But yoga changed that. Instead of 'hoping' my cancer will not return, I have the perfect prescription, YOGA. – Grace

I walked into yoga class feeling pretty shattered. I walked out feeling powerful and more confident.

### - Margaret

Thanks to y4c my weekly class give me the courage and healing power of yoga to keep my life in balance and the community support I need to move forward. – Janet

y4c classes have helped me in many ways. They are a safe place to share with other survivors. I don't have to worry about bringing up what I've gone through because everyone understands. – Lisa

yoga4cancer

### Jen's Corner





ever in my life did I think I'd be writing this, for a magazine for adolescents and young adults affected by cancer. But then again, never did I think I'd get the exclusive invite to this horrible cancer club. But here I am, and if you're reading this, chances are you're in the club too. So let me introduce myself!

I'm Jennifer Anand.

My golden ticket to this society was given to me on January 10th, 2012. My life was on a perfect trajectory — I was in my final semester of high school. I had been accepted into both the colleges I had applied too, and was on the brink of a full ride to both. I was competing in science fairs, and music scholarships. And then, one Tuesday at my annual pediatrician visit, I described to her the swollen nodes that had been under my arms and neck for months.

And for just one split second, I saw my doctor's face and I knew my life would never be the same.

That afternoon, I had a chest x-ray on the way home. That night, I got a call that there was a ten-inch mass in my lungs, and that CT and PET scans had been scheduled for Wednesday morning.

Thursday I had a surgery consult.

Friday I had my senior pictures taken. Pictures that show my long curly black hair. The numbers 2-0-1-2 spread on the floor in front me, my violin in my hands. Pictures that captured my life, up until that that January morning.

The next Wednesday, I had a mediport surgically implanted, and immediately began chemotherapy for stage four Hodgkin's lymphoma.

To finish this summary, I had chemo and radiation for eight months, began college at the University of Akron, and then relapsed on Christmas Eve 2012.

In March 2013, I had an autologous bone marrow transplant.

This year, I celebrated five years! I'll delve much more in my cancer experiences through the course of these posts, but I'd like to share when and why I started writing. I've been blessed with the writing gene from my mother. Her handwriting and the content are incredible, and I'll never match her abilities. But that's not going to stop me from writing!

I began my formal writing through a blog I started when I relapsed. Through my cancers, I realized two main things: young adults weren't sure what to expect when they were diagnosed with cancer, and non-cancer people had no idea the type or extent of the struggles we endure. The day I was diagnosed, one of my dad's coworkers emailed him his blog, after his life with cancer. It helped my dad get a better idea of the road ahead, and cause him to worry less.

I want my writing to do the same — to encourage the cancer peeps, and educate others. I want to allow people into my life. To give them a glimpse of the struggles, of the disappointment, the successes, the victories, the friendships and opportunities, and so much more that come with cancer experiences. So through this column, I want you to share in my life. I want to share with you things I wish people had told me.

My life will never be the same, and my hope is to use my experiences to better prepare you for your journey, encourage you in your struggles, commiserate in your disappointments and show the world that cancer will not overcome us.

**RELAPSE STORY** 

### HOW TO TELL PEOPLE YOU HAVE CANCER.

YOU HAVE CANCER. The three words you never want to hear. But how about "I have cancer". The three words you never want to say. But, somehow I have a feeling most of us have said those words, multiple times. It's not easy to share with people. Even now, five years out, sometimes I struggle with find-

ing the right time and words to tell people how cancer has shaped my life. A few thoughts I had on telling people...

### YOU CONTROL WHO YOU TELL.

This is your story. You control who gets to know about it. Even post treatment, sometimes I don't tell people my story. I share my story with the people who I feel will support or encourage me. There's a person in my life who often brings up whatever I've said in a mocking-sarcastic way. I've never told her my story, though it is public and I'm sure she knows bits and pieces of it (and a Google search will probably tell her the rest of it). I don't feel safe telling her, so I haven't. Even if you're bald, or skinny, or physically show your cancer, you control who you tell. Just because someone is staring, doesn't mean they're owed an explanation. Cancer can take some things away from us, but it can't take way our control of who gets to know about it.

### YOU DECIDE WHEN TO TELL.

This is your story. Maybe it will take you a while to share it with your friends and close circle. One of my friends made a statement to the effect of "how can I expect other people to deal with my diagnosis when I haven't dealt with it myself?" She's so right. Sometimes we need to take time for ourselves, to process the information. Even now, I tell people when I'm comfortable, and ready to invite them into my story. Now, I don't have the "cancer look" of baldness and general sickness. Most people can't see how cancer has left its lasting impact on me physically, so I can get away without people knowing. I was at an engi-

neering breakfast last week, and the people at my table began speaking about oncology doctors and nurses, one of the most amazing groups of individuals I have ever met. And while the discussion wasn't exactly negative, there really wasn't any respect or awe that I feel is owed this group. I was really torn about shutting up a few loud-mouthed college kids, with the C-bomb, when I caught the eye of my friend across the table. She knew my past, and did not appreciate the conversation at all either. But I realized this wasn't

Jen's Corner

when to tell these girls. They didn't really care, as they

weren't curious or trying to learn or understand. Telling them
would simply make
them break out into
the token "You're so
strong. I could never
do that" that seems
obligatory to respond
when someone tells
you they have cancer. In
good time, they'll learn my
story, and hopefully how better

to discuss cancer and its related issues. I'm happy about my decision, to share it only when it felt right and safe.

