

BEYOND BLUE

FIGHT COLORECTAL CANCER

VOLUME 17 • ISSUE 2



The SURVIVORSHIP

MOVEMENT

DEFINE: SURVIVOR

Who is a CANCER SURVIVOR?

BELL RINGERS

TO RING or NOT TO RING

AFFORDING CANCER

HOW SURVIVORS and
CAREGIVERS PAY THE BILLS

SURVIVOR (n) one who remains alive and continues to function after overcoming hardship or life-threatening illness. In cancer, a person is considered to be a survivor from the time of diagnosis until the end of life.

SURVIVOR (n) anyone who has ever been diagnosed with cancer, no matter where they are in the course of their disease.

A Magazine for
RELENTLESS CHAMPIONS
OF HOPE IN THE FIGHT AGAINST
COLORECTAL CANCER

SURVIVOR (n) a person who has had cancer. "Co-survivor?" is sometimes used to describe a person who has cared for a loved one with cancer.

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We FIGHT to cure
colorectal cancer
and serve as relentless
champions of hope for
all affected by this disease
through informed patient
support, impactful policy
change, and breakthrough
research endeavors.

Learn more at [FightCRC.org](https://fightcrc.org)



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Jokes

I ate four cans of alphabet soup yesterday.

Then I had probably the biggest vowel movement ever.

Submitted by survivor Cheryl Alston, Md.

What's something great about poop jokes?

They'll make your cheeks hurt.

Submitted by survivor Spencer Dayton, Calif.

Why was the poop sad?

He got dumped!

Submitted by survivor Liz Dennis, Ariz.

SUBMIT A JOKE!

Email danielle@fightcrc.org

Word Search

SURVIVORSHIP: *It's Complex*

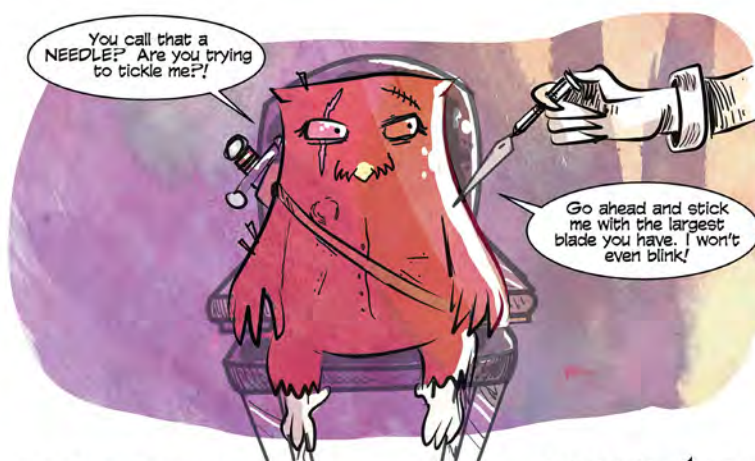
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Y U Y T P K W C K W G C O M P L E X

Comic

Before Cancer Treatments



After Cancer Treatments



© 2018 Matthew Paul Mewhorter

cancerowl.com

CANCER OWL is a creation of stage II survivor Matthew Paul Mewhorter. Visit his work at cancerowl.com. Comic reprinted with permission.

WORD BANK

acceptance	coping	radiation	thriving
anxiety	fear	recurrence	treatments
appreciation	guilt	relief	trials
celebrate	healthy	remission	uncertainty
changed	hope	strength	
chemo	life	surgery	
complex	NED	survivor	



**FOLLOW
ANJEE!**

@anjeedavis



A Seed of Hope

The dictionary defines survivor as “a person who copes well with difficulties in their life.” You are a survivor from the moment you are diagnosed. Every personal cancer experience is unique and so incomparably hard.

I was diagnosed with breast cancer on Feb. 4, 2020. I didn’t feel like a survivor at that moment, before or after surgery, or during treatment. I, for sure, don’t think I was coping well. In fact, it took me a while to pull it together. And I don’t mean “a few hours.” I mean several months. Several CT scans and surgeries later, I am cancer free.

Then two years later, when I finally felt mostly over the trauma of my cancer diagnosis—because you never are fully over the trauma—my brother and I had to tell my mom that she had cancer. The flood of emotions came back. Our whole family has been impacted by cancer physically, emotionally, spirituality, and socially. We’ve learned to embrace all of the moments: the ones where we’re fighting hard and moving forward, and the ones where we feel stuck and spinning, not wanting to get out of bed. It’s all part of the process.

There is a saying in Tibet, “Tragedy should be utilized as a source of strength.” No matter what sort of difficulties we endure, or how painful the experience is, if we lose our hope, that’s our real disaster. Part of living as a cancer survivor is never losing hope. Hope is the tenacity and the relentlessness within yourself that keeps you fighting. Hope pushes you on.

Two years ago, I found a tiny seed of hope, and I shared it with my family. That seed has been nurtured by the love and support of friends, fellow survivors, and family. It takes time, and it takes a community to thrive. That is the miracle of hope. And it helps.

Whether you’re a survivor, a caregiver, or a medical professional fighting cancer, we share a bond. At Fight CRC, we aren’t just a community, we’re a family pushing one another through this journey of survivorship to never lose hope and never forget. You inspire us to keep going. I hope this issue of *Beyond Blue* helps you find a little seed of hope that keeps you going.

YOURS IN THE FIGHT,

ANJEE DAVIS, MPPA | FIGHT CRC PRESIDENT



*It takes time, and it takes a community to thrive. That is the **MIRACLE of HOPE.***

Q • What about cancer survivorship surprised you?



