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heal

VOL.9 NO.2 / **SPRING 2021**

Sex after **CANCER**

What are the most common sexual side effects cancer survivors face, and how are they treated?

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**Slow Walking Could
Be Cause for Alarm in
Survivors**

**200,000 TikTok
Followers Show One
Survivor Support**

**How to Get Through
Fear of Recurrence**

**Spring Into a
New Season with
New Recipes**

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living well *after* cancer

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**Vice President & Executive Producer,
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circulation@mjhassoc.com

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Managing Editor Darlene Dobkowski;
editor@curetoday.com

Editor Antonia DePace

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Editorial & Business Office
MJH Life Sciences, LLC.
2 Clarke Drive, Suite 100
Cranbury, NJ 08512
609-716-7777

Talking About the Sexual Side Effects of Cancer

SPRING IS UPON US. During this season of renewal, rebirth and reawakening, be sure you're listening to your body and asking your doctor about any side effects or symptoms that you might be experiencing after cancer, no matter how off-limits you might feel they are.

A study from the Sidney Kimmel Cancer Center at Thomas Jefferson University in Philadelphia found that 87% of survivors of breast, pelvic, endometrial, prostate, bladder and rectal cancers experience challenges in their sexual desire and function after treatment.

So if sexual side effects are so common, then why aren't they being talked about more? Many survivors who have sexual side effects after treatment feel too uncomfortable to share this information with their doctor, and some doctors may not know how to address it with their patients.

In this issue of *Heal*®, we explore this topic. We hear from two survivors — one man, one woman — about how cancer and treatment affected their sex lives. We also hear from doctors about why survivors might experience these side effects and how to treat them.

In addition, we hear from a survivor who decided to document her journey with stage 4 lymphoma on the social media platform TikTok, which gained her nearly 200,000 supporters and helped her find purpose.

Also in this issue: A penile cancer survivor discusses “scanxiety” — the fear that occurs in the weeks and days leading up to your next scan because you're worried about cancer coming back. This very real fear can make you irritable and “irrational” (as he puts it) and make it very easy to lash out at loved ones.

Finally, celebrate the spring season with some new recipes, including a kale salad and a chickpea curry. No need to wonder, “What should I eat for dinner?” or “What can I make that's healthy?” because these recipes are perfect options. And remember to save room for dessert! (Hint: It involves chocolate.)

As always, we hope you find this issue both informative and helpful. And who knows, it just might inspire you to share *your* story with us. [H](#)

MIKE HENNESSY SR.

Chairman and Founder



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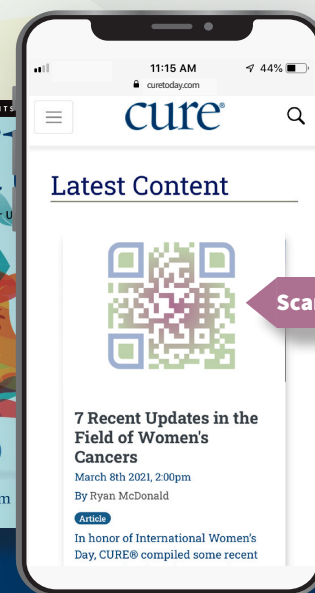
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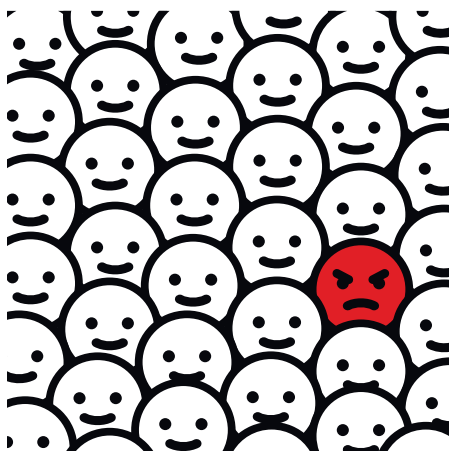
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‘Scanxiety’ Can Make Us Irrational and Irritable

A penile cancer survivor discusses how easy it is to lash out at loved ones and be frustrated by every little thing in the days leading up to a surveillance scan. BY JONATHAN LITTLE

IT HAS BEEN GOING ON for a while now. It always follows the same routine.

Somehow, subconsciously, I just know it’s coming. I start to tense up and my sleep starts to suffer. The sleep I manage to get, I spend grinding my teeth.

When I’m awake, I’m just snapping at people or being irrational. Cancer does that to you. All that broken sleep ages you, too.

“Oh, you look tired.”

“Yeah, Karen, I haven’t slept in three weeks.”

It’s not actually “the cancer” though. It’s the fear of it coming back.

WHY DO I FEEL LIKE THIS?

I’ve been in remission for a year now, and I’m writing this a day before my next scan. It will be the eighth surveillance scan I’ve had since they last found any new disease.

When I first received a diagnosis of penile cancer in 2019, it was all a bit of a whirlwind. By the time my staging was complete, I was told that I had stage 3, grade 3 cancer.

It had spread from the primary tumor in my penis to the next set of lymph nodes in my groin. After having nodes removed in my pelvis as a precaution, I got the incredible news that there was no sign of disease. Or, as some like to say — that I was cancer free.

Next, I went through a few weeks of chemoradiation to give me the best chance that cancer wouldn’t come back. It was tough, but I knew it was worth it.

IT’S JUST GREAT TO BE ME AGAIN, WHILE IT LASTS

The scans and the months go by, and in the gaps between, you grow in confidence. Things get back to normal, and the smile comes back to your face. You’re not a victim anymore.

Then, just as you’re thinking how great the world is, the call comes: “Hello. Your consultant has asked us to contact you about coming in for a scan. How is three weeks, this Thursday?”

Well, it’s terrible. I never want another scan in my life. But you know you have to. You know that speed is everything when it comes to cancer. The earlier you catch it, the better the chances of killing it.

But as soon as that appointment is made, the clock starts ticking. The little arguments start at home, lashing out at the people you love. The silly frustrations at the simplest tasks and being overcome with emotion about the supermarket being out of edamame beans. The dull ache in your side and in the pit of your stomach that mimic a tumor.

SO MANY QUESTIONS

What if it’s come back? What if they didn’t find all the microscopic disease? What if the surgery wasn’t radical enough, or what if the cancer took a detour and it’s growing farther up my body? What happens then? It took less than three months to grow a tumor the size of a tennis ball in my groin. What if it’s in my liver or something?

Am I being irrational? Of course I am. But cancer does that. It destroys your belief system and what you think is normal. Simple logic becomes difficult to handle. Surely, I’d know if it had come back? I only ever ask myself the questions that I know I can’t answer.

I JUST WANT TO BE ME AGAIN

The crazy thing is that I’m not scared of the treatment. I’m not bothered about operations or spending time in a chair getting chemo. I am not worried about the radiotherapy. The side effects are the worst part, but I can handle those, too. I know what to expect.

It’s the disruption that bothers me. My cancer puts everyone’s lives on hold, and everything has to revolve around me.

I’m supposed to be a parent, a husband and a leader. People depend on me to be there, to be involved. More than anything, I really want to be there. I want to be me.

That’s why I hate scans — because I know I’m only ever “I have some bad news” from taking me away from the best job in the world. **h**

Advice From People Like You

We asked readers
What is the best advice you've gotten on your cancer journey?
Here's what they told us.

"I am not defined by my cancer!"
—CAROL

"I have two things. 1. Do not do any research on the internet. 2. Keep a three-ring binder with all your schedules, payments, paperwork, etc. You will have to refer back to the past, and my binder helped in more ways than one. It was my brain when my brain was tired and fatigued. —VICKI"

"Keep your cards and notes in a binder so you can go look back at all the support from people that love and care about you on those days that you're not feeling so wonderful. —KARI"

"Humor produces endorphins that will help ease your journey! —RON"

"You can be sad or depressed but don't stay there. Look around, then get out. —KATHRYN"

"One day at a time. —SANDI"

"Ride the waves. You will be angry, sad and a whole lot of other emotions. And that's normal. You don't have to force yourself to be positive. —TIFFANY"



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AYA Cancer Survivors Experience Mental Health Impact Long After Treatment

Adolescents and young adults who receive and survive a cancer diagnosis experience a 20% higher risk of a psychotic episode and a 30% higher chance of an outpatient mental health visit compared with individuals who have no history of cancer.

By COLLEEN MORETTI

SURVIVORS OF ADOLESCENT OR young adult (AYA) cancers, especially those treated at an adult cancer center, experience poorer long-term mental health outcomes compared with their peers who have never received a diagnosis, according to data published in the *Journal of Clinical Oncology*.

Previous study findings revealed a higher risk of psychiatric diagnoses among survivors. “Our study confirms this elevated risk and shows that it exists across a spectrum of severity (whether outpatient visits or hospitalizations) and is prolonged,” the researchers wrote. The increased burden of outpatient visits was seen 15 years after five-year survivorship.

AYA patients often become long-term survivors of cancer, but studies on their mental health status are rare and often overlooked. Researchers in this study aimed to evaluate the long-term mental health effects in survivors of AYA cancers, analyzing factors such as demographics, disease, treatment and treatment setting.

Using the Initiative to Maximize Progress in Adolescent and Young Adult Cancer Therapy database, a database of individuals who received a diagnosis of AYA cancer, researchers studied 2,208 survivors who had cancer between 1992 and 2012 and were at least five years out from their last cancer event and 10,457 people with no cancer

history. All individuals were 15 to 21 years old and from Ontario.