### YOU CHOOSE WHAT TO TELL.

This is your story. Not everyone needs to know your entire story, no matter how much they may prod and pry. I've had people dig for all the details. But they're mine to share. And frankly the more you pry looking for a juicy story, the less I want to tell you anything. There are those that I've met, however, who I know have a genuine interest so they can be a better friend to me or to others with cancer. You can always pick those people out. They ask questions like "what can I send", or "I don't know what to say. Do you have a suggestion". They always open the conversation with a disclaimer that you don't need to share if you don't want to.

### YOU DON'T HAVE TO TELL.

A bit redundant, but some people Do. Not. Deserve. a place in your story. Someone said that people have to earn the right to your story. If you wouldn't share it for a different part of your life (a family death, or divorcee, or move, or job) then why share it for this huge, life-altering diagnosis? It's your life. It's your story. It's your choice.

### FALL 2012. I HAD CONQUERED CAN-

CER. Graduated high school. Turned 18 and got my driver's license. And began college at the University of Akron. I was bald, but I had a group of kids I was friends with. Life was improving since my initial diagnosis. I got up super early Black Friday...and went to get my three-month PET and CT scans. It was a long day, as scan days usually are, but I was too thrilled at the idea that I was going to finish my first semester of college! I'd always been a very academically driven person, and I had been scared that cancer wouldn't allow me to go to college. But, it hadn't stopped me and here I was!

I began college in mechanical engineering. Our intro class final project was to make a mouse trap car that would compete in elimination rounds. I remember that night. My car team and a few other friends' team had built our own cardboard ramp in the basement kitchen of the Honors Complex. We all so desperately wanted to have a working and winning car, so we weren't going to take any chances about our vehicles not performing up to standards. And then my phone rang. I had been expecting a call from oncology with my scan results. Typically, I got a call in a day or so, but I expected that the holidays had delayed their call. But I was surprised, because it was after 7PM. It was Dr. Peters, my oncology fellow. He began by saying, "I'm sure it's nothing at all, but I'd like to get some more images," a phrase I'd learn to dread. In that moment I knew, in my heart of hearts, as I gazed into the kitchen and saw my classmates so carefree and cheerfully working away, I knew I was leaving them. I knew that despite what Dr. Peters was saying or thinking, I was very sick and the cancer was back.

It's harder the second time. The first time you're diagnosed, you're all "Rah, rah rah! I'm ready to beat this! Fight like a girl!" etc. The second time, you know the reality of what it is going to take. The awful medications. The hair loss and weight gain. The incessant nausea and puking. You know it's going to take everything you have, and then some, to keep fighting.

The day after my last final I had those further images. And then a needle biopsy of my spleen. And then the visit on Christmas Eve

morning 2012, 108 days after my last cancer treatment, to hear the words "you have relapsed Hodgkin's Lymphoma." I didn't burst into tears or anything dramatic. I quietly took the news I and my family had anticipated.

Christmas was "normal." We did our traditions, and did our celebrations, knowing it may be our last Christmas together. The new year brought in a really hard-hitting chemo, in preparation for a bone marrow transplant (another story for another time).

I never cried once. I couldn't keep food down and I chewed mint gum almost round the clock. Then sometime during that January round of chemo, I checked out. I didn't talk and I didn't eat. My mind felt numb. Nothing I could think or do could shake me from the fact that I was going through hell, again. I existed physically, but in no other capacity. This went on for probably close to two weeks. My family started to worry. I distanced myself from the reality of my life, because frankly that reality



Jen (back row, middle) and her family at Christmas 2012

really, really, sucked. My mind, expressions, and emotions were blanks and non-existent.

At my weekly Monday oncology visit, my dad told my dear nurse Ceci his worry on my state. I listlessly lay on the bed, oblivious to the medical talks and tests swirling in the room around me. Then I saw the only thing that could pierce through the concrete shell I had built — a pet pal dog. My dad always shares how my eyes finally looked alive for a second. He saw that flicker of hope and ran out of the room and literally dragged the dog in. And in that moment reality hit. I held that pupper and released my incredible sadness into its soft fur. That was a turning point for

me. Ceci came and gave me a dose of Ativan — enough to encourage me to sleep. I slept for a few hours, and awoke to a child life specialist Ceci had sent to see me. Linda was a middle-aged, motherly woman. She was also a stranger to me, and met me at literally the most vulnerable point in my life. She didn't know any of my past accomplishments, or talents, or anything. She saw a girl who was at the very end of her rope. She talked to me, encouraging me to fight, and reminding me of those who loved me. That day ended with a hug from my beloved nurse. And finally I cried. As I sobbed into her shoulder, I knew this was a sucky situation, but I knew that no matter what I lost or how bad it became, I'd always, always have hope and people who loved me.

Celebrate the people you are with. Celebrate where you are, and appreciate the memories you make.

**⇒** JENNIFER ANAND, SURVIVOR

### RAISING YOUR ENERGY LEVEL (AND ADDING SPOONS!)

**Have you ever heard of the spoon theory?** Look it up, it's incredible. It's a simplified way of telling the non-cancer world that we have limited time and energy to spend with them as even the simplest daily tasks like a shower will use up our finite number of spoons. I had breakfast with a 26-yr. old friend last week, who has several chronic illnesses. We were commiserating on our lack of spoons and how tricky that's made our lives.

Any nearby diner would have thought we were two 80-yr old women having breakfast, not two young adults who should be in the prime health of their lives.

I thought my energy would increase once I was off treatment. Unfortunately, due to the lack of high-dose-steroids, I find my energy has actually plummeted. It's so unpredictable to see what my energy will be. Maybe today I'll wake up doing great, and accomplish everything I need to, and life is awesome. Maybe tomorrow I can barely make it out of bed and my body screams in pain and tiredness. I won't be able to make it to lunch without a nap.