A:

WALTER HICKMAN

*Stage II Survivor
Diagnosed in 2013*

"During the time I was fighting this disease, I looked forward to the day I would be cancer free. The most surprising thing was how I have stayed on high alert with any changes in my body and my children's bodies. My wife and I stay on top of their health. If you are not first advocating in your own household, what good is receiving the gift of survivorship?"



A:

PAM SEIJO

*Stage IV Survivor
Diagnosed in 2001*

"What surprised me the most about cancer survivorship is your life never goes back to what it was before your diagnosis—physically, emotionally, and spiritually. The hardest for me is the raw emotions of guilt I feel when I lose a friend to colorectal cancer and I'm still living. The most positive thing I discovered with survivorship is that it pushes me daily to do things I never thought I'd attempt, and to appreciate everything in life, big or small."



A:

BRIAN SHAWN

*Stage IIIb Survivor
Diagnosed in 2021*

"I think the biggest thing you realize is that if you just keep going week-by-week, treatment-by-treatment, you can get through it. It is all so daunting initially, but I have met so many people that have been impacted by cancer and are now disease free. It's amazing how many great individuals you meet and the strong bond you create with them and their families. I also think it's an opportunity to provide hope for others and advocate for more prevention and screening as well."



A:

JULIE BROWN

*Stage III Survivor
Diagnosed in 2010*

"I think the thing that surprised me the most is the tremendous highs and lows and constant changes. I thought once I was NED, life would go back to normal, things would resume as they were, and I would be done with cancer. But the reality is, things will never be the same, I have had amazing new life changes, and there are some changes that haven't been easy. It's a constant roller coaster, and you're on the survivorship ride for a lot longer than you had anticipated."



A:

MELVIN FERNANDES

*Stage IIIC Survivor
Diagnosed in 2016*

"When I started telling my story, I was surprised about how many people were receptive to the message of, 'Get screened, don't end up like me.' I continue to hear from people who I didn't think were listening that they went and got a colonoscopy. It has encouraged me to keep using my voice."



SUBSCRIBE TO BEYOND BLUE

Beyond Blue is a free magazine curated by and for members of the colorectal cancer community, published each spring and fall.

To get a free copy of each issue mailed to you, subscribe at FightCRC.org/BeyondBlue.

GO THE EXTRA MILE

Become a Resource Champion in your community. You'll receive a **FREE** box of 10 magazines and other resources to distribute.



Sign up at FightCRC.org/ResourceChampions.

The Survivor Story

Two years ago, I published a coming-of-age memoir, *Blush*, to share about how I survived colon cancer in high school and in my 20s.

There are many reasons I wrote the book; for starters, it was great therapy. Writing became a way for me to “pay it forward.” By sharing my experiences, others could relate and find words for their own. They didn’t feel so alone. Ultimately though, I wrote *Blush* for my daughter. I wanted her to know my survival story.

My process of writing a book had a lot of similarities to living as a cancer survivor. In the early stages of book writing, *Blush* is all I could think about: It consumed me. I shifted my schedule, cut out commitments, and designated spots in my house for writing. It was a lot like my early days of living with cancer: It also took over my life.

Cancer demanded all of my attention at first, but as surgeries and treatments got behind me, I fell into a “new normal” with less demands and spread-out follow-up plans. I hit a similar stride when *Blush* went into editing, design, production, and distribution. What once took all of me gradually needed less. Today, *Blush* proudly sits on the shelves of my readers and in my home. I’ll always be an author. But, book writing is not my only gig. In the same way, I’ll always be a cancer survivor, but it’s one of my many roles. Surviving cancer is one of several defining moments of my life.

We’re fully aware at Fight CRC that advocates find themselves in different places along the survivorship continuum. Some are on day one; others are in year 21. No matter how long you’ve been fighting colorectal cancer, we wrote this issue for you. We’re here for you: You don’t have to fight...or survive...alone. You have a story, and we’re here to help you tell it. It’s going to take stories like yours, stories like mine, to keep growing the survivorship movement.

STAY STRONG,

Danielle Ripley-Burgess

Danielle Ripley-Burgess

EDITOR-IN-CHIEF & TWO-TIME SURVIVOR



FOLLOW DANIELLE!

@DanielleisB



ABOUT THE EDITOR

Danielle Ripley-Burgess is a 21-year colorectal cancer survivor first diagnosed at age 17. Today, she’s in remission. Danielle is an award-winning communications professional, author of *Blush: How I Barely Survived 17*, and she serves as Fight CRC’s Chief Storyteller.

Book SHELF

**RECOMMENDED READS
WRITTEN BY**

Fight CRC Advocates

POWERED BY HOPE

By Teri Grieger

ONE DROP OF RAIN

*By Molly McMaster
Morgoslepov*

MY CANCER YEAR

By Curt Pesmen

**WHAT I WASN’T
EXPECTING WHEN
I WAS EXPECTING**

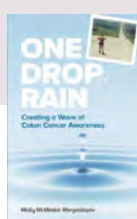
By Kristina Smith

**LIFE-SAVING
GRATITUDE**

By Bunny Terry

**Do you have a book
you want us to review
or to donate for our
Care Packs?**

Email danielle@fightcrc.org.





FIGHT CRC *at the* WHITE HOUSE

Fight CRC has been a frequent guest at the White House this year.

In May, President Anjee Davis accepted an invitation to attend the Cancer Moonshot Goals Forum. On July 25, Fight CRC convened a meeting at the White House with advocacy and industry leaders, patient advocacy groups, and survivors to respond to the President's call to improve and increase access to colorectal cancer screening.

Read more about this in the Advocacy Column on page 29.

MORE NEWS

**To see all news and updates from
Fight CRC, visit FightCRC.org/PressRoom.**



**FIND A
DOCTOR**

Fight CRC has launched an online Provider Finder, powered by Komodo Health.