The researchers sought to identify outpatient visits, such as a visit to a family physician or psychiatrist for a mental health complaint, as well as severe psychotic episodes, including emergency department visits, hospitalization or suicide. Rates of each were compared between the AYA survivor group and those without a history of cancer.

Survivors experienced a 30% higher rate of outpatient mental health visits compared with the group without cancer. Most visits were linked to anxiety disorders, which supports findings from a previous study showing that survivors had a 60% higher risk of anxiety and adjustment disorders than their siblings.

Female survivors, those with outpatient mental health visits prior to the cancer diagnosis and those treated with methotrexate were all associated with an increased rate of outpatient visits in survivorship.

Specifically, there was a 17.4% incidence of a severe psychiatric event among survivors compared with a 13.9% incidence among those without a history of cancer at 15 years after five-year survivorship. Survivors had a 20% higher risk of a psychiatric event and had a significantly higher chance of association with schizophrenia or another psychotic


disorder. Rural residence and prior mental health care visits also were associated with severe psychotic episodes among survivors.

Interestingly, the researchers noted that survivors treated at an adult cancer treatment center had an 80% increased rate of outpatient mental health visits compared with survivors treated at a pediatric center.

“Available psychological support may vary between pediatric and adult settings, given differences in patient volumes, although this has not been well studied,” the researchers wrote.

They added that future studies should examine if psychological support during treatment is associated with improved long-term mental health, which may help support the need for psychological resources for AYA patients during and after cancer treatment.

The researchers concluded that “further studies should endeavor to understand mechanisms underlying these associations and to identify interventions both during and after treatment, which can mitigate this risk.”

Limitations of this study included lack of outcomes from mental services provided by nonphysicians such as social workers, no data on patients who cannot or choose to not have access to health care, and other potential factors to poor mental health such as race, ethnicity or sexual orientation. 

Coping With Fear of Recurrence

Some worry is normal, but certain patient traits are linked with higher anxiety about cancer returning. Consider these strategies to feel more secure about survivorship. By BRIELLE BENYON

THE AMERICAN CANCER SOCIETY estimates that at least 70% of survivors experience fear of recurrence, and that percentage may be even higher among patients with certain characteristics.

“One of the most common concerns of cancer survivors (after cancer treatment is the fear of cancer coming back — what we refer to as fear of cancer recurrence,” says Jacqueline Galica, an assistant professor at Queen’s University School of Nursing in Ontario, who worked as an oncology nurse before pursuing her doctorate.

Galica’s research primarily explores the psychosocial needs of post-treatment survivors and seeks to identify methods to help them to meet these needs. After seeing firsthand the stress that survivors experience about their cancer coming back, she decided to conduct research to determine if certain characteristics are associated with fear of recurrence.

“We used a theory, Leventhal’s common sense model,” she says. The model is used to understand people’s responses to illness and is “commonly used to understand cancer recurrence. We used this to identify what could be important characteristics to look at amongst cancer survivors.”

CHARACTERISTICS LINKED TO FEAR OF RECURRENCE

Galica’s findings, as well as results from other studies, show that certain patient characteristics are associated with higher rates of fear of recurrence.

- Younger survivors have higher anxiety about recurrence compared with older survivors.
- Women worry about recurrence more than men.
- As more time elapses since diagnosis and treatment, a survivor’s fear of recurrence tends to increase. This could be a result of the constant reminders and uncertainty, as survivors continue to have follow-ups and screenings.
- Individuals who have symptoms they perceive to be cancer related worry more about recurrence.
- Individuals with low self-esteem have higher anxiety about cancer returning.

People who are more pessimistic tend to have lower rates of fear of recurrence. “This might be their type of coping,” Galica says. “They’re maybe ... more likely to deny or disengage and give in to their circumstances.”

STRATEGIES TO REDUCE FEAR AND COPE BETTER

Survivors can take steps to decrease their feelings of fear of recurrence, and these steps, says Galica, can actually promote better behavior.

“Low levels of fear of recurrence can actually be motivating,” she says.

“It can motivate us to make healthy behavioral changes, like quitting smoking, for instance.”

However, fear of recurrence can also have an opposite effect, such as survivors not going to follow-up appointments or cancer screenings.

If survivors feel they have a debilitating level of fear or if that fear frequently interferes with their daily living, Galica suggests they seek out professional help, such as a cognitive behavioral therapist.

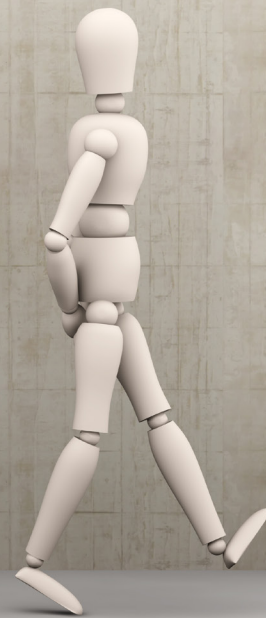
Survivors can also use other methods to help curb their negative feelings, such as gratitude journaling and talking to supportive people, especially other survivors who understand and feel the same way. Doing so can help people realize that fear of recurrence is a common and normal emotion.

Says Galica: “Sometimes those thoughts will creep in — we’re human — but (it’s important to) reframe and focus on what’s true.”



Slow Walking Pace May Be Cause for Alarm in Survivors

A slower walking pace may be associated with a higher risk of mortality rate in survivors of cancer compared with their healthy matched peers, according to an expert. By COLLEEN MORETTI



SURVIVORS OF CANCER ARE 42% more likely to walk at a slower pace and experience mobility disability compared with healthy peers, which may be associated with a higher mortality rate for up to five years after treatment, according to data published in the *American Association for Cancer Research*.

Results of this study demonstrated that a cancer diagnosis was associated with poor ambulatory function, or a slower walking pace. A significant association with slow walking was seen in those with a previous diagnosis of breast, colon, oral, prostate, rectal, respiratory, soft tissue, stomach and urinary cancers. The same diagnoses, as well as endometrial, were also associated with a greater risk of being disabled compared with cancer-free, age-matched peers.

A slower walking pace was associated with a higher risk of all-cause and cancer-specific mortality. When comparing survivors with slow and fast walking paces, those with a slower pace had more than double the risk for all-cause mortality. A similar association was also seen in mobility disability and all-cause mortality.

In an interview with *Heal*[®], lead author of the study Elizabeth Salerno, assistant professor of surgery at Washington University School of Medicine in St. Louis, discussed the study and what it means for survivors.

Q: *Heal*[®]: What are some key highlights and takeaways from the study for survivors in particular?

A: **Salerno:** We really had two key takeaways and findings. We found that the risk for poor ambulatory function as we measure it — so, slower walking pace or having mobility disability — was higher in cancer survivors compared with cancer-free, age-matched controls. And then we also found

that survivors who reported slower walking or having mobility disability were at a higher risk for all-cause mortality. And I think one of the big takeaways here is that these findings were consistent across several different types of cancer.

Q: What does “poor ambulatory function” mean?

A: In our study, poor ambulatory function was indicated by self-reporting a slow walking pace (less than 2 mph) or being unable to walk.

Q: Why was this study conducted?

A: So, it's likely no surprise to you and many others that cancer survivors are now living longer than ever before, which is exciting, and we love to see that. But understanding how the diagnosis of all these different types of cancers can affect ambulatory function — which is potentially modifiable — could lead to new treatment strategies, new rehabilitation strategies and, ultimately, improve the health and longevity of survivors. And so that really was the impetus for us studying this particular ambulatory function.

Q: What do the implications of this study mean for survivors?

A: I think this study, hopefully, lays a foundation for future work to better understand some of these associations. So, with this, one of the first questions on the questionnaire asked survivors to report their normal walking pace. (We) really need to better understand if we can intervene with targeted interventions like physical activity (to) actually increase walking speed or improve mobility so that we can

“ Our findings suggest that survivors would do well to watch for poor ambulatory function after a diagnosis and to reach out to their physicians if they are concerned about a loss in mobility or slower walking pace. — *ELIZABETH SALERNO* ”

ultimately improve the lives of cancer survivors. There's a lot more to be done, but this lays us a nice foundation, particularly for wide surveillance of cancer survivors.

Q: Why are we seeing people have poor ambulatory function after surviving cancer?

A: That's a great question and something that I wish we knew more about in the research community. Poor ambulatory function after receiving a diagnosis of cancer and the cause of that is certainly thought to be multifactorial. And we certainly weren't able to analyze that in this study, and we don't necessarily demonstrate a causal relationship. But there is a lot of thought about accelerated or accentuated aging that we often see after a diagnosis of cancer. So reduced functional levels certainly could be a part of that.

It could be due to the cancer itself or to changing behavioral factors after a receiving diagnosis of cancer or before that, (which) may predispose an individual to develop cancer in the first place. Or (it could be due) to treatment-related factors. So, all of that is something that we (should) certainly do more research on.

Q: Could something be done during cancer treatment to help prevent this?

A: Something that we always think about is: When is the optimal time for us to intervene? When is the optimal time for us to be assessing a lot of these different indicators?

I don't know what this study necessarily tells us about when we need to intervene or when we need to monitor, but it definitely tells us that ambulatory function is important, at least in this context. So (do) we need to be monitoring this earlier — during active treatment, right after active treatment? It's definitely worth further study.