I recently read some online posts on others who have trouble leaving the house, and it made me really sad. I know a lot of non-cancer people think everything's hunky dory after treatment, but that's not always the case. Your

body rallied and is fighting/fought cancer. And now it's tired.

Here are four tips for raising your energy levels and increasing the number of spoons:

Rest: After cancer I wanted to do something. I wanted to make up for lost time. I didn't allow myself the time my body needed to rest after its horrible ordeal. Take the time for yourself.

Exercise: I've heard this from a number of people. Mild exercise helps your body get back on track. I took a karate class right after my first cancer. I had poor reflex and tripped over my own feet all the time. I found the karate class helped me regain my sense of balance and helped me be able to just walk better! It helped increase my energy, confidence, and gave me a sense that just like Po, I too could fight off any dragons.

Friends: We all have friends who have offered to help us out. Maybe you're like me and too proud to accept their offers. Cancer is humbling and it's OK to accept their help. Maybe it's carrying your books at school, or coming and cleaning your house, or even just bringing by dinner. That's one less thing you have to do, one more spoon you can dedicate somewhere else.

Readjust expectations: This is probably the hardest thing for me. Ever. But this is what my dear nurse kept telling me. It seems like such a simple phrase. Life post-cancer is not what I had pictured, expected, or hoped. It's crazy hard. But I need to celebrate the little things. The fact that I cleaned my room and the kitchen. I completed my work and hung out with friends. I took a walk and did an exercise video. Some days I just want to curl into a ball and cry. I hired on with three other newly graduated engineers

at my job. I feel like they're making it. They're keeping up with the visits and the travel and the reports. And me? I'm over here barely hanging on. I do a visit then crash for a nap in my hotel room before I begin my report. I drive to another city then need a nap before I can catch up on my emails. I walk my plant all morning then am ready to collapse by lunch time. Many days I wake up wondering if I'll be able to go on as a functioning adult because sometimes this low-energy life really, really sucks.

The good news is none of us are alone. A co-worker with cancer, and a few similarly aged friends have echoed the same low-energy struggles and they're plodding through. They've told me about their good days and bad. These four tips are just as much for me as they are for you. Maybe one of these tips helps you a lot and your life suddenly becomes loads easier.

I highly doubt that, but I wish you the best. But more importantly, if you're struggling with not having enough spoons, I hope you realize that I am too.

## A College Tale

EMERGING FROM THE DARKNESS

y name is Tess Blasko and I am 23 a year old cancer survivor. It was Osteosarcoma that slithered its way into my life. Being diagnosed with cancer brings you into a world where you never want to be.

Constant doctors appointments, constant worries, constant sickness, and your skin turns into needle fun-land because you are constantly being poked and pricked. Lets not even talk about the chemo hangovers where you can't even lift your head from the pillow. It was constant misery. There was never a break and I couldn't even plan anything because when I would plan something it always fell through when my body would decide to do some funny business.

Even life after cancer is difficult. I have such a strong fear that the demon is going to return and I might not come out as strong as I did the first time. I was bald, super skinny, pale, constantly throwing up, and so mentally drained. Throughout my journey I put on such a fake front to people. I always tried putting a smile on my face to whomever I was talking to even though deep down I was screaming and hating everything. I think I did that because it was easier to just smile rather than explain the 657 reasons why I was upset.

Also, I hated when my family would see me upset, I always tried being strong for them even though I was the one going through it. Funny what you try to shield from your loved ones.

Okay enough of the sob story of the awfulness you know cancer brings, I can proudly say I am back on my feet and currently back in school! I changed my major to human development and life studies and hope to become a child life specialist one day.

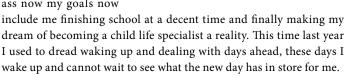
Life after cancer is strange to say the least. I no longer have that weekly routine of chemo and hospital stays. I can walk around without instantly getting tired and out of breath. I have color in my cheeks and baby soft crazy curly hair.

Looking at me now you would never think that this time last year I was battling cancer. I look back on pictures and it scares the crap out of me. I have so many more happy days now rather than sad days. My self-confidence is built back up to a certain extent and it feels so damn good to no longer be bald! My hair is so crazy these days and even though it drives me up the wall I am thankful for it. I now actually get excited for plans because nine times out of ten it's going to happen.

We all know there is no planning ahead in the cancer world. As I walk down memory lane, it makes me realize that I put my cancer life

so far in the back of my head that sometimes it doesn't even feel real. I am so caught up in my life these days its crazy to believe this time last year I was so sick in a hospital bed.

My goals last year were to survive to kick cancers ass now my goals now



My social life is great, my grades are all still passing, and my boyfriend and I got a puppy! Her name is Milly and she is my pride and

joy. One thing I would recommend to all cancer survivors; puppies/dogs bring a light into your life that you never knew you needed. She became my fur daughter and on my saddest days she brings me so much happiness.

We all need something to bring us out of darkness. My life really is good right now but I still have my moments of despair, worry, and sadness. Some days are harder than others and some days I am perfectly fine. I constantly have to remind myself of where I was a year ago and compare it to

where I am now. I always tell myself that I am a bad ass and I can make it through anything! You're a bad ass too! Never forget that.

My story is still being written and I am so excited to share my story and live this new life after cancer that I have been blessed with. Whoever is reading this; lift your head up and tell yourself you're going to make it through. Never stop pushing yourself, and always look for the light at the end of the dark tunnel. Cancer brings the flames and you'll come out stronger than you ever thought is possible.