Now, patients can look for physicians near them. Results will show doctors who are familiar with clinical trials, those ordering biomarker testing, and doctors who see a high volume of colorectal cancer patients. Start searching at FightCRC.org/ProviderFinder.



Blue Knots Live On

The Kiel Colon Cancer Foundation, a friend and nonprofit partner of Fight CRC, closed its doors after seven years of service to the community.

The foundation asked Fight CRC to carry on its work by running out the #BlueKnots social media campaign, and educating and resourcing the Black community about colorectal cancer. Blue shoelaces can now be found in the Fight CRC store; shop at [Shop.FightCRC.org](https://shop.fightcrc.org).



CORNHOLE'S BACK!

Big thanks to country music singer-songwriter Craig Campbell for raising over \$20,000 through his annual Cornhole Challenge.

After several years of postponing the event due to COVID-19, our spokesman gathered up his friends for a bag-tossing good time during Nashville's CMA Fest again.

THE "MIRACLE" RECTAL CANCER STUDY



Hope filled the hearts of many patients when news about a remarkable study involving rectal cancer patients at Memorial-Sloan Kettering Hospital broke, and researchers quickly jumped in to explain the trial results and how they apply to patients. During an Instagram Live, Dr. Cathy Eng, a renowned researcher and physician who leads the GI Steering Committee at the NCI, broke down the trial, explained who it applies to, and emphasized other clinical trials patients may want to consider joining.



Policy Update

Since Call-on Congress in March 2022, both the House and Senate released FY23 appropriations bills, and both chambers included the report language Fight CRC drafted to direct the National Cancer Institute (NCI) to create a strategic action plan to guide colorectal cancer research.

The House and Senate will both have to pass their bills, and then the two chambers will need to work out any differences between them. For updates and ways to advocate, sign up at [FightCRC.org/Advocacy](https://fightcrc.org/advocacy).



REPLAY

Scan this QR code to watch the replay.



Define SUR·VI·VOR/

Who is a cancer survivor? Someone with active disease? Someone finished with treatment? Someone in remission? A caregiver who lost a loved one? Are you still a cancer survivor if you die from cancer?

One of the hottest debates in the cancer community, many opinions exist on when and who to call a cancer survivor.

While the term is regularly evaluated for its relevance in describing cancer patients, research shows that most patients like being called a survivor.

To understand where and how this term originated, we turned to our friends at the National Coalition for Cancer Survivorship (NCCS):

In the first three-quarters of the 20th century, human beings had learned that deadly diseases were contagious. Based on that premise, it was presumed cancer was contagious as well. Those with a history of the disease kept quiet about it. They could lose their jobs and their health insurance (if they had that luxury); they couldn't join the military, and they couldn't adopt children. If invited to others' homes for a meal, they were served with disposable plates, cups, and silverware so their "germs" wouldn't be spread. They lived as social pariahs, if they lived at all.

Survivorship numbers hovered between 30% and 45% until the 1970s, when a marriage between politics and research took place. The prospect of President Richard Nixon having a second term was looking iffy. The nation was embroiled in an unwinnable war in Vietnam, for which Nixon had claimed knowledge of a secret, albeit

never appearing, solution. Racial and anti-war protests topped the headlines, along with the President's declining popularity. And then, aides brought Nixon news of a bill making its way through Congress. Among other items (most of which were tossed out before they were done), the bill would infuse \$1.3 billion into cancer research (the equivalent of \$8.4 billion today).

Cancer was a bipartisan disease. Democrats feared it as much as Republicans. Such a bill would certainly improve Nixon's popularity and deliver him a second term. So on December 23, 1971, he signed the National Cancer Act and won reelection the following year. Some in the administration even claimed that research from the "war on cancer" would produce a cure by the nation's bicentennial. That, of course, didn't happen, but another miracle did: Treatments improved and people actually began surviving. They still, however, lived in the shadows.

Referred to as "victims," the unconscionable cancer myths persisted. Equally frustrating was the fact that there was no research about and little support for the people who finished the acute phase of their treatment.

Dr. Fitzhugh Mullan, a co-founder of NCCS and a cancer survivor himself, described the scenario eloquently: "It is as if we have invented sophisticated techniques to save people from drowning, but once they have been pulled from the water, we leave them on the dock to cough and splutter on their own in the belief that we have done all that we can."

A group of 23 gathered in Albuquerque in October 1986, who would become the founders of the National Coalition for Cancer Survivorship (NCCS), gave post-treatment patients a name and defined survivorship: "From the time of its discovery and for the balance of life, an individual diagnosed with cancer is a survivor."

Diagnosis is the moment we begin surviving cancer, not the moving goal line of three or five or 10 years, depending on type and stage.

Because of the dedication of that first group, and all who have come after in the movement, survivorship came out of the shadows.

NATIONAL CANCER INSTITUTE (NCI)

SURVIVOR. (n) One who remains alive and continues to function during and after overcoming a serious hardship or life-threatening disease. In cancer, a person is considered to be a survivor from the time of diagnosis until the end of life.

AMERICAN CANCER SOCIETY

SURVIVOR. (n) Anyone who has ever been diagnosed with cancer no matter where they are in the course of their disease.

AMERICAN SOCIETY OF CLINICAL ONCOLOGY (ASCO)

SURVIVOR. (n) A person who has had cancer. "Co-survivor" is sometimes used to describe a person who has cared for a loved one with cancer.

NATIONAL COALITION FOR CANCER SURVIVORSHIP (NCCS)*

SURVIVOR. (n) From the time of its discovery and for the balance of life, an individual diagnosed with cancer is a survivor.