Q: Should this and will this change survivorship care?

I think the monitoring is something of utmost importance for providers and for clinicians, making sure we have continuity of care — and so really thinking about this indicator, function and walking speed because they are potentially modifiable. So, I think if we do some research to better understand the mechanisms of why certain cancers

have stronger associations, then absolutely, I can certainly see targeted interventions being developed and then, of course, delivered at appropriate times.

Q: What does this study mean for survivors right now? Is there anything they can do to help themselves if they do experience poor ambulatory function?

A: Our findings suggest that survivors would do well to watch for poor ambulatory function after a diagnosis and to reach out to their physicians if they are concerned about a loss in mobility or slowed walking pace. Research from other studies suggests that physical activity may improve function during survivorship, and a necessary next step is identifying the extent to which targeted physical activity interventions may improve self-reported ambulatory function after cancer.

Q: What further research should be done?

A: Certainly more immediate steps would be understanding why certain cancers have those stronger associations with (ambulatory) function and then, of course, (ambulatory) function (association) with mortality than others.

To our understanding, this was the first study to do this analysis in 15 different cancer types. So now we really need to dig further into why we see some of these associations. That may include looking at behavioral factors, biological factors and cancer-specific factors that may be changing from diagnosis all the way well into survivorship. And it'll really be important for us to better characterize these associations within unique, specific cancer types.

Then, of course, maybe long-term steps would be including measured and self-reported ambulatory function like walking pace or mobility disability, as well as objective measures (for which) we have people come into the clinic and actually time how quickly they walk.

So these results provide a nice signal for the cancer-function mortality relationship in a larger population that we really need to (examine) a bit further. Because again, this would allow us to determine how we need to be targeting ambulatory function so that we can have a lasting impact on survival. [h](#)

SEX *after* CANCER



What are the most common sexual side effects survivors of cancer face, and how are they treated?

By KATHERINE MALMO

A month after Alegra Woodard received a diagnosis of stage 1 cervical cancer, she underwent a radical hysterectomy, a surgery that removes the uterus, ovaries, fallopian tubes, left and right pelvic nodes, cervix, tissue around the cervix, and the upper part of the vagina. She was just 36 years old, a wife and mother working as an information technology practitioner in Honolulu.

Her life changed overnight.

“The next day I felt like another person,” Woodard says. “The change was drastic. I went into full menopause. I started sweating, my sexual desire (was) nonexistent, and intercourse became very difficult because it felt like someone had poured sand in my vaginal area.”

Woodard isn't alone. A study out of Sidney Kimmel Cancer Center (SKCC) at Thomas Jefferson University in Philadelphia found that 87% of survivors of breast, pelvic, endometrial, prostate, bladder and rectal cancer said treatment affected their sexual function or desire. Although sexual side effects are more often reported by women, they affect men as well. »



▲ **ALEGRA WOODARD'S**
sex life changed overnight
when she underwent a
radical hysterectomy.



ALEGRIA WOODWARD wishes someone would have told her about the sexual side effects that would come after surviving cancer.

Steven Dupin, a personal trainer, comedian, author and patient advocate for the Prostate Cancer Foundation, (visit their site to learn more about the side effects of prostate cancer), lives in Los Angeles and was 42 when he started having problems with frequent urination and prostate pain. However, he didn't receive a diagnosis of prostate cancer until two years later, when his doctor ran a routine PSA blood test, which is used to screen for prostate cancer. Dupin says that his biggest fear, besides dying, was that he would have problems with sexual intimacy as a result of treatment. Both of these fears are common.

"The No. 1 question I get from other men I talk to is 'Does the plumbing still work?'" Dupin says. "I always say, 'Sure. The only difference is that now instead of ejaculate, fairy dust and glitter come out.'"

That last part, of course, isn't true. But the stories patients tell of sexual side effects resulting from cancer treatment are.

So, what causes these problems, and what solutions are available for survivors?

COMMON SIDE EFFECTS AND CAUSES

In Women

The SKCC study found that the most common sexual side effects were painful intercourse (73%), body image distortion (54%) and the inability to achieve orgasm (42%).

According to Ashley Arkema, a nurse practitioner in the Female Sexual Medicine and Women's Health Program at Memorial Sloan Kettering Cancer Center, the most common concerns reported by the patients she sees are low libido, sexual pain, diminished arousal and changes in body image. Fatigue, anxiety and depression can also affect sexual function. And she attributes these problems primarily to cancer treatment, including surgery, chemotherapy, hormone therapy and pelvic radiation, which often cause sexual side effects that are associated with hormone depletion. For younger patients this is especially true. Abrupt early surgical menopause or chemical menopause causes a rapid drop in estrogen, leading to more severe and sudden symptoms. Hormone therapy, including tamoxifen and aromatase inhibitors, commonly used in breast cancer treatment, can also have a negative impact on sexual function. And pelvic radiation can lead to menopause, vaginal narrowing and scarring.

Dr. Mindy Goldman, director of the Gynecology Center for Cancer Survivors and At-Risk Women at the University of California, San Francisco, who serves as the chair of the menopause panel and the co-chair of the sexual function panel for the

National Comprehensive Cancer Network (NCCN), agrees that the lack of estrogen causes many of the most common forms of sexual dysfunction in women. However, there are other causes.

"There are many aspects of cancer treatment that can cause sexual dysfunction, and the causes are often multifactorial," Goldman says. "Vaginal dryness can lead to pain and decreased desire. Surgeries can lead to body image changes. Stem cell transplants can cause graft-versus-host disease that can lead to scarring, pain and decreased arousal. Radiation can lead to pain and scarring. The cancer itself can cause pain. And then (a lot of women) also have cancer-related stress, anxiety and depression that can affect their overall sexual functioning."

She says the key to treating patients is a multifactorial approach and finding safe and effective options, especially for those who shouldn't use hormone therapies.

In Men

Dr. Gregory Broderick, a urologist at Mayo Clinic and a professor of urology with Mayo Clinic Alix School of Medical Education in Jacksonville, Florida, sees male patients who have cancer who've experienced sexual dysfunction, incontinence (loss of bladder control) and urethral strictures (scarring that narrows the tube that carries urine out of the body).

Together, Goldman and Broderick co-chair NCCN's panel on sexual health. NCCN is a nonprofit alliance of 30 cancer centers that partner to improve cancer care and survivor issues by reviewing and updating guidelines. They want to make sure certain side effects (like this one) are not overlooked.

The most common problems he sees are erectile and ejaculatory dysfunction, loss of libido, incontinence or other urinary problems like climacturia (when a man leaks urine as he ejaculates). There can also be body image challenges, especially for men who live with a stoma or ostomy bag after colorectal or bladder surgery.

"In terms of the prostate surgery, a significant risk to a man's erectile function status is whether or not the pelvic nerves that regulate erection can be spared at the time of surgery," Broderick says, noting that a more recent approach to the operation, called robotic prostatectomy, has advantages because "patients don't require a large abdominal incision, have much less bleeding, and can get back to work sooner."

Dupin was able to have robotic surgery, and he is able to have sex and achieve orgasm. He doesn't have problems

with a lack of libido or incontinence. The only sexual side effect he's experienced is the loss of ejaculate.

TREATMENTS

For Women

After Woodward's surgery in 1999, she was prescribed a topical vaginal medication called Premarin (conjugated estrogens) to lubricate and improve dryness. But this still left her unsatisfied.

"All of the large guiding organizations say to use over-the-counter topical agents first," Goldman says. "This includes things like moisturizers, pH balanced gels, soothing agents, oils and lubricants. Some of these things can alleviate symptoms if they're used regularly."

Arkema says her first few recommendations include a variety of over-the-counter products, but these solutions don't always work for everyone.

Goldman notes there are vaginal hormones that can help treat dryness and sexual pain by targeting the tissue directly. The most common are vaginal estrogens which exist in a cream, a ring formulation and a suppository.

Furthermore, Goldman says there are now Food and Drug Administration (FDA) approved prescription medications that treat various types of sexual dysfunction. Ospheña (ospemifene) and Intrarosa (prasterone) are approved for treatment of painful sex. Finally, there are also female versions of Viagra, as well as the FDA approved Addyi (fibanserin) and Vyleesi (bremelanotide), which are both approved for treatment of hypoactive sexual desire disorder in women. »



HELP FOR WOMEN WHO EXPERIENCE SEXUAL SIDE EFFECTS

Arkema's Recommendations for women who experience sexual dysfunction:

- ☐ Discuss your symptoms and concerns with a health care provider.
- ☐ For vaginal dryness and pain (likely due to menopause) she recommends non-hormonal moisturizers and lubricants on a regular basis, typically three or four times per week at bedtime. Some examples include Replens long-lasting moisturizer and hyaluronic acid products, Revaree and HyaloGYN.
- ☐ For lube she recommends avoiding flavored and tingling lubricants, as well as those containing common irritants such as propylene glycol, glycerin and Paroex Oral Rinse (chlorohexidine). She often recommends a water-based product like Good Clean Love. She advises against using soaps and douches in the vagina.
- ☐ Vaginal dilators are crucial to avoid vaginal narrowing and scarring in patients treated with pelvic radiation. They can also be helpful for anyone experiencing pain or vaginal tightness with penetration.
- ☐ She usually gives patients education handbooks like the "Improving Your Vulvovaginal Health," a Memorial Sloan Kettering Cancer Center resource available online.
- ☐ If these strategies don't work, she recommends the patient consult with a women's health provider to discuss additional options such as low dose vaginal estrogen.
- ☐ For individuals experiencing low libido, addressing the underlying cause is the first step. Adequate sleep, regular exercise, mindfulness, and sex therapy or couples counseling may be helpful.