**➡ TESS BLASKO, SURVIVOR** 





HEALTH BENEFITS

of pet owners reported mental health improvements from pet

reported a friend's or family member's mental health has improved from pet ownership

"Puppies/dogs bring

a light into your life

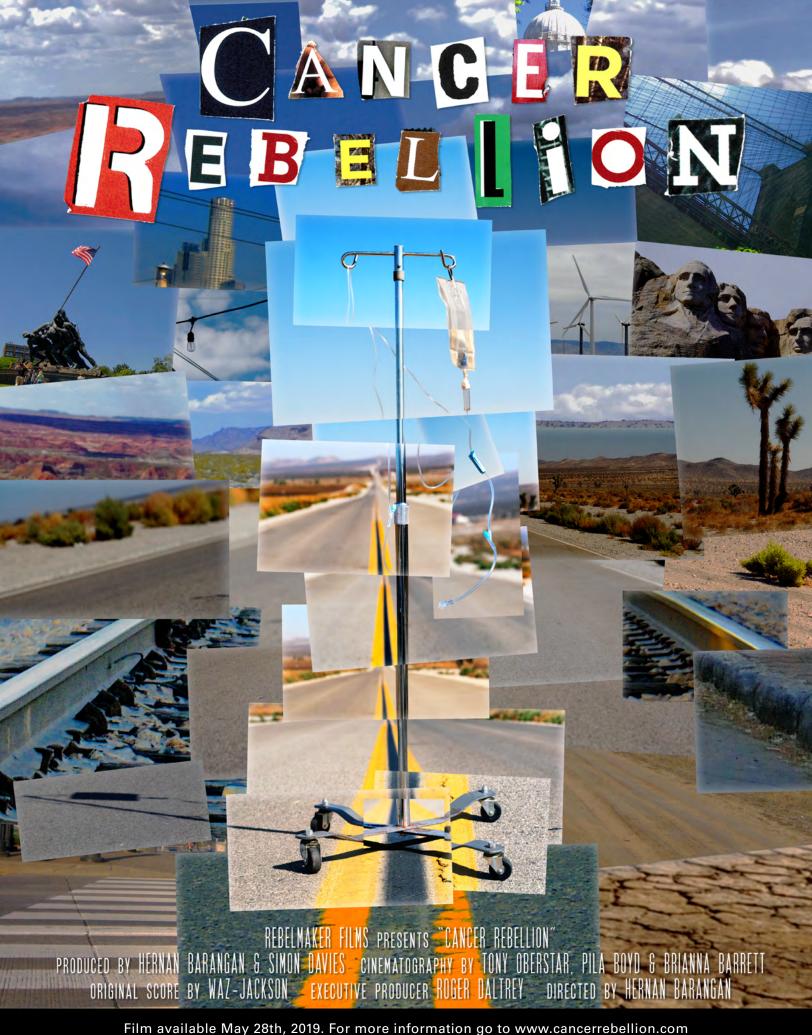
that you never knew

you needed."

reported physical health improvements from pet ownership

reported a friend's or family member's physical health improved from pet







# I Never Thought This Would Happen To Me

started my cancer "journey" in July of 2017 and I never thought cancer could happen to me. It has been a long and rough ride, but I think I am starting to see the smoother part. There will never

be a time that you are not going through the "journey" as cancer has life long issues. Although as an oncology patient there will always be fear that cancer will come back, but you try to get through the rest of your life as best as you can.

One of the problems that I faced and continually face is the dreaded chemo brain. People who haven't had chemo think there is no such thing. Scientist say there is little to no change in the chemical make up after chemo, but you and I both know that its real. You feel like Ariel and you can't remember the name of fire but remembers that it burns. Now, it's not a drastic change like one day you don't remember anything. It's a gradual forgetting what the fridge is called but describing (example: it keeps the food cold and freezes ice). It is also forgetting what

doctors' names are, what they look like, your prescriptions, even what has happened in the last few days, weeks or months. It's not as bad as it seems but you probably will have to remind yourself of a few things as

Sam (far right) at University Hospitals in Cleveland, being visited by Seth Devalve and Joe Schobert of the Cleveland Browns.

the days go on. There will be some days where you wake up and for a few seconds you think about your old life; but then reality sets in and you remember what your life is like now. I like those moments; they keep me grounded to what is important.

I found out there are people who care about you and those who just want to make themselves feel better. The distinction between the two is the people who care about you, spend time with you and those who will avoid you when you are sick. Your emotional health is just as important as your physical health. Your emotions can manifest in physical symptoms. If you are upset or anxious about a test you might be more nauseous than usual (there isn't a time that you are not nauseous). If you are bottling in your emotions all the time you could get body pains, headaches, or you could get angry at the wrong person. If you feel like crap tell someone, trust me you aren't alone in your fight or in your life. Always remember it is OK to feel weak and have bad days, but you make the choice every day when you wake up how you day is going to go. You can feel bad about having cancer or you can say to yourself, out loud or not, that cancer isn't going to take you out.

One of the biggest helps was talking to a social worker and getting social security and help paying some of my bills because I couldn't work for almost an entire year. My social worker and I were able to fill out a few documents and they were able to help me get on Medicaid and social security. If my so-

cial worker couldn't help me with any of the financial issues I would be in debt of \$500,000, at the very least, for lifesaving medicine and treatment. I lost my job and my insurance there was no way to support

> myself. Luckily there are a few foundations out in the world that help cancer patients pay some bills for a bit, because we as patients didn't try to get cancer, it just happens.

> The biggest thing that I can give to people is be your own advocate. If you think there is something wrong, then say and fight your medical team to make sure the proper tests are done. If you don't like a specific doctor, nurse, or transport person, you can tell them to not come back or you don't want them treating you. You have rights as patients. If you want to order food from the children's menu or have Chinese delivered, you have the right to eat what you want (unless it's for a medical reason example: surgery, transplant, or food restriction). If you want to sit in the dark in your room and

avoid all contact with people you can do that too. No one can force you to do what you don't feel like doing.