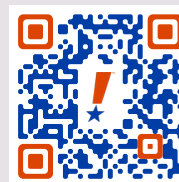
** NCCS's definition of survivor coined in 1986, an effort to move away from the term "cancer victim," is now the norm for the cancer community and beyond. NCCS has expanded its definition of survivor to include family, friends, and caregivers.*

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At first, I would get a little offended when I'd hear someone stand up and say, 'I don't like the term survivor.' I want to be a thriver, a warrior, etc. But what I realized over the years is that it's progress. Survivor was such a positive term in the '80s. It has grown and developed into something much more positive. They're all labels anyway, so find the label that works. Many don't call themselves cancer survivors, but I will until the very end."

SUSAN LEIGH, BSN, RN

5x cancer survivor and one of the original founders of NCCS and the Survivorship Movement



KEEP READING

Read the full article, "The Birth of the Cancer Survivorship Movement and How It Transformed Cancer Care for Millions."



Written by Judith L. Pearson, best-selling author of *From Shadows to Life: A Biography of the Cancer Survivorship Movement for NCCS*. Reprinted with permission. To learn more about NCCS, visit canceradvocacy.org.



BELL RINGERS

By **DANIELLE RIPLEY-BURGESS**

Outside the debate of calling cancer patients "survivors," few other facets of cancer survivorship bring up such a visceral, complex set of emotions than "the bell."

Some call it the victory bell, others the chemo bell. Some love it: It's a symbol of hope and a goal to achieve. And...some don't.

For bell supporters, it serves as a special memory about the time they gathered around to ring it, often surrounded by loved ones, nurses, and staff who witnessed and supported through grueling rounds of treatment. The bell signals joy and a celebratory ending, a milestone of sorts, marking the end of one chapter and the beginning of the next. It's a beacon of hope.

"I rang the bell after each successful round of treatment mostly to give hope to the other patients in the room," said Greg Vaughn, a stage IV survivor. "It brought tears to my eyes each time I heard it during my treatments, and I knew it wouldn't be long until it was my turn to wake everyone up!"

Survivor Jody Lee Breslin also rang the bell.

"My bell ringing was a heavy moment," she said. "I was filled with happiness that my chemo journey was over. But, it was the first week of the pandemic in March 2020, and my family could not be beside me. My beautiful oncology nurse and staff celebrated with me as I rang the bell. Then, they held the door open so my family, standing outside in the cold, could peer through the glass. The most moving moment was as my family and I left the facility, there was a parade of friends standing 6-feet apart on the sidewalk, dressed in blue and masked up, ringing bells for me as I went home to sleep off my last chemo. It even made the local news. I felt so extremely loved and blessed."

But for others, the bell isn't so pleasant. Hearing it echo throughout the treatment room is painful. It can be a sign of defeat that makes "chemo for life" or metastatic colorectal cancer more devastating with each chime heard. Stage I survivors who don't receive chemotherapy or radiation may never encounter the bell. Some cancer centers don't have one. Some patients are afraid to ring it, not wanting to celebrate out of fear of recurrence. In *JAMA Oncology*, Kevin Gale wrote about how hearing the bell brought his mother painful tears as she fought stage IV colorectal cancer and resolved to never become a bell ringer herself.

"The victory bell makes me upset," Gale wrote. "Why do oncology clinics install the victory bell in the infusion room or lobby, usually within earshot of terminal patients? Is it important to continue this celebratory tradition, even if it brings sadness and tears to a minority of terminal patients?"

At Fight CRC, we are fighting for prevention and treatment advances that would eliminate patients encountering the bell all together.

But, like it or not, the bell has become a very meaningful stop along many cancer patients' journeys. So who is a bell ringer, and should bells even be rung? These are hard, complex questions that unfortunately don't come with easy or "correct" answers.

WHERE DID THE BELL COME FROM?

The origin of the cancer victory bell ties back to a head and neck cancer survivor being treated at MD Anderson in Houston. The patient, Irve Le Moynes, a rear admiral in the U.S. Navy, had just finished his radiation treatments.

"He told his doctor he planned to follow a Navy tradition of ringing a bell to signify 'when the job was done,'" wrote MD Anderson. "He brought a brass bell to his last treatment, rang it several times, and left it as a donation."

MD Anderson mounted the bell on the wall with a plaque and this inscription, written by Le Moynes:

Ringing Out

Ring this bell

Three times well

Its toll to clearly say,

My treatment's done

This course is run

And I am on my way!

—IRVE LE MOYNES

The tradition struck a chord with other cancer patients, and soon they too were ringing bells to mark the end of their treatments, whether for radiation or chemotherapy.

The symbolic act of bell ringing began traveling to other cancer centers as more and more patients found it to be hopeful and heartwarming. Gale's 2018 abstract in *JAMA Oncology* stated that 51 of 62 National Cancer Institute-designated cancer centers offer a bell for patients to ring upon a cancer victory.

Today, bells are rung during a variety of ceremonies when a community wants to honor and remember strength and service. In the cancer community, most colorectal cancer survivors have either seen, experienced, or heard of the "chemo bell." It's become one of the most prominent symbols of cancer survivorship.

DID YOU RING THE BELL?

Why or why not?

ST Sherre Tomblin

There was no bell that I knew of, and I wouldn't have wanted to ring it if there was. I feel blessed to still be alive, and not cancer free yet, with high recurrence rates of stage IV colon cancer.



CW Chastity Wentworth

I rang the bell after my 28 days of radiation treatment. I did not after chemo as I was unsure if there was an end to that or not, but I knew there was an end to radiation! 28 days of chemoradiation, going every day, and I was so excited to finally finish and ring that dang bell! 🙌



MPM Maria Pirillo Madar

That damn bell. My hubby wanted to ring it because he was DONE having chemo (after eight rounds he was stable so he said no more). The nurse told him he couldn't because he hadn't completed all 12 rounds. He did it anyway!!!