“I think there’s a common misconception that nothing can be done,” Goldman notes. “Some providers assume the only treatment options are hormones, and for many breast cancer patients these are contraindicated (not advisable). Even so, there are lots of other options.”

For Men

Broderick says that when meeting with a new patient, he starts by looking into how they were treated because the type of therapy often dictates the sexual side effects and recommendations. The primary treatment options include PDE5 inhibitors (which block the PDE5 enzyme, allowing blood vessels to relax and increasing blood flow), such as Viagra (sildenafil citrate), Levitra (vardenafil), Cialis (tadalafil) or Stendra (avanafil); penile injectable therapy; penile prosthesis; and the use of a vacuum erection device.

Although robotic surgery has come a long way, some men still struggle with incontinence, which quickly becomes a critical sexual side effect.

“When a male patient comes to me with incontinence and erectile dysfunction, I start by asking where their partner is sleeping, because one thing I’ve learned is that partners will not sleep in the bed with someone who is incontinent,” Broderick notes. “And they’re less likely to become intimate with someone who isn’t in the same bed. So, you really need to address the incontinence first.”

After a prostatectomy, Broderick says all patients go through a phase of neuropraxia (when the nerves aren’t working quite right). It takes time to return to normal erectile status. Generally, erectile function begins to come back after about six months. He says if it hasn’t come back by 18 months, it probably won’t.

Furthermore, radiotherapy, which is good at killing cancer, affects small-vessel blood flow, so patients who have been through radiation can have difficulty initiating and maintaining erections. Most of these patients, however, respond to PDE5 inhibitors like Viagra. On the other hand, a man who has lost nerve function from a prostatectomy needs direct vascular stimulants like penile injectable therapy.

“So, I have a counseling plan for patients depending upon whether I’m seeing him six, 12 or 18 months after his operation and his willingness to undergo rehabilitative strategies,” Broderick says. “Some patients come in and they’re part of a couple who are both in their 70s, and the erectile dysfunction is not as impactful for them simply because they weren’t all that sexually active prior to the surgery. Maybe his partner has gone through menopause and is less receptive of penetrative sex. What she’s really looking for is the maintenance of their intimacy without penetrative sex. Sometimes my job is just getting the two partners to understand where they both are with all of that.”

TALK IT UP

Although the range and severity of sexual side effects can vary greatly, one thing that helps across the board to increase treatment rates is talking about what’s going on.

Findings from the SKCC survey of 400 survivors found that 87% said they experienced sexual side effects — but most also said their oncologist had not asked them about these side effects. And patients often don’t bring up the topic themselves, reporting that they feel embarrassed, think there’s no help

“After STEVEN DUPIN’S diagnosis his biggest fear, after the chance of dying, was the impact treatment would have on his sexual intimacy.



“The No. 1 question I get from other men is “Does the plumbing still work?””

—STEVE DUPIN

for the problem or don't know which type of physician to talk to about it.

Woodard says she wishes someone would have talked to her about what to expect before her surgery, but at the time she was being treated in a military clinic. She received her diagnosis from a nurse practitioner and then transferred to the hospital to meet with the surgeon and oncologist.

“I remember that session when I met with the oncologist who looked at my chart and said, ‘You have cancer? That’s odd,’” Woodard recalls. “These conversations were never about gutting me out like a fish and what would happen afterward.”

She went into surgery without any idea about what was coming.

“There’s a stigma or discomfort for many physicians in talking about this,” Goldman says. “There’s a study that showed that if the patient feels discomfort coming from their provider, they often won’t bring the issue up. So there (are) a lot of people who may assume that this is something they have to live with.”

Goldman sees no reason that sexual dysfunction can’t be talked about like the other side effects of treatment, such as neuropathy, hair loss and pain.

At Mayo Clinic, Broderick says they train their surgeons to do exactly that: talk about all the possible side effects.

Fortunately for Dupin, the possibility of sexual side effects was addressed. His doctor told him he may experience erectile dysfunction and gave him a prescription for Viagra that he decided not to use.

Sexual side effects of cancer treatment are common, and Goldman wants patients to understand this and feel comfortable asking about what treatments are available.



Woodard, who now volunteers with the National Cervical Cancer Coalition, (their website can help patients and survivors understand their side effects more and offers support), agrees that patients need to speak up.

“My advice is to be more demanding,” she says. “Ask for resources. Often treatment is not only a physical procedure but one that affects your mental and emotional health. You should be in touch with an advisor or someone that can help you navigate the emotional part of this.”

More importantly, Woodard wants patients to know they’re not alone. “There (are) a number of us out here,” she says. “Seek help, ask questions, be persistent and don’t give up. Don’t give in.” **15**

How TikTok Helped One Survivor Discover Connection and Community

Lymphoma survivor Nina Luker talks about receiving a diagnosis at age 24 and how sharing her story with nearly 200,000 supporters on social media helped her find purpose.

By JESSICA SKARZYNSKI

IN EARLY 2020, 24-year-old Nina Luker was completely blindsided when she received a diagnosis of stage 4 lymphoma. It felt like a “death sentence,” she says.

While powering through treatments in the thick of the COVID-19 pandemic, Luker turned to social media to document and share her experience in a raw and unrehearsed way — and soon gained nearly 200,000 followers on TikTok, a popular social media platform that allows users to share short videos with their followers and the public, who identified with her situation and cheered her on every step of the way.

Now officially cancer free, Luker joined us on the “CURE® Talks Cancer™” podcast to share her cancer journey, her work with the Lymphoma Research Foundation and her advice to those who may have recently received a diagnosis of their own.

Q: **CURE®: Can you start off by telling us a little bit about your cancer journey and how you came to receive a diagnosis?**

A: **Luker:** So about a year ago, (on March 11), which happened to be the day the World Health Organization declared COVID-19 a pandemic, I was also diagnosed with stage 4 diffuse large B-cell lymphoma. And I was 24 years old at the time. I was a Division I athlete at the University of North Carolina, and health and fitness were at the forefront of my mind throughout my entire life. So to hear the word “cancer” was heartbreaking and mind numbing.

Given my history of having such a healthy lifestyle, it really shocked my family. It is not something that runs in the family; I have no extended family members or immediate family members who have ever had cancer, so (this was) news to us.

And the symptoms I was having before I was diagnosed were really unsubstantial. I had a few body aches here and

➤ **NINA LUKER** found nearly 200,000 extra supporters through TikTok during her journey with cancer.

there, and they were pretty severe, but nothing that alarmed me or anyone around me. And I only had two occasions of night sweats. So for me to be at stage 4 with such a limited amount of symptoms — again, massive shock to myself and my family.

I found out through a biopsy that my dad encouraged me to get. He is, ironically, in the pharmaceutical business and sells a drug for classical Hodgkin lymphoma. So I had the most knowledgeable expert closest to me, and he was the one to say things aren't adding up. And even though my blood work and my scans came back normal, he was the one to push for a biopsy. I attribute almost my life to that moment when he said I (should) follow through with more screening and testing — because without him, I could have let this go on and it could have cost me my life.

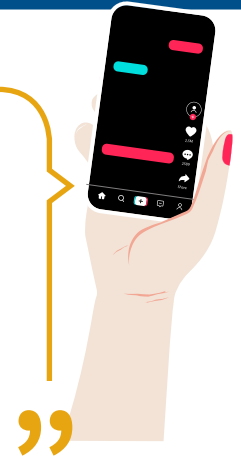
On March 11, (2020), I received a diagnosis, and one week later I started my six treatments of R-CHOP (Rituxan or rituximab, Cytoxan or cyclophosphamide, Lipodox or doxorubicin hydrochloride, Marqibo or vincristine and Pre-Mild or prednisolone). I was having this chemotherapy regimen every three weeks, which totaled ... five months. I did not undergo any radiation. And one of the biggest hurdles I faced as a young female was the inability to freeze my eggs. I had only a week or two from the initial diagnosis to my treatment day. ... So that was really difficult, and I still don't know how my fertility was affected. But five months later, after six rounds of treatment, I was put into remission. I have had three clear scans now and have my fourth in a week.

Q: What went through your head when you heard the word “cancer”?

A: I remember the night like it was yesterday. I was walking home from work, and I had just told myself, “I’m going to stop at the grocery store.” I had forgotten that I was going to get a call from my oncologist with my biopsy results. It had been 10 days (since) my biopsy, and no one said the word cancer. People even said, “This is just you guys being extra cautious.” ... So I was by myself walking home (and) ended up missing the block (for the grocery store) and said, “I’ll just go back another time.” I walked through my apartment door. I was by myself. My roommates weren’t home. I heard the phone ringing, and I was like, “Oh my gosh, I totally forgot, I had this call.” I walked into my room, and I remember looking outside the window. And the moment I heard my doctor’s voice, I knew.

I had to patch in my family members ... because they were not with me. And he didn’t say anything other than “I have really tough news, Nina. Your biopsy came back, and you have non-Hodgkin lymphoma.” And at that moment, I sank to the floor. I put myself on mute, and I couldn’t tell you a single thing that was said after that — except for the sounds of my mom and my dad just trying to process through teary-eyed, muffled sounds. So that word “cancer” at that moment was the most shocking word.