⇒ SAMANTHA KRIZO, SURVIVOR

"Your emotional health is just as important as your physical health.
Your emotions can manifest in physical symptoms."



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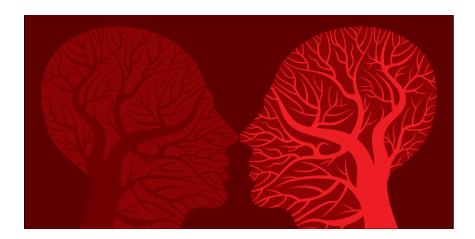
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- Parents and family members of cancer patients and survivors
- Caregivers to the AYA cancer community







# Your Brain in the Bedroom

et's start off with a bit of trivia. And it isn't a trick question, I promise. What's the biggest sex organ? If you guessed the brain, you're right! Wait, did the title of this post give it away? Ok, that's fair. But now that I have your attention... While it's true that the physiological aspects of sexual functioning, like vaginal lubrication, erection, and orgasm, are impacted in part by both our hormones and the health of the blood vessels and nerves that supply our nether-regions, that's not the whole story. As it turns out, the more subjective or cognitive components of sexual functioning, like our interest in engaging in sexual activity and how we perceive and respond to sexually relevant stimuli (our partner touching our back, for example, or giving us "the glance") totally depends on our mental and emotional state of mind.

If you think about it, this makes a lot of sense. Things like fear, anxiety, or worry tend to activate our brain's stress response — the same stress response that was responsible for saving our ancestors from getting eaten back in the day. It's our brain's job to ignore sexy stimuli when it feels like there's trouble lurking. Essentially, it's thinking "I ain't got time for that! We're going to die!" I mean, if our ancestors were too busy getting distracted by the sheer ecstasy of getting it on to run away from lions and tigers and bears, well....

Prioritizing stress over sex is normal. Our brains are built to do this, and they're really good at it. Sometimes TOO good. Sometimes, even when we want to be able to enjoy a sexual experience, or we want to want sex with our partner, our stressed out brain gets in the way.

That's the bad news. The good news is that once we understand that our interest in and ability to enjoy sexual experiences can be inhibited by negative thoughts, feelings, and emotions, we can then deduce (correctly!) that working to change our state of mind can help. This is the magic of understanding the brain-as-a-sex-organ. Let's call it your B-spot, shall we?

The full potential of the B-spot depends on a couple of things. First, you gotta clear away all the noisy clutter that's taking all your brain space. Secondly, you gotta figure out what kind of stimulation your B-spot responds to. How can these things be accomplished, you ask? Let me count the ways!

### IDENTIFY AND ADDRESS YOUR STRESSORS

Cancer sucks, and there is a whole crap-ton of stress that comes with it. Things like anger or grief over losses, changes in our bodies and our self-confidence, uncertainty about the future, or fears of recurrence can follow us through treatment and beyond. I call these our existential stressors.

When it comes to sadness, fears, or anxieties, expressing yourself can be really, really helpful. Truly honest conversations with a close friend, your family, or a support group can ease distress. So can expressive writing or art therapy. When negative thoughts or feelings are persistent and interfere with sleep, the things you used to enjoy, or your work or social life, it is important to seek professional help. Sometimes our stress can be related to changes in our romantic relationships after cancer, and it can really help to

involve your partner in counseling sessions, too.

Identifying and addressing your stressors is easier said than done, I know. But this is crucial. No matter how much effort you put in to implementing any of the other suggestions to follow, if there are things on your mind that are stressing you out, your brain will absolutely focus attention on what's stressful instead of prioritizing any other want or desire. Minimizing the stress that can hog brain power leaves room for potentially sexy stimuli to get noticed as... potentially sexy!

#### **MAKE SPACE FOR RELAXING ROUTINES**

But what about those super annoying day-to-day stressors? Dishes, laundry, traffic jams...All of these can add up, and to our brain, stress is stress is stress. Whether from a lion, the fear of missing a deadline, or the fact that your partner left their dirty socks on the floor again, these types of stressors are as equally as likely as our existential stressors to be hitting the breaks on our potential for getting hot-and-heavy.

This is where "me-time" can play a role. In addition to your daily or weekly to-do's (because, yes, it DOES feel good to check things off the list!), make a list of activities that bring you pure joy — spending time in the garden, puttering around the garage, bubble baths, reading a good book, being creative with wood-working or writing, enjoying the stars, whatever. Make it a habit to set aside time for yourself. Intentionally making space for doing the things that we enjoy is what keeps us sane, and what reminds us of the good things in life. And there are lots of good things in life... like being intimate with our partner.

### **PRACTICE MINDFULNESS**

Alright, so you took to heart suggestions #1 and #2, and what happened? Your brain wouldn't shut up? Instead of inner Zen, you had a constant stream of distracting thoughts? Totally common. Totally normal. And totally manageable... by strengthening your mindfulness skills.

Mindfulness is the act of focusing your awareness on the present moment, being attuned to physical sensations, and ignoring distractions. It's beneficial for all kinds of reasons. Studies have shown that over time, practicing mindfulness can increase your sense of well-being, promote energy, combat fatigue, and decrease depression and anxiety. All of which, by the way, can really put a little spring in your step, or your libido. Mindfulness, though, can also help us avoid distractions during intimacy. Being mindful improves our ability to tune out the noise of negative thoughts and tune into whatever pleasurable sensations are happening right now — whether physical ("That feels good!") or emotional ("I really enjoy spending time with my partner!") Sounds like B-spot stimulation to me...