DR Deanna Roadruck

No, I was by myself and felt very self-conscious about it, and kind of afraid I'd jinx myself. 🙄



DID YOU RING THE BELL?

Why or why not?

HA **Holly Ann**

I did. Honestly I wish I had more energy back then to make it a celebration, but it was bittersweet. Felt rough, looked rough, so no video or pics. Back then I didn't want to remember any of that time. Today I wish I documented to look back at how far I came!



DB **Dawn Blatt**

There was no bell at my treatment center, at least that I knew of. It would have been a nice way for me to end treatment. Instead I just walked out with a weird feeling. There was no acknowledgment of this milestone (at least that's how I felt). I do understand why places do not have a bell, since others may not get this opportunity.



RD **Rob Douglas**

Did not ring a bell, nor was I particularly interested to ring a bell. I bowed my head in a prayer of thanksgiving after finishing my last treatment. Stage III survivor of just over three years.



PW **Phyllis White**

I rang the bell once my chemo and radiation were done, it brought tears to my eyes and was overwhelming to me for some reason.



CONTROVERSY

Controversy is no stranger within the cancer community, especially when it comes to the bell.

In 2020, one study found that out of 200 patients, half who rang the bell and half who had not, those who rang it actually reported more distress.

"We think this is because ringing the bell creates a 'flashbulb event' in a patient's life – that is, a vivid snapshot of their memories from that time," wrote Patrick A. Williams, MD. "Rather than locking in the good feelings that come with completing treatment, however, ringing the bell appears to lock in the stressful feelings associated with being treated for cancer."

Not everyone agrees with this though, including Lindsay Norris. She was working as an oncology nurse at the University of Kansas Cancer Center when she was diagnosed with stage III rectal cancer at age 33. She underwent radiation, surgery, and chemotherapy. At the end of her treatments, she debated on whether or not to ring the bell and faced mixed feelings. She felt anxiety and worries of jinxing herself. But, she ultimately chose to ring it.

"I rang the bell for my kids, for my husband, for my family, friends, and work family," she said. "I let myself have that victory. I reminded myself that not everyone gets an 'end of treatment' celebration and if anything, I should do it to honor all those who couldn't and who have gone before me. I rang it to signify winning that battle, even when I didn't know how many battles it might take to win the war. I'm lucky to say that five years later, I have not had to sit back in the treatment chair, and I don't regret ringing the bell. In fact, later on, I met a stage IV friend who recalled hearing

66

WE HOLD THIS
AS A HAPPY
MEMORY.
AND LOOKING
BACK, I NOW
REALIZE THAT
DAY WAS WHEN
THE *real*
PROCESSING
BEGAN."

LINDSAY NORRIS



my bell ringing on her very first treatment day. She said it made her feel hope. I'm cognizant of how tough it must be to hear bells ringing as a chemo-for-life or end-stage patient, but for me and my friend that day (and my sweet 4-year-old son who got to help), we hold this as a happy memory. And looking back, I now realize that day was when the real processing began."

TO RING OR NOT TO RING?

Ringing the bell is a celebration according to some survivors, and a tradition that needs to end according to others. Some survivors were never offered the chance to ring, while others passed it up. Unlike treatment guidelines, there's not a clear path for how to move ahead.

"The final day of treatment can be one of mixed emotions," said Jana Bolduan Lomax, Psy.D. "Bell ringing has become a common rite of passage in many cancer centers to commemorate treatment completion. However, some individuals do not feel celebratory as they exit their final treatment. They may experience anxiety, fear, sadness, and even guilt. An individual could be offered the choice to 'ring the bell' or not. If you prefer not to, you can choose other

meaningful ways of marking treatment milestones. For example, a meditation, a walk, meet with a friend/loved one, burn a candle, etc."

At Fight CRC, we believe that what really matters is that patients and caregivers choose to be relentless champions of hope. And one thing relentless champions do is celebrate and recognize cancer milestones. This is important for patients and caregivers alike.

Cancer patients' bell ringings are a "mountaintop" moment for many families, and they can create very memorable experiences for survivors. But, ringing a bell is not the only way to celebrate.

Some climb mountains; some advocate and contact members of Congress; others distribute resources and share their stories online.

There are lots of ways to recognize strength and celebrate victories along the cancer continuum. Ringing a bell is one of many.

HOW DO *you* **celebrate** **CANCER** MILESTONES?



Christine Bronstein

DIAGNOSED: 2022

CURRENT STATUS: *Active treatment*

I celebrate my nurses every chemo round. I am so grateful for them.

They take such thoughtful and personalized care of each patient. Their smiling faces got me in that door when all I wanted to do was turn around. Sometimes I take coffee and pastries, sometimes gift cards. They constantly celebrate every patient, always making us laugh during the hardest moments. They were there for me even when my pump started beeping at all hours of the night. I don't yet know how, or if, I will celebrate milestones, but I will always celebrate the spectacular people I have met on my cancer journey.



Valerie & Manoli Savvenas

DIAGNOSED: 2021

CURRENT STATUS: *Manoli is in active treatment*

We haven't really celebrated any milestones yet; we haven't really thought about it.

We work five days a week, but we hope to go to Greece for vacation next summer.



Yasmeem Watson

DIAGNOSED: 2013

CURRENT STATUS: *NED*

I was never given the option to ring the bell; I would have loved to.

Each year I take time out to acknowledge the past suffering caused by this disease. At my fifth year, I gave myself a party, and I will do the same next year at my 10th.

DID YOU RING THE BELL?

Why or why not?

THP

Tammy Holley-Padgett

People ringing the bell makes us happy for them, but it also makes me cry because my husband will always be on chemo for the rest of his life. So we really don't like to hear the bell ringing.