“To be given a number is nothing I would ever want for another person because it feels like that number controls you. — **NINA LUKER**”



Q: Once you got that news, what was the next step?

A: The next step was finding out what stage I was at. I had to go through a PET (positron emission tomography) scan after my biopsy, and I was told that this could be really early on, given that I had nearly no symptoms. So again, I was set up to expect better results than I had. I was immediately put into an appointment for a PET scan, and that day, I would find out that I was stage 4.

Now, knowing nothing about cancer and having had no cancer in my family, stage 4 to us at that moment was a death sentence. On top of hearing “You have cancer,” it was stage 4. The news was exactly the opposite of what we had expected. So I quickly had to understand (that) stage 4 non-Hodgkin lymphoma is a different type of severity than other cancers and that this is treatable. I was given a 66% chance of surviving, and in most cancers, that’s a very good number.

But to be given a number is nothing I would ever want for another person because it feels like that number controls you. And that feeling is the worst feeling in the world.

Q: What was treatment like? Having to go through that at the beginning of a pandemic had to affect how treatment went and even how you went about finding treatment.

A: I had the best resource by my side. I was set up immediately with the most incredible doctors at Penn Medicine and had an amazing support system behind me. And a week later, I would start my R-CHOP treatment.

Now I was the only person who could go into every single doctor’s appointment and every single chemo session. And as a 24-year-old who honestly (didn’t have) a single word to say because I didn’t know what was going on ... It was setting me up for not success. And this was no one’s fault, other than the timing of this being a pandemic. So I would call in my parents and have them on speakerphone with me during doctor’s meetings and appointments and during my treatment, which would typically last seven to eight hours. It was me, myself and I with my nurses.

Not having someone by my side actually was a relief to me because I didn’t feel like I had to entertain them while »

I was going through something that my body just couldn't handle. I had really bad allergic reactions to all of my medications every single time. So to have someone else's fear and worry plastered on their faces while I was going through this probably would have actually made it more difficult. So ... not having the closest people in my life by my side was extremely difficult, but at the same time, I was able to focus on the one thing I could — and that was myself.

Q: Eventually you turned to social media to chronicle your story, and now you have more than 200,000 followers on TikTok. How would you say social media has helped you through not just the pandemic but also cancer?

A: I could go on and on about this. And before this, I would have said social media is kind of fluff, both Instagram and TikTok. There's not a lot of authenticity, not a lot of vulnerability. And I can say confidently now, that is totally not the case, especially for myself.

My goal was not to become this widely known person. My goal was to document in a video setting my story so I could look back and see what I was feeling, what I was going through and kind of what I looked like through the process. It ended up being the most natural and authentic way for me to share, and people immediately gravitated to my story.

I'm someone who is always positive, and I have a demeanor that looks at life like a glass half full. So for me to bring that into my cancer journey and document it in a way that was real positivity mixed with raw emotion ... I don't know if there's another person who has touched that. And I was able to do this in a way that was short and sweet.

And I could reap the support from each of these strangers who gave me everything. I mean, I would get ... hundreds of messages a day from people saying, "Your story has touched me," "I had a loved one who went through this," and "I've shared your story, and it's given them optimism and hope" or "I myself am going through this, and I'd love to lean on you for some emotional support because we're going through the same thing."

To know that you're making a difference while going through something so tragic makes you feel grateful (about) what you are given.

Q: Your post that you're cancer free back in August has more than 350,000 views. What was it like sharing that news with all of these people? What kind of support have you gotten since then?

A: It's a bit interesting. When I post on TikTok or on social media, I do it in a way that is immediate — this is how I feel. I don't edit anything. So I just put up what I was feeling, and then I closed the app and let it sit and really focused on myself because I was just overwhelmed with emotion — excitement ... mixed with fear and happiness. And all of these messages came flooding in.

So it was a lot. I'll be honest, it was both the most miraculous thing I had but at the same time, there were a lot of eyeballs on me. And it put a lot of pressure on. Whether you

can control what's going on or not, it's still pressure that you want to share your life. And this was my life. This was life or death. I wasn't sharing that I got a new job. I was sharing that my life could keep going. And that is a very powerful thing to put into the universe. So I didn't take it lightly. And to this day, I still get messages all the time and opportunities to speak to people who need that support. I just find it to be, I think, the purpose of why I'm here and why I was given what I was given.



Q: Now you're working as an ambassador with the Lymphoma Research Foundation (LRF). Can you tell me little bit about that?

A: It was through social media that they found me, and they are a large community. Unfortunately, this is a disease that touches millions of people. But to have a community like LRF, who gave every ounce of support, encouragement, resources, mentors, workshops ... They provided me with a group of like-minded individuals who understood what I was going through. Not a single other person in my life could actually relate to what was going on in my body and my mind. And they gave me that port. They found me organically through TikTok, and I ended up becoming an ambassador thanks to the power of what I was expressing.

Q: What kind of work are you doing with them as an ambassador?

A: I'm super early on. I was onboarded about a month and a half ago as an ambassador. So I'd be lying to say I'm doing all of these extravagant things. But the hope is to not only raise awareness for LRF but also to be a spokesperson on the resources and show that optimism and cancer can share the same dialogue. I see such a massive opportunity to be a spokesperson that shines light in the most vulnerable way on what cancer means. And as a young female, I hope no one my age ever has to go through this, but it's likely they will. And to be able to turn to someone who's gone through that journey and to have a community supporting you is my hope and ... the hope of LRF.

Q: What advice do you have for someone who may have just received a diagnosis?

A: Advice is a very difficult thing. I sometimes steer clear of trying to give my opinion on how to feel because when you're given something like that, no person is going to handle it the same. But there are a few things that I did in my life and that I changed that helped me for the better. I can share those and hope that those encourage others.

A few of them are creating a daily movement and exercise routine. And I know a lot of people might (ask), "Why are you doing that? You can barely get out of bed," but it gave me something to look forward to that would strengthen my body.

I also created a nutrition and diet (routine) that would support my body. I took away sugars and made sure I was eating whole natural foods, which actually encouraged me to start my own vegetable garden. So, I poured my entire love into this garden that was at a community-supported agriculture (a farm operation that is supported by shareholders within the community, who share in food production) nearby. And I was able to meet new people and escape into nature and do something that really filled my heart.

And then lastly, being able to connect with people was the single most important part of my journey. And I would go on Zoom calls with my friends and bake muffins or make dinner with them. I would do arts and crafts with friends, like I was a kindergartener. And being able to have that face-to-face experience, whether it's over a screen or in person, gives you strength and makes you feel normal again. And feeling normal as a 24-year-old was extremely important to me. And it really took all of those pieces to help me get through what I did.

Q: How would you say cancer has changed your outlook on life?

A: Cancer was probably the most difficult, yet most enlightening, experience of my life. And so, I (say this) and it's a little, not gruesome, but what I was able to

experience was as if I was living in my own funeral. I was able to hear and see the support as if I had passed away, but I was alive. And not many people get to see the impact they've made on other people until they've passed. Yet I got to see that and I got to feel it for five months into present day.


So the perspective I have is a sense of gratitude. If I could go back and change my life, I would keep cancer in the mix. I would keep it because I have become a person who is more aware of what brings them joy (and) is more able to see the simple pleasures in life and to treat people with the utmost respect because you don't know what they're going through.

Q: Is there anything that we haven't touched on that you think our audience might be interested in hearing?

A: Well, there's one thing. If you or a loved one has received a diagnosis of a life-threatening or not even life-threatening disease — it does not have to be cancer — there are a few things that I learned that really helped me, because not everyone knows how to help support those going through hard times. And one of those is checking in regularly (with those who receive a diagnosis) but not expecting a response. This is something that people take personally, and everyone expects the same treatment of getting all the updates, hearing how they're (the person who has been diagnosed) doing. But when it comes to something so severe, they're (the person who had been diagnosed) getting inundated with questions.

So to offer that love and support and say, "I'm here and I'm thinking about you, but don't feel as though you need to call me and give me all the updates" is a huge burden lifted from the person going through this. This could be virtual. It could be in person.

Also, try not to ask every single question (about) what they're going through, and really try to make them feel normal. They don't want to be talking about every single hard thing that they went through that week. Even though there's curiosity behind the scenes, there is a time and place to discuss.

And lastly, just be open and listen without trying to fix the issue. No one has the right answers, and if you can listen and be in (the present) with them, that is enough. 



TO SEE SOME OF NINA LUKER'S JOURNEY SCAN THE QR CODE to visit her TikTok page - @ninaluker

Survivorship Champions

How one survivor's journey led to her realization of what survivorship care is lacking and the importance of advocating for yourself during survivorship.

BY SHELLEY FULD NASSO, M.P.P.; CEO, NATIONAL COALITION FOR CANCER SURVIVORSHIP



SARAH COHN KNOWS HOW to advocate for herself. In February 2014, at the age of 30, Cohn received a diagnosis of acute promyelocytic leukemia, a rare form of leukemia that required her to be hospitalized for over a month for intensive treatment. Inspired by a caring, compassionate nurse, she learned to educate herself, ask questions and be her own advocate.

Through her experience, Cohn discovered the deficiencies in cancer survivorship care. Oncologists focus on treatment but not always on the long-term side effects of those treatments. Many primary care physicians want to help their survivor patients of cancer with chronic health issues, but they often lack the necessary training to do so.