If you are an evidence-based kind of person, I hear ya, and I'm happy to report that there is a whole body of research devoted to the idea of mindfulness and sex. Check out Dr. Lori Brotto's book, titled Mindfulness and Sex, to dig into how and why mindfulness is so awesome.

#### **DEVELOP A SEXUAL FANTASY**

Thinking about a sexy scenario before or during sexual activity can lead to a chain reaction of increased desire and arousal, and can even help with achieving orgasm. Sexual fantasies are really, really good at stimulating the B-Spot!

When it comes to what turns us on, we're all a little different. If you're not sure exactly what you find stimulating (some of us have never really thought about this before), or if you feel like you never experience sexy thoughts, consider keeping a desire diary. This exercise was outlined by Dr. Leslie R. Schover in the 2007 American Cancer Society publication Sexuality for the Man with Cancer (but it works for the ladies, too), and it looks like this: Every day for a week, carry a paper with you wherever you go, and whenever you have a sexual thought or feeling, write down where you were, time of day, activity, what triggered the thought or feeling, who you were with, and what you did about it. That's it!

Our brains are so good at shutting down sexy thoughts when they show up at inconvenient or inappropriate times (in the check-out line at the grocery store, say?) that we hardly even recognize our own arousal reaction sometimes. Making note of these fleeting thoughts can teach us a lot about ourselves, and can be really helpful in a couple of ways. Firstly, you might be surprised at how often you actually have thoughts about sex, and simply having this awareness can improve interest. Secondly, you might find patterns in what turns you on, and you can use what you've learned to put yourself and your partner in these mood-enhancing situations, or for creating a private sexual fantasy all your own. Happy day-dreaming, my friend.

### TAKE ADVANTAGE OF YOUR PARTNER'S LIBIDO

You may not have a fully spontaneous urge to initiate sexual activity, but that doesn't mean that a sexual encounter is out of the question.

This might seem counter-intuitive, because we are taught that desire is the obligatory first step in sexual response. Not true! Sometimes, once you've made the conscious choice to participate in sexy activities and things get going, you end up finding that sexual "wanting more" feeling. This is called responsive desire (vs. the spontaneous kind), and can happen for both men and women. In fact, for women in particular, this is the most common way desire is experienced.

Have you ever found yourself not thinking about sex or not feeling particularly sexual, but your partner initiated something and you thought "Sure, what the heck?" and when it was all over, you thought, "OMG, that was great! Why don't we do this more often?" That's responsive desire.

Sometimes our brains have to be reminded of how fun sexy encounters can be, and how great we feel afterward (all that oxytocin promoting bonding, affection, and love, blah blah blah). We don't need to be actively seeking sexual pleasure in order to enjoy it once we've decided to engage. So what if it wasn't on your radar two minutes ago? Allowing your brain to be stimulated with a little bit of action (B-Spot!), can leave you wanting more. Not that you are required to say Yes to your partner every time he or she asks (absolutely not!) ... but ... What if the next time your partner brushes up behind you, instead of an immediate "Nope!" reaction, you lean in and think, "Maybe....?"

#### **CREATIVITY AND IMAGINATION**

If you have a long-term romantic partner, no doubt that you probably have a fairly routine sexual script that has developed over time. After all, practice makes perfect! Knowing what works and how to make it happen is great... until something like cancer comes along and suddenly you don't, and it isn't. Like I said before, cancer can change our self-concept, self-confidence, and how our bodies work. Now what?

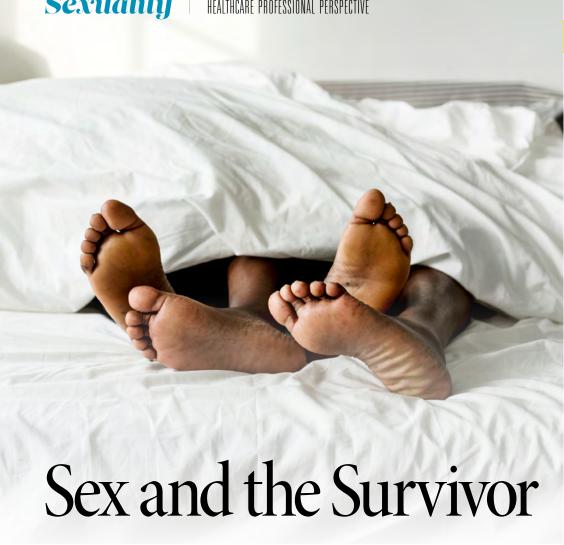
It's important to keep an open mind and drop the idea of some arbitrary end-goal; there's more than one way to give and receive pleasure! Embracing curiosity and playfulness can be a no-pressure way for you and your partner learn what's changed and what works. Challenge your sexual "status quo" by trying different positions, different times of day, using pillows, and experimenting with "extras" (lube, personal massagers, etc), manual or oral stimulation, and sensual massage (which may lead to discovery of new erogenous zones). Embrace planning over spontaneity. It may take a little extra effort to set yourself up for a satisfying sexual encounter, but with preparation and thought comes anticipation, and that's just another prime example of B-Spot stimulation.

Bottom line: Don't underestimate the B-spot! Your brain can be your biggest barrier or greatest ally when it comes to sex. With practice and patience, we can learn how to give less attention to what's stressing us out and more attention to what makes us feel good. Cancer brings challenges, but it also brings opportunity. Time to see what your mind is made of!

**►** MARLOE ESCH, SURVIVOR



Introducing Marloe to the Herd! Marloe Esch, RN, BSN, Oncology Certified Nurse (OCN), and young adult cancer survivor, graduated from the University of Wisconsin-Madison School of Nursing (Go Badgers!) in 2008. 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.