♥ 🗨 📌 🏠

KH

Kristi Holcomb

After 28 radiation treatments that left me with horrific burns and blisters for weeks-on-end, of course, I wanted to ring the bell. ♥ Watching those before me get to ring the bell were some of my first moments of hope. If others could do it, so could I. It was the ONLY moment in my 13-month cancer journey that I felt rewarded for a "job well done." A moment when I was in control, in an uncontrollable environment. I did it—I stayed strong—I did not give up—and I rang the bell.

♥ 🗨 📌 🏠

TM

Tim McDonald

I hope to get to, but I may never know when my last infusion will be. No matter what, the possibility of being back in chemo is very real after my liver transplant. Only 25% of transplant patients have no recurrence. For this reason, I don't find it appropriate to ring. But if I can inspire others I will. This journey isn't just about me, it's about all of us.

♥ 🗨 📌 🏠

DID YOU RING THE BELL?

Why or why not?

LG **Laura Galbraith**

My oncologist didn't have a bell. My last day of chemo the nurses all came into the room where I'd just had my last pump removed and sang congratulations to me and gave me hugs and a graduation certificate. I was glad they were so happy for me because I felt horrible and I probably looked pretty bad too.



RD **Raegan Downing**

When I finished the first journey, I couldn't ring the bell even if I wanted to, I felt so sick and just wanted to go home. Then it returned. If I finish this second journey, honestly I probably won't because it's really not over. I'll be looking over my shoulder the rest of my life. I wish I felt differently about it!



NTC **Nicole Torres-Cooke**

There was no bell to ring at my oncology center, but my bestie left a package for me at the front desk. It was a giant red cowbell for me to ring in my car. Made me laugh and cry at the same time.



RD **Zachary Corbin**

In the Navy, ringing the bell was something I never even had in my mind. For chemo, it was my main focus. 🙌



Comments were posted in the Advocates of Fight CRC Facebook group and printed with user permission.



Yvette Perry

DIAGNOSED: 2014 (Stage 1) & 2018 (Stage 4)

CURRENT STATUS: *NED*

We get cake when there's a cancer milestone, especially as a stage IV patient.

In particular, on the anniversary day of diagnosis. That's a huge milestone because it means I made it another year. NED (no evidence of disease) or stable scans is a cake-celebrating moment as well. I celebrate the date of my first surgery. That surgery got me on a path that has kept me alive. It was pretty major and included CRS and HIPEC, which was many surgeries combined into one with an internal chemo bath at the end. That's like my new birthday. Every day I get to be here feels like it should be cause for celebration. I try to keep that in my mind daily. I also buy myself funny t-shirts to celebrate surgeries or CRC. I am currently in remission, and one of the ladies at the front desk said, 'You should ring the bell on your way out!' But I couldn't do it. I told her I'd go have some cake instead. Hearing the bell gives some hope. I've heard it ring as I sat in the treatment chair, and while it made me happy for the person who rang it, it also made me incredibly sad. I didn't ring it for those like me. Instead, I go online and tell my story so people like me can have hope.

HOW DO you celebrate CANCER MILESTONES?



Chris Carvalho

DIAGNOSED: 2010
CURRENT STATUS: *NED*

My partner and I celebrated the end of chemoradiation with a trip to New Mexico.

We stayed at a lodge in the mountains in early summer, hiking and enjoying normal life again. Because the subsequent surgery left me with Low Anterior Resection Syndrome (LARS), it was the last time I could eat anything I wanted with no issues. I miss Hatch chile peppers so much. About a year after completing surgery, I traveled to New Zealand to backpack the famous Milford Track. It was a memorable trip, even though there were challenges I needed to manage carefully with a much more finicky gut. I don't enjoy celebrating with big meals anymore, but for my 10th cancer-free anniversary in 2021, we did enjoy an excellent glass of wine. If a cure for LARS is developed, that will be time for a major celebration, and I look forward to that day.



J.J. Singleton

DIAGNOSED: 2015
CURRENT STATUS: *Chemo for Life*

I will never get to ring the bell, but I absolutely love hearing it get rung.

For me, when I hit a new year survived or a major chemo number, I'll have a small get together with friends and family just to celebrate still being alive.

When our 12-year-old kids turn 20,
colorectal cancer may be THE No. 1
cause of cancer death in the U.S.

**We must do more to stop this.
We must act now.**

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MORE



Why am I experiencing unintended appetite and weight loss?

Two side effects some colorectal cancer patients experience are appetite loss and weight loss.

While some of this is to be expected, given the stress of treatment on both the mind and body, a metabolic condition called cachexia may actually be the cause.

Lee Jones, a Fight CRC research advocate and stage IV colon cancer survivor who has experienced cachexia himself (losing 18% of his body weight during treatment), interviewed Dr. Eric Roeland to better understand cachexia, and how patients can identify and manage this condition.

Q What is cachexia?

A Most patients and caregivers have never heard the term 'cachexia.' The first thing is to recognize what it is and is not. It is not starvation. Cachexia is a syndrome in which your metabolism is increased. You lose your appetite, leading to loss of weight, muscle, and quality of life, as well as increased toxicity and poor survival. Cachexia describes a phenomenon in multiple disease types, but we often talk about it most frequently in cancer.

Most people think of severely emaciated patients as cachectic, but we've recognized that there are three phases of cachexia: pre-cachexia, cachexia, and refractory cachexia.

Q What is the difference among the three types of cancer cachexia?

A **Precachexia:** Weight loss of less than 5%, along with other symptoms, such as impaired glucose tolerance or anorexia

Cachexia: Weight loss greater than 5%, or other symptoms and conditions consistent with the diagnostic criteria for cachexia

Refractory cachexia: No longer responsive to cancer treatment, have a low-performance score, and a life expectancy of less than three months



Q What causes cachexia? Does cancer itself cause it? Or is it caused by my treatment?