Most of Cohn's survivorship care is now with the primary care physician she has had since she was 18 years old.

"I only see my oncologist once a year now, which is exciting but also a little bit scary to not have that constant check-in," she says. "My primary care physician was always an advocate for me, but she's not trained in taking care of cancer survivors. She's really used to dealing with patients who have more common comorbidities like high blood pressure and diabetes. She's not used to a 30-something-year-old cancer survivor dealing with these really strange side effects that she knows nothing about."

Today, Cohn is a patient advisor for National Coalition for Cancer Survivorship's (NCCS) Survivorship Champions, a new initiative to support clinicians and researchers, both oncology and primary care, who are interested in improving survivorship care and primary care's role in caring for survivors of cancer. Survivorship Champions members can access resources and training materials. In addition, NCCS has created a Survivorship 101 presentation and a Survivorship Champions Grand Rounds curriculum that can be shared with interested programs and institutions, including a discussion of survivors' needs, a survivor's story and data from NCCS' State of Cancer Survivorship Survey.

As treatments for cancer improve, more people are living with a history of cancer and the long-term effects of cancer treatment. With more than 17 million survivors of cancer in the United States, the oncology workforce is not sufficient to handle the acute needs of patients who are in treatment, as well as those who have completed treatment. Thus, some of the responsibility for providing survivorship care shifts from oncologists to primary care. Even survivors who require



» SARAH COHN
became her own
advocate after
surviving cancer.

continued follow-up by their oncology team need primary care physicians who understand their cancer experience and their health needs.

For the Survivorship Champions initiative, NCCS is partnering with Dr. Ana María López, a medical oncologist at Sidney Kimmel Cancer Center – Jefferson Health. As past president of the American College of Physicians, Lopez understands the challenges primary care physicians face in their practice, as well as their desire to learn more about the needs of their patients who are survivors of cancer.

"In my career, I have seen the gaps in care that cancer patients face during treatment and as they transition to post treatment care. Cancer survivors face lifelong effects of their treatment — physically, emotionally and functionally — and they need support from their clinicians to manage their care," she says.

As part of the launch of Survivorship Champions, NCCS interviewed a group of long-term survivors and asked them what they wanted primary care physicians to understand about caring for survivors of cancer. Several themes emerged, including the following:

» **Take our concerns seriously.** People talk about a “new normal” after cancer, but many survivors say that there is no such thing. After a cancer diagnosis, their lives have been changed forever. Fear of recurrence is a significant and often debilitating concern for many survivors. And the effects of cancer treatment are long lasting.

» **Understand collateral damage of cancer treatment.** Cancer treatment has long-lasting effects on a survivor’s physical health, mental health and quality of life. Some treatments cause infertility, heart damage, neuropathy and other significant health effects. Survivors are not always prepared for the long-term effects, and they wish their primary care team better understood these effects of cancer treatment.

» **Communication is critical.** Patients and survivors of cancer see multiple doctors, and often the task of coordinating among different clinicians falls on the patient. Many survivors become strong advocates for themselves and share

information among their providers, but it can be a huge burden. Communication between the oncology team and primary care physician is essential to ensure coordination of care.

» **Mental health is a top concern.** A cancer diagnosis takes a huge toll on mental health. In NCCS’ 2020 State of Cancer Survivorship Survey, fatigue and mental health issues are among the most common side effects reported by patients and survivors, yet few reported that their health care teams were very helpful in addressing these concerns during treatment, and most reported their doctors did not bring up mental health during post-treatment care.

» **Survivors of cancer are unique patients.** Cancer is a life-changing experience, which affects survivors’ health, finances, family, careers and mental health. Survivors often take on the responsibility of managing their treatments and coordinating among multiple providers. As a result, they often know an incredible amount of information about their own health and the health care system. Meeting patients where they are and listening to their concerns are critical.



Cohn is a self-described “nonscience science geek,” so she learned how to read research studies, ask the right questions and even make suggestions to her primary care physician. But she is quick to point out that not all patients and survivors are as empowered as she is.

“There are a lot of patients and survivors who are really great advocates for themselves, but there are also patients who don’t know how to (be),” she says. “And they depend on their providers to be their advocate and (to) ask them questions because (these survivors) might not even realize that they’re dealing with survivorship issues.”

Her advice to physicians is to pay special attention to the patients who are not as able to ask questions.

“You should be really focused on the people who aren’t asking you questions and who aren’t involved in their own care,” Cohn says. “Those are the ones you should be focusing on.” **h**



To learn more about Survivorship Champions, **scan the QR code** or go to www.canceradvocacy.org/champions.

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After Weighing the Pros and Cons of Getting a COVID-19 Vaccine, She Decided to Get One

In our previous issue of HEAL® a survivor debated whether she should receive the vaccine or not. This is her follow-up on why she decided to get it.

By TAMERA ANDERSON-HANNA

THERE ARE MANY THINGS to think about when it comes to COVID-19.

As I wrote about in December, one choice I pondered was following up with the opportunity to get vaccinated. I faced some negative feedback from a few individuals, but overall, I was given support to make an educated decision about whether or not to receive the vaccine.

To weigh the pros and cons, I met with three specialists from my medical care team, and all three agreed the COVID-19 vaccine was a good fit for me. One even stated, “Get whatever version is first available to you.” I am at higher risk of COVID-19 complications, not because of my breast cancer history, but due to asthma and working as a first responder.

Following receipt of the vaccine, I am someone who will likely be required to go back to working unrestricted with individuals with a known or unknown COVID-19 status.

To further clarify, I was also cleared by all three of my specialists despite having allergies, which require monthly immunotherapy treatments. My immunologist said I could receive any of the currently available vaccines. The rule of thumb — as his research suggested — is that if I haven’t had a negative reaction to any prior vaccinations, such as the pneumonia or shingles vaccine, then I wouldn’t be expected to have an adverse reaction to the COVID-19 vaccine. But I do encourage individuals with allergies to speak to their immunologist as a precaution before getting vaccinated.

The next step was getting access to the vaccine. I believed I would receive

the vaccine as a first responder, but by mid-January, neither I nor my co-workers had been vaccinated. I was fortunate to begin receiving the Pfizer-BioNTech COVID-19 vaccine at the Miami Cancer Institute in South Florida. The staff was great and had everyone wait for up to 30 minutes after the injection to assess any potential concerns or a rare reaction.

I did not experience any reaction with either injection, and I did not experience any muscular pain. In fact, it was the most pleasant of any vaccine I have ever been given. I would even say my allergy shots probably hurt more than the COVID-19 vaccine did.

During my second injection, the nurse explained the key to administration is to give the shot three fingers down from your shoulder into the deltoid to help avoid unnecessary soreness and difficulty moving your arm following the injection. They also did not squeeze my arm during the injection but only held the sides of my arm to prevent movement.

As a precaution, however, I asked to receive the shot in the arm from which I have not had lymph nodes removed. I have since heard from at least one fellow survivor that she received one dose of a vaccine in her nondominant arm (where she had lymph nodes removed) as advised in case of any soreness, but she felt it was a mistake because it may have triggered her previous experiences with lymphedema, a condition in which excess fluid collects in tissues and causes swelling.

This is something for other individuals to discuss with their oncologist to avoid a potential lymphedema flare-up, because maybe soreness in a dominant arm is better than triggering symptoms of a breast cancer treatment-related side effect.

I am aware of some peers who have had their second injection and experienced flu-like symptoms. I feel it is just a sign the vaccine is working and would expect needing no more than a day off from work to rest and manage.

My symptoms following the second injection included mild fatigue, some mild body aches, a feeling of swelling in my armpit on the side the shot was given and a bit of stomach upset on the final day. My symptoms began approximately 24 hours after the second dose and ended after approximately one day.

The choice to get vaccinated is a personal one. I appreciate individuals who don’t care to receive the vaccine due to their own beliefs or concerns, but I hope such individuals respect the choice of those who do receive the vaccine. Although Veklury (remdesivir) and convalescent plasma are now game changers for those who develop a severe complication due to a COVID-19 infection — these were available to one of my family members — I hope not to end up needing such treatment or risking damage to my lungs.

I am presently NED (no evidence of disease), but I would be making the same choice to get vaccinated if undergoing treatment unless contraindicated for some reason. I am grateful to the staff of Miami Cancer Institute, my oncologist and my primary care physician for having me on a list to receive the vaccine and for the opportunity to get vaccinated. [h](#)



TAMERA ANDERSON-HANNA

Finding Motivation During COVID-19

A cancer survivor laments the difficulty of dealing with the pandemic and shares a quote that changed her outlook.

By JANE BIEHL, PH.D.



I HAVE TO ADMIT THAT after battling cancer for over 10 years, I am presently struggling more with the pandemic than the cancer.

I hate being uncertain about when I will go out of remission — and it is a question of when, not *if*. I keep saying that I cherish every day, but to be candid, I do worry about the future. And this pandemic that seems to go on forever has only made it worse.

All of us have been affected, from school-age children to people in nursing homes; to those in the workforce to the heroic essential workers. For survivors of cancer, every single procedure is worsened by the pandemic. In addition, we no longer can visit loved ones or have someone accompany us to treatments. Justifiably, we worry constantly about becoming ill or that something terrible will happen to our loved ones. Tragically, in some cases, we have lost family and friends.