The impact of cancer and cancer treatment can physically and psychologically affect our relationships, this can be especially true when it comes to romance and/or intimate relationships.

Whether you are dating or in a committed relationship talking about the possibility of cancer, recurrence/ relapse, physical limitations, body image changes, fertility issues, and your feelings can be frightening, scary, or daunting. Take a few deep breaths and consider being honest with your partner about what you are thinking and feeling. Chances are they have concerns of their own, it's likely that they have been waiting for just the "right time", to talk to you about them. By opening up and communicating you are creating the opportunity to work through both of your concerns together. Go team!



Amelia Baffa is a Nurse Navigator at Angie Fowler Adolescent and Young Adult Cancer at UH Rainbow Babies & Children's Hospital. As a Psychiatric Mental Health Nurse Practitioner, with years of experience working with adolescent and young adult cancer patients, Amelia provides the reader with factual information as well as helpful steps to take when dealing with the sensitive issues of sexuality as a cancer survivor.



### TALKING TO YOUR **DOCTOR OR NURSE**

- · Ask about sexual concerns that could happen after treatment.
- Write down questions and symptoms. Knowing what you want to ask ahead of time can conquer any shyness and embarrassment. If you feel too embarrassed to discuss your concerns you can email your provider before your appointment with your questions and concerns, this way they'll be aware and prepared to discuss at the visit.
- Some people find it helpful to bring their partner with them, and that way they can discuss their concerns together.
- Be specific. For example "I am having pain during sex, and it's really upsetting. It could be from all the chemo/radiation therapy I received. Will this get better? What can I do about it?"
- If you feel uncomfortable you can practice what you want to say before the visit, or jot down your thoughts.
- Lastly it's normal to feel embarrassed, but here's the thing, if you don't talk about your sexual concerns you may not get the help you need. Even if your doctor or nurse don't have all the answers they can direct to you to professionals who do. Note: there are healthcare providers that specialize in individuals/ couples experiencing sexual issues, they are called Sex Therapists.

### THE GENDER CHALLENGE:

Female cancer survivors tend to be more affected than their males. According to Dr. Brad Zebrack over 52% of females report experiencing at "least a little problem" in one or more areas of their sex life while 32% of the male survivors reported experiencing issues with their sexual functioning (Zebrack, Foley, Wittman, &Leonard, 2010.) Females also report feeling more distress/anxiety regarding their sexual difficulties than males and more sexual symptoms, while males tend to experience more distress related to sexual difficulties.

### WHAT CAN HAPPEN AFTER TREATMENT

Reported issues in sex life:







- · Loss of interest in sex
- Trouble getting excited or enjoying sex
- Bad thoughts or feelings about sex
- Trouble having an orgasm (climax)
- Dryness or tightness in the vagina
- Pain during sex or when the genitals are touched
- Effects of chemopause (early menopause) such as vaginal dryness, hot flashes, and painful intercourse
- Body image changes



- · Loss of interest in sex
- Trouble getting or keeping an erection that is firm enough for sex (erectile dysfunction)
- Trouble having an orgasm (climax)
- Having orgasms that are shorter, not as intense, dry
- Leaking urine during an orgasm instead of semen
- Pain in the testicle during sex
- · Body image changes

### **SURVIVORS: HOW TO TALK TO YOUR PARTNER**

Conversation starters. It's simple, start communicating and keep communicating. By maintaining open dialogue about what you are thinking and feeling, you'll know what's on one another's mind, which will help you face your concerns as a couple. If you have to discuss a delicate issue and you're afraid of offending your partner try starting with an "I" statement, such as "I feel sad when I 'm too tired to be with you." This take the focus away from your partner and focuses/ identifies with what you are thinking and feeling, this opens up the way for them to listen to your concerns without making it personal.

**Be truthful.** Be honest about your feelings. Good communication is the foundation of any stable relationship. Remember the goal is to get through this together.

**Mind Reading.** Chances are neither you nor your partner are mind readers. Let your partner know how you feel and what's on your mind, chances are they are waiting for a clue from you, so they know what they can do to help.

Love and be loved. Practice loving yourself and being loved. Consider your strengths, maybe you make the best brownies this side of the Mississippi, practice random acts of kindness every chance you get, or volunteer at the local animal shelter. Whatever it is, feel the positivity, the sense of gratitude that comes from being in touch with the goodness is present within you.

### **SURVIVORS: TAKING CARE OF YOURSELF**

**Schedule an Assessment.** Don't suffer in silence, talk to a healthcare professional. They can help you to identify potential causes and treatments, for changes in your sexual health and function.

Take a broader view of sex. Cancer treatment can lessen sexual desire. Yet people with cancer still need and desire physical closeness. Hugging, caressing, massaging, cuddling and kissing can satisfy you and your partner.

**Take it slow.** There is no need to rush. If you are not ready for sex, don't feel pressured to be more or less sexual than you want to be. Being intimate can center on pleasure and being together.

Talk with your partner. If your partner is silent or appears withdrawn, it doesn't' mean he or she is not concerned about what you are going through. They may be unsure of how to show affection or worry about hurting you or causing you pain. Talk to your partner about any concerns you may have about physical touch and sex. Be honest about what you want and need, what feels good and what doesn't.

**Stay the course.** What's that old saying, "Rome wasn't built in a day?" Don't give up, be patient, and above all things maintain your sense of humor.

**Change your techniques.** Spend more time on foreplay. Try different positions that may be more comfortable or pleasurable. Try different things to get you in the mood.

Talk to your partner about our fantasies and feelings. Communicate with your partner about what feels good and about new things you may want to try. Get creative!