A We think the cancer itself causes cachexia. If you can control cancer with therapy, people can actually gain weight. That's why we call some chemotherapy "palliative chemotherapy," because its use can improve symptoms. It's essential to recognize that cachexia impacts multiple things, and one of them is weight. Historically, we've defined weight loss over a certain amount of time to describe cachexia. However, we're learning this definition probably doesn't capture the true experience of cancer cachexia. We're advocating to change that definition, so patients recognize that a loss of appetite and loss of muscle are early signs of the syndrome that need to be addressed.

Q How many colorectal cancer patients experience cachexia?

A I would say all of my patients with advanced illness, meaning stage III or stage IV, already have cancer cachexia. It's a huge issue. I think we often attribute their experience to cancer and its treatment, but if you sit down and talk to patients, they'll use all sorts of words to describe not



wanting to eat. Those are all signals that we need to assess. If you look at the actual numbers and studies, there's this huge range from 30% to 80% of patients who experience cachexia. This is because cachexia is still so poorly defined.

Q How do you explain cachexia to your patients/ caregivers? How do you communicate what they're experiencing, and how you would treat it?

A Cachexia includes loss of appetite, fatigue, and weakness—this is something that we see especially in the proximal muscles. These are muscles in the shoulders—what I like to call the “shampoo

muscles,” as well as the muscles you use to get up from sitting in a chair, or what I like to call “toilet muscles.” These are some of the classic signs. Again, the challenge with defining the syndrome is that historically it has been defined in so many different ways, even amongst researchers and regulators. I choose to focus on the patient experience and say these symptoms are related to the cachexia syndrome.

Multiple experts need to be involved early on in your care, including a registered dietitian. We like to have nurses, social workers, or psychologists talk to you and your caregiver about food challenges. I like to talk to both the patients and their caregivers because everyone needs to understand what's going on with the patient's body. Caregivers will often feel like they're not doing a good job because their loved one is not eating, and patients feel bad because they're not eating, so it's important to normalize this experience and have strategies ready to go. The palliative care team is critical because if you have any symptoms that are not controlled, such as pain, constipation, nausea, or vomiting, you're not going to eat. Physical therapists and occupational therapists are a vital part of the team as well because they can help teach you how to continue to move safely. Making sure that all your symptoms are well-controlled is incredibly important.

Q Can you reverse cachexia?

A The only way you can stop the syndrome itself is by stopping your cancer. A good example of this is to take a step back and think of pain. When patients have pain from their cancer, the cause of that pain is the cancer itself. Treating cancer makes the pain better, but at the same time, we also have tools to treat pain. My goal is that we recognize that you can do both simultaneously. You can treat the underlying cause, and you can treat the symptoms. And so that has been a challenge in cancer cachexia because we don't have great tools to treat cancer cachexia, and many medications we use as clinicians actually may not help.

Q How does exercise impact the condition?

A Exercise is, in fact, the only thing that has worked for cancer-related fatigue. Low-to moderate-intensity exercise is incredibly important, and that's exactly what people don't want to do when they feel crappy. So, I encourage people to rethink what it means to exercise. Many people think they've got to go to the gym and spend an hour exercising, but it could be walking around the house a couple times or performing some light resistance exercise. But yes, you need to get up and move to remain less fatigued, which sounds horrible for so many people who are not feeling great.

Q What resources exist for colorectal cancer patients who are facing cachexia?

A There's very little data or tools out there that are patient-facing. Patients need to be empowered, and honestly, if you approach your doctor and don't look emaciated and say, “I think I have cachexia,” I imagine a lot of doctors would say, “No you don't,” and they'd be wrong because they are unaware of all the phases of cachexia. Patient-facing materials are a huge need.



LEARN MORE

Scan to learn more and get resources for cachexia.



All content was written and edited by Fight Colorectal Cancer. Thank you to Pfizer for sponsoring this content.



ERIC ROELAND, MD, FAAHPM

Assistant Professor of Medicine at Oregon Health and Science University (OHSU) Knight Cancer Institute; medical oncologist and palliative care specialist



Sexual health is an emotionally and physically complicated issue. When you add a colorectal cancer diagnosis, the topic becomes downright uncomfortable. And it shouldn't be.

Megan Ingram Forshey, LCSW, a social worker and program manager for Gilda's Club Middle Tennessee, works with individuals and couples to help them navigate through the emotional aspects of sexual health and cancer. She also helps identify other organizations and resources that can offer additional information and support.

"Sexual health is a complex issue because it involves so many variables and is unique for each individual and couple," Forshey said.

During colorectal cancer treatment, a survivor may become uncomfortable with their body or body image. Physically, sex may be uncomfortable or hurt. And let's face it: People just aren't comfortable talking about sexual health. But, there's hope, and we can help.

LET'S TALK ABOUT SEX

For more than 18 years with Gilda's Club, Forshey said she has learned from the real experts around this topic—the individuals

and couples navigating their cancer diagnosis and treatment.

Communication is key according to Forshey. Communication within an established couple, in a new relationship, and also with your medical team during treatment for colorectal cancer.

"Let's have conversations about these questions and challenges that nobody feels comfortable talking about," Forshey said. "We want to make it easier to talk about all these related topics, even if it feels awkward at first."

DON'T BE AFRAID TO ASK THE QUESTIONS

A survivor's treatment team is focused on creating the best strategy for that person's long-term survival. Understandably, sexual health may not be your medical team's priority. But it's important to bring up the topic and talk to your medical team.

"Medical professionals are humans, too, and sometimes have a hard time approaching the subject with patients," Forshey said. "But every physician I know would ABSOLUTELY want you to bring that up and ask any questions you have."