For me, this time of despair has caused my depression to increase with a vengeance. I used to love getting up in the morning and going to the YMCA, church, movies and plays with friends or just going out to eat. Visiting my relatives over the holidays was special, and I anticipated yearly cruises with glee.

But lately, I have been waking up and not wanting to get out of bed.



JANE BIEHL, PH.D.

“ I have two clear choices: I can wait until this is all over to be happy, or I can be productive and do what I can because precious time is passing me by — no matter which choice I make. —JANE BIEHL ”

I cannot see my friends and am tired of Zoom. Cruises

are a long way off from being safe again, and flying is downright dangerous. I live alone and sometimes ask why I bother to get up. Somehow, I force myself to get dressed and move.

Once I do get out of bed, I find things to do around my apartment, calls to make, emails and texts to send to stay in contact. What gives me the most pleasure is writing cards to friends and sending surprises through the mail. My writing has kept me sane (although some people may be questioning that). I am editing another book, too.

Then I found this quote by Lady Bird Johnson, a former first lady who lived from 1912-2007: “Become so wrapped up in something that you forget to be afraid.” I always liked her better than her overbearing husband, former President Lyndon B. Johnson, though I respected him. I don’t think she had an easy life, but she wrapped herself up in

several causes and did a lot of good for others.

After reading that quote, I thought “Bingo!” When I am writing, reaching out, reading a good book or sending positive messages, I don’t have time to fear the future, wonder when I will get my vaccine or worry about the monster virus. Lying in bed feeling sorry for myself accomplishes nothing except to make me more depressed.

Doing constructive activities does help. Just waiting it out until the virus is over and doing very little is not working well. I did not get my Ph.D. until age 48. When I got discouraged about how long it was taking and how old I was, one of my wise professors used to tell me, “You are going to be 48 whether you get your degree or not!”

I have two clear choices: I can wait until this is all over to be happy. Or, I can be productive and do what I can because precious time is passing me by — no matter which choice I make. **h**

My New Career as a ‘Sit-Down’ Comedian

When remission set in and his funny bone perked back up, this survivor learned that making people laugh makes him happy too. By RON COOPER



DID YOU HEAR THE ONE about the cancer procedure that went terribly wrong? It turned out to be a bi-oopsie!

What's a tumor called at Christmas? A nod-yule.

OK, OK. I own up to writing those silly jokes. With the help of my Gilda's Club, I've launched a brand-new career: a sit-down comedian — on Zoom!

JOKING AROUND WITH FELLOW SURVIVORS

Gilda's Club hosts a Lunch and Laughs get-together twice a week, where our goofy gang shares a few jokes to get us through this endless pandemic. I found it to be a good place to warm up for my own comedy special on Netflix.

Since I've been living with prostate cancer for six years, it was about time to poke a little fun at myself. I'm allowed. With cancer, the joke's on me. Here's another of my originals:

What did the urologist say to the baseball player before his prostate exam? "Bladder up!"

CAUTION: GROANERS AHEAD

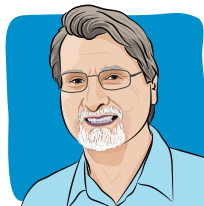
Had enough? I won't blame you a bit if you skip to the next article. But if you're like me, you're tired of crying a river of tears over your cancer and might want to lighten up some.

What got me started writing cancer jokes? At first, I Googled "prostate cancer jokes" and found tons of gems. I started snickering so hard I almost forgot to get my next PSA blood test. Here are a couple of my early discoveries:

- What does a prostate cancer patient have in common with a basketball player? They both dribble.
- What's the worst thing to hear after a prostate exam? A nurse walking in and asking, "Who was that guy?"
- What did the snowman die of? Frostate cancer.

HOW THIS ALL STARTED

During the first few years after my diagnosis, my sense of humor collapsed under the weight of depression and anxiety. But gradually, as post-surgery treatments took hold and remission set in, my funny bone started to perk back up.



RON COOPER

I nurtured it by bingeing on stand-up comedy routines on Netflix and Pluto TV, watching countless silly sitcoms (thanks, "Superstore") and circling back to my favorite comedians, the Marx Brothers, to re-watch, "Night at the Opera" and "Duck Soup." I love Groucho's one-liners!

Then last April, with lockdown in full swing, I joined the Lunch and Laughs group at Gilda's Club. My "audience" has put up with many groaners, including these I found on the internet:

- My dad's brother is a cancer doctor. He's an uncologist.
- I paid my oncologist big bucks for this hairstyle.
- Doctor: "You have cancer and Alzheimer's." Patient: "At least I don't have cancer."
- What do you call a fish looking for cancer treatment? "Finding chemo."

WRAPPING UP

I recall a book title from one of my favorite humorists, Erma Bombeck: "If Life's a Bowl of Cherries, What Am I Doing in the Pits?" That perfectly sums up the cancer experience, with a little tongue-in-cheek humor thrown in for good measure.

No, cancer is not all chuckles, but sometimes we just need to giggle, tee-hee and even chortle to kick off those beneficial endorphins that will help boost our battered immune systems as we line up for our COVID-19 vaccination shots.

By the way, Netflix hasn't called back yet about my comedy special. Meanwhile, I'll be here all week!

As Unique as We Are the Same

When we recognize and accept our differences, and move forward together, survivors can create real change and beauty. By DANIELLE RIPLEY-BURGESS

LIKE MANY PARTS OF the country, my hometown of Kansas City is blanketed in a layer of snow, as I write this. Despite the hazardous road conditions and freezing temperatures, it's really pretty.

When I was growing up I heard that no two snowflakes are exactly alike. I would test the theory by pressing my nose against a cold windowpane to study the flakes caught in the screen during a snowfall. As far as I could tell, the adults were right. No two snowflakes had the exact same pattern, shape and design. I found this to be a good way to view people, too, the older I got.

As a young girl, I embraced being a tomboy and preferred basketball over Barbies. I also loved books, piano and theater. All this made me unique; I enjoyed both sports and the arts, and I rejected anything frilly. While many of the other girls took dance, played with dolls and loved wearing dresses, I was different. I was secure in this uniqueness until I hit the infamous tween years. During what felt like a sudden change, I was embarrassed that I had never owned ballet shoes and didn't know how to plie. I thought my clothes needed to come from certain stores in the mall, and I spent \$100 of my own money on Doc Martens. I needed to be the same as the other students in my middle and high school. I needed to fit in, for that meant survival.

At 17 years old, something happened that took away the relevance of my Docs and gave me a new understanding of survival. I received a diagnosis of colon cancer my junior year of high school.

Suddenly, I felt like an odd ball out — again — and my name-brand clothes couldn't help. I started doing school from home decades before virtual schooling became a thing. While my peers were congregating near their lockers and cramming for math tests, I was getting chemo. To get through



DANIELLE RIPLEY-
BURGESS

the shock, pain and grief of losing a “normal” high school experience, I had to accept my uniqueness again. It took time, but I eventually became proud of being a teenage survivor of colon cancer. It's something very few others in the world can say.

Part of getting to this point involved joining advocate communities, where I've met other survivors who can relate. Through the Colon Club and Fight Colorectal Cancer, I have met a handful of others who received a diagnosis in their teens and 20s. I've met patients with Lynch syndrome, those who've undergone a subtotal colectomy and other long-term survivors who also deal with radiation side effects decades after treatment. Thanks to these groups, I know I'm not the only one who has adopted (a child) after cancer, written a book or gotten fired up about early-age-onset colorectal cancer (a term now used to describe what happened to me). In fact, I get together with advocates each March to tell my story during Call-on Congress and ask lawmakers to support policies like a younger screening age, more research funding and access to care for everyone, not only a well-insured, privileged few.

From the outside, our stories may look the same, like a blanket of snow

covering the ground. And typically, we present similar asks — that's how advocacy works. But just like the tiny flakes after a fresh snow, if you get personal with patients, you'll quickly notice differences in both personality and experience. Despite similarities, no two survivors are exactly alike.

Some can eat french fries and ice cream; others said goodbye to meat and dairy a long time ago. Intimacy is a struggle for some but not for others. Some survivors of colorectal cancer have ostomies, neuropathy and hair loss; others don't face any of those things. Some survivors can laugh and joke about their experiences, and others tear up at the thought or get really angry.

Some are very private while others start Facebook groups, Twitter accounts and Instagram hashtags. Some had to fight to get access to screening, and others were basically bribed by a doctor to get checked. Some survivors are mad at God; others can't imagine surviving cancer without their faith.

Like any other group, cancer survivors are as unique as they are the same. What I've learned about survivorship after all these years is that it works a lot like the snow. When we recognize and accept our differences, yet resolve to move forward together, it can create real change and beautiful things. [In](#)

SHARE YOUR STORY!

Whether you are a patient, survivor, caregiver or health care provider, we want to publish your stories about cancer and the people, places and moments of the experience. They can be funny, poignant or practical. Send stories to editor@curetoday.com, or share on our Facebook page at [facebook.com/curemagazine](https://www.facebook.com/curemagazine). Submissions should be no more than 600 words and include your name, phone number and email.



Life, Like Gardening, Requires Weeding

Spring is a time of renewal and growth, writes a cancer survivor. Make room for what brings you joy by holding on to friends who nourish you and saying goodbye to those who don't. By BONNIE ANNIS

SPRING WILL BE HERE SHORTLY.