### CONCLUSION

Throughout all that you and your loved one have been through you have built something very powerful... that something is called resilience. Resilience is defined as the ability to recover from difficulties: a toughness. It's akin to one of my favorite words, grit, which is basically a quality that embodies perseverance and passion. It's that place within you that says "Dammit I am not giving up!" Step back are reflect on how far you have come, and know that within yourself you have the strength to recover and thrive in all aspects of your life. The good news is, and research supports the fact that the majority of survivors go on to have a healthy sex lives, that means

➡ AMELIA BAFFA, NURSE NAVIGATOR

### ADDITIONAL INFORMATION:

The American
Cancer Society at
www.cancer.org, and
search for articles
titled: "Sex and the
Woman with Cancer,"
"Sex and the Man
with Cancer," and
"How Cancer Affects
Sexuality."

CancerCare at www.cancercare.org and search the article titled "Intimacy During and After Cancer Treatment."



### 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.



### 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.



### 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 Children Hospital in Cleveland, OH. The Smoothie Day Program provides a nutritious snack and a healthy break from the world of cancer.



### 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.



### True North Treks truenorthtreks.org

At True North Treks, we help teens & young adults with cancer find direction through connection after the very disconnecting 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.



### 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) 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.



# Why partner with us?

*Elephants and Tea* is striving to become the center hub for sharing stories to inspire and provide information in the adolescent and young adult (AYA) cancer community to support patients and survivors in their cancer journey.



- Be listed on our *partners page* on our website and each print issue
- Have your own customizable page on our website to direct traffic to your resources
- Have Your resources listed within stories that are related to your focus
- Highlighted in our weekly "The Herd" digital newsletter delivered into our subscribers mailboxes
- Promote resources and events via our social media network accounts
- Submit stories and content to be feature on our website

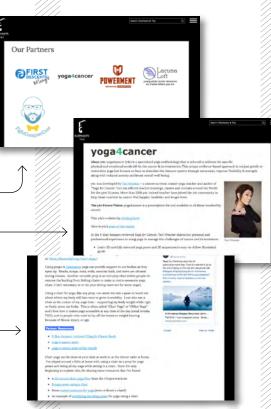
## ELEPHANTS AND TEA IS THE ONLY MAGAZINE FOCUSED SOLELY ON AYA CANCER PATIENTS AND SURVIVORS.

### **5 MAIN AREAS OF FOCUS**

- Wellness and Nutrition
- **◆** Emotional Support
- ◆ College, Career & Cash
- Sexuality
- ◆ Chemo Brain

### **TARGET AUDIENCE:**

- ◆ 15-39 year old male/female cancer patients and survivors
- Parents and family members of cancer patients and survivors
- Caregivers to the AYA cancer community



### **WOULD YOU LIKE TO PARTNER WITH US?**

CONTACT NICK@ELEPHANTSANDTEA.COM FOR INFORMATION

Elephantsandtea.com

AND DON'T FORGET...
PARTNERING
WITH US IS
FREE!

### A Letter from a Mother



Imagine you are told your child has cancer. They survive. And then they get diagnosed a second time. And they survive. IMAGINE! Two cancer experiences.

Diagnosis. Chemotherapy. Surgery. Radiation. Chemotherapy. NED (No Evidence of Disease). Proclaimed a survivor. Second diagnosis. Chemotherapy. BMT (Bone Marrow Transplant). NED.

#### **SURVIVORSHIP**

Life has been a whirlwind since my son Steven was first diagnosed with cancer in 2006. I found the only thing that kept me going was praying. Praying as I became educated about my son's illness and treatments; praying for patience as a caregiver to a teenager and then a young adult; and making sense of the entire cancer journey. His BMT (Bone Marrow

Transplant) put an exclamation point on my emotions — as I was told that there were no guarantees of the cancer never returning - and set a fire within me to passionately engage the entire world of adolescent young adult (AYA) cancer! I disengaged from my former self as a college professor and looked to the future with determination to become a change maker.

I wanted to learn what AYA cancer really meant. What kind research would impact this population? Who were the decision makers in policy making, service providing, and advocacy? How I could squeeze myself into this new world?

I traveled throughout the country meeting many wonderful advocates representing the research and medical communities, parents like myself, and the survivors of AYA cancers. I learned that medical research is happening and making headway to identify the best ways to treat and hopefully cure many of these rare cancers. I learned that some of the more common "older adult cancers" like breast and colon are often more aggressive in the young adult populations. I learned that AYA's were best served in environments designed to meet the needs of their age group — not with young children or older adults. And, lastly, that research has identified a set of psychosocial needs for AYA cancer patients and survivors that are often unique to their age group.

Enter son Nick — President of Elephants

Nick and I explored ways to best get the word out and provide an outlet to AYA cancer patients and survivors. We wanted to establish a media platform that encouraged self-expression through narrative formats, art work and poetry. In other words a creative energy platform for members of "THE HERD" — but... also a place where resources would be incorporated into the stories being shared to our readers.

So here we are today with a magazine and website where patients, survivors, caregivers and advocates can share, visit, and learn what it truly means to be an AYA cancer patient and survivor when life and all its promise and plans have come to a screeching halt.

Thank you for picking up our magazine and for reading my letter. I hope you will join us. Be Heard. Join the Herd.

➡ ANGIE GIALLOURAKIS, PH.D., CEO AND CO-FOUNDER OF ELEPHANTS AND TEA



Research has identified a set of psychosocial needs for AYA cancer patients and survivors that are often unique to their age group.



## 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

Include a message "for Wellness Kit" and your name(s)

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

### 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:**

ThriveTM Causemetics



Thank you to our generous sponsors:







young adult cancer resources no matter where you are