The days will be longer and the weather warmer. Those who've been cooped up inside will begin to slowly emerge, looking for ways to enjoy spending time in the glorious sunshine and fresh air.

Some will focus on hobbies like gardening. Spring is the perfect time for planting, especially after the danger of frost has passed. With the ground warm enough, avid gardeners will begin planting seeds for their vegetable or flower gardens, but it's not an easy task.

Preparing garden beds is hard work! Pulling weeds, tilling soil and adding amendments like compost and lime take time and energy. That's why it's so important for those affected by cancer to pace themselves.

It's easy to get caught up in the busyness of doing and forget physical limitations, only to suffer from them later in the day. I've found, with lymphedema, that breaking large projects into smaller chunks is helpful. Instead of trying to complete everything in one day, I stretch my projects out over several days.

This year, instead of turning my entire backyard into a vegetable garden, I decided to use raised beds. They provide smaller spaces, which make weeding and watering much easier. They also make gardening easier because the beds are raised to waist-high levels. That means less bending and back pain.



BONNIE ANNIS

Weeding is one of my least favorite gardening chores. It doesn't matter how many times I pull the weeds; they always seem to come back. If it weren't for the weeds, gardening would be such a pleasure. Gardening is like life, and we have to deal with challenges.

And that brings me to another gardening-related topic: ridding oneself of toxic things. It's important for the person with cancer to guard not only their physical health but also their mental health. Just like pulling obnoxious weeds that might choke

out and damage new plants, sometimes a person needs to reevaluate their friend base. In gardening, a proper growing environment is conducive to producing healthy plants, and setting boundaries provides a way of removing toxicity caused by those who poison the relationships.

But how does one recognize a toxic relationship?

A toxic relationship is any relationship that causes you to feel drained, discouraged, doubtful or debilitated. If you dread being around someone, more than likely that person is toxic in your life.

What can you do to eliminate a toxic relationship? Although you can't put weed killer on a toxic person like you can on problem plants in the garden, there are ways of ridding yourself of "weed type" people.

Boundaries are one of the best ways to control exposure to toxic people. Consider the following tips:

- **Make yourself a priority.** Give yourself permission to evaluate relationships and cut ties with the unhealthy ones.
- **Seek the support of close family.**
- **Don't be afraid to be assertive.** It's important to guard your mental well-being. You are the gatekeeper. You can hold on to friends who nourish you and say goodbye to those who don't. Ending relationships can be difficult. Go slow and easy. Take one step at a time.

Spring is a time of renewal and new growth. It's a time for celebrating life and doing things that bring joy. If there are relationships that rob you of joy or cause you to feel fearful or dread, it's time to end those relationships.

It may be time to do a mental health inventory. So, let go of whatever causes you to feel weighed down and burdened. Mahatma Gandhi said, "I will not let anyone walk through my mind with their dirty feet." That sounds like a good motto for gardeners and those affected by cancer.

Boundaries can make a huge difference. You have the power to set them. Why let your garden of friends be filled with annoying weeds? Eliminate the toxic ones and enjoy a thriving, beautiful garden filled with those who love and support you. **h**



Nominate your **Lung Cancer Hero** today!

CURE® is now accepting nominations to recognize our 2021 Class of Lung Cancer Heroes®, individuals who go above and beyond to make a difference in the lives of those affected by lung cancer. Each hero is nominated by patients, caregivers, and fellow health care professionals for their heroic contributions in the field of lung cancer, or in the individual lives of people with lung cancer.

Submit yours by June 30, 2021.

Three Lung Cancer Heroes®, along with their nominators, will be interviewed by CURE® and honored at a special reception to be held later in 2021. More details will be announced as they become available.

Submit your essay today at
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CURE®, Takeda, Lung Cancer Heroes®, and the advocacy community are dedicated to bringing together the lung cancer community to end the stigma, inform, connect, and empower anyone who has been impacted by lung cancer.

Spring Into the Season With New Recipes

Enjoy a refreshing kale salad on a sunny afternoon and a savory chickpea curry during an April shower. And don't forget to treat yourself with kindness — and pudding!

RECIPES by JULIE LANFORD, M.P.H., RD, CSO, LDN, WELLNESS DIRECTOR OF CANCER SERVICES INC. AND A REGISTERED DIETITIAN, LICENSED NUTRITIONIST AND BOARD-CERTIFIED SPECIALIST IN ONCOLOGY NUTRITION



Best Kale Salad Ever

INGREDIENTS

- 2 bunches kale (or 1 large bunch)
- 1/3 cup olive oil
- 1/3 cup lemon juice
- 3 large cloves garlic, minced
- 1 tablespoon reduced-sodium soy sauce
- 1/2 teaspoon freshly ground pepper
- 1/4 teaspoon salt
- 1 cup pistachios
- Red pepper flakes to taste
- 1/2 cup freshly grated Parmesan cheese (optional)

DIRECTIONS

1. Strip kale leaves from the stems (discard stems). Wash and dry the leaves. Tear the leaves into pieces and place in a bowl.
2. Mix oil, lemon juice, garlic, soy sauce, black pepper and salt in a jar, small bowl or salad dressing container. Pour over kale.
3. With clean hands, firmly massage and crush the greens to work in the ingredients.
4. Stop when the volume of greens is reduced by about half. The greens should look a little darker and somewhat shiny.
5. Taste and adjust seasoning (if desired) with more lemon juice, garlic, soy sauce and pepper. Add red pepper flakes to taste.
6. Top with pistachios for a crunch.
7. Add freshly grated Parmesan cheese (if desired).



Tasty Tofu Chocolate Pudding

INGREDIENTS

- 14 ounces soft silken tofu
- 1/4 cup unsweetened cocoa powder
- 1/4 cup agave nectar (or honey or maple syrup)
- 1 1/2 teaspoons pure vanilla extract
- Optional toppings: berries, sliced banana, nuts, etc.

DIRECTIONS

1. Purée tofu, cocoa powder, agave nectar and vanilla in food processor.
2. Pour into serving dishes. Add toppings (if desired).



Flavorful Chickpea Curry

INGREDIENTS

- 1 zucchini, sliced
- 1 tablespoon garlic, minced
- 1 tablespoon ginger, grated
- 1 small onion
- 1 can chickpeas
- Ground cumin (optional), to taste
- Ground red pepper (optional for flavor/heat), to taste
- 1 tablespoon curry paste
- 1 can coconut milk
- 1 tablespoon reduced-sodium soy sauce
- 1 lime
- 1 cup of brown rice

DIRECTIONS

1. Cook 1 cup of brown rice, following package instructions.
2. Sauté zucchini until soft, about 3 to 4 minutes, and add ginger, garlic and onion.
3. Add chickpeas, and cook for an additional 2 to 3 minutes.
4. Add curry paste and, if desired, cumin and red pepper. Mix. Cook for about 1 minute.
5. Pour in the coconut milk and soy sauce. Simmer for 8 to 10 minutes.
6. Turn off the heat and add in lime juice.
7. Serve over rice.

You're Invited!

Let's gather to celebrate this year's extraordinary healers!

Together, we will honor and express our heartfelt gratitude to this year's winners and finalists of the 2021 Extraordinary Healer® Award for Oncology Nursing, and the Finest Hour Award.

Save the Date Thursday, April 29, 2021

Join the virtual celebration!

In addition to hearing the compassionate stories of this amazing group of nurses, we have a very special celebrity keynote speaker who will be joining us online this year. You do not want to miss this extraordinary recognition event!

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**Elizabeth "Liz" Farrat,
BSN, CCRN**
Winner of 2020
Finest Hour Award



**Christie Santure,
BSN, RN, OCN**
Winner of 2020
Extraordinary Healer Award

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We are helping to move mountains for myeloma patients

Moving Mountains for Multiple Myeloma, (MM4MM), is an award-winning collaboration between CURE Media Group and the Multiple Myeloma Research Foundation (MMRF) which raises funds and awareness for myeloma research.

Since its inception in 2016, Moving Mountains for Multiple Myeloma teams have climbed Mt. Kilimanjaro, hiked the Grand Canyon, summited Mount Fuji, trekked the Inca Trail to Machu Picchu, reached Everest Base Camp and conquered Iceland's many landscapes. Our team members have raised over \$2.9 million, 100% of which goes directly to the MMRF, which spearheads and funds critical myeloma research. These amazing journeys are captured via blogs, social media posts, and video.

Due to COVID-19 the 2020 program has shifted - all 2020 teams will continue fundraising and training this year and will hike in early 2021.

Patients, caregivers, myeloma loved ones, and others impacted directly by multiple myeloma will take on the Alaskan Kenai Peninsula, summit Mount Washington, explore the terrain of Greenland, and more! They will raise funds for multiple myeloma research and demonstrate that the advancements being made in recent years, led by the MMRF, are helping patients live longer with a higher quality of life than ever before.

To learn more and join a MM4MM team visit:
MovingMountainsForMultipleMyeloma.com

To learn more about the MMRF, visit **TheMMRF.org**

LEARN MORE ABOUT OUR CLIMBS!

2020 TREKS IN 2021!

Mount Washington Hike

July 9-12, 2021

Greenland Trek

To be determined

Alaskan Kenai Peninsula Trek

June 20-26, 2021

Kilimanjaro Trek

March 6-16, 2021

Machu Picchu Trek

May 1-11, 2021

New 2021 hikes & dates coming soon!

Email **teammanager@themmrf.org** to get on our waitlist!