Forshey recommends finding the person on your medical team you are most comfortable with to start the conversation. If you don't see your primary oncologist often, you may feel more at ease with your nurse practitioner, infusion nurse, or social worker. Don't suffer in silence.

Your medical team is there to provide help and guidance in your treatment as a whole person, not just a person with colorectal cancer.

Don't be shy. Become informed. You don't deserve a mediocre life because you are a survivor of colorectal cancer. Everyone deserves a well-lived and well-loved life.

SPECIAL CONCERNS FOR YOUNG ADULTS

By 2030 colorectal cancer is expected to become the No. 1 cause of cancer deaths for people ages 20–49. Forshey acknowledges that early-age onset diagnoses bring the sexual health discussion to the forefront and encompass the topics of body image, dating and relationships, sexuality, intimacy, and fertility and family planning.

Forshey recommends keeping communication open.

"We communicate all the time," she said. "Even when we're not talking, we're communicating."

Recognize that sexual health may be uncomfortable to talk about, then communicate about it however best works for you. There's no one right way. It's OK if it's a little (or a lot!) fumbly and awkward.

WHAT HAPPENED TO MY LIBIDO?

Often times, a couple's sex life and physical intimacy may grind to a halt when one of the partners is diagnosed with colorectal cancer. One or both are shocked and scared initially. But once they settle into a diagnosis and treatment schedule, they may begin to fall back into a rhythm, only to find things have changed.

Forshey says it is important to talk about getting back to the loving relationship of being a couple. Intimacy doesn't necessarily equal getting back to sex, but rather is about turning back within the couple to each other.

STARTING OVER

Part of physical sexual intimacy is figuring each other out again. Forshey says it's important to consider that when someone is undergoing treatment, their body may physically hurt. Reassure your partner that it's OK to tell you if they're uncomfortable or if something hurts.

Be specific and talk about ways to be intimate. This doesn't have to include physical touch. Also, have these conversations without phone, TV, or other distractions, and have these conversations outside the bedroom.

It's difficult after a colorectal cancer diagnosis to figure out when to start the conversation on sexual health. All you need to say is, "I'm missing you. Let's talk about it."

It's impossible to know what your partner is thinking or feeling, which is why communication is important. While it's thoughtful to try to anticipate your partner's needs, you also have needs of your own. When you talk about sexual health, you are making sure both your and your partner's needs are being expressed and met.

If your partner's body hurts, it's OK to say, "Can I sit next to you? I miss you near me."

SEXUAL HEALTH ACROSS THE CONTINUUM

Not everyone is dating or has a partner. Just as there are challenges within relationships, starting a new relationship may be stressful or feel difficult. So, how do you take a chance if you want to begin a relationship?

Forshey says the answer varies from person to person, but she believes survivors can always benefit from connecting with other people "who get it." There are young adult groups and single people that have traveled a similar path as you. People do begin relationships and fall in love after being diagnosed and starting treatment.

Young adults can connect through Gilda's Club (more than 40 across the U.S.) or Cancer Support Community (more than 175 worldwide) near them or online. These organizations provide free social and emotional support for anyone impacted by cancer, including family members and friends. COVID-19 made meeting up online commonplace and convenient so you don't have to travel long distances to find support.

KEEP ON KEEPIN' ON

Couples will find it's necessary to redefine their relationship and physical intimacy, whether during treatment or into survivorship. Forshey says it's important to have specific conversations about what feels OK. She emphasizes the importance of not pushing or having specific timelines, if it feels uncomfortable to either party.

An individual or couples therapist can be extremely helpful with processing how cancer is impacting your life and relationships. The therapist can also help identify strategies that work and help to navigate hard conversations, while also help reaffirm existing strengths in a safe and supportive environment.

Forshey recommends reassurance along the way and letting your partner know, "I love you. I'm not going anywhere."

Give yourself and your partner grace as you work together to rediscover your relationship and find your way back to things you love and cherish about each other.

LET'S
TALK
about
SEX

CONVERSATION STARTERS

Questions to ask your doctor about sex:

- Is it safe for my partner and me to have sex?
- Are there precautions we should take?
- I'm young: What can I do to preserve fertility?
- I am upset by how my body looks and functions. What can I do?
- Women may ask, "Radiation and expanders have made sex physically uncomfortable and painful for me. Is there anything I can do to make sex pleasurable again?"
- Men may wonder, "Radiation has made sex difficult for me with being able to maintain and sustain an erection. Is there anything I can do to make sex enjoyable again?"



LEARN MORE

Scan this QR code to read survivors share their experiences and to get more sexual health resources.



MEGAN INGRAM FORSHEY, LCSW

Social Worker & Program Manager for Gilda's Club Middle Tennessee

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WIPES



SLEEP, please!

Struggle with sleep?

You're not alone. We talked to Douglas E. Guggenheim, MD, about some of the most common struggles cancer patients and caregivers face when it comes to getting some zzzzs.



[READ MORE](#)

Scan to read sleep strategies

Palliative Care

Palliative care focuses on relieving the symptoms and stress of any serious illness, and it provides an extra layer of support for the patient and family dealing with a serious illness.

The goal is improving the patient's quality of life.



[READ OUR BLOG](#)

Scan to read our blog, "Top 7 Questions About Palliative Care"

Survivorship

Fight CRC worked with the top experts in survivorship care to curate videos, blogs, podcasts, and more for cancer survivors—those who have completed treatment, as well as those with metastatic disease or those on maintenance therapy.



SCAN TO GET MORE INFORMATION ABOUT:

- Survivorship Care Plans
- Physical Activity and Nutrition
- Managing Mental Health



FREE RESOURCES

Did you know Fight CRC offers a deep dive on certain topics?

Free patient resources are available at **FightCRC.org**, or you can also browse our store at **Shop.FightCRC.org**.

Are you a medical professional? Contact us to order materials for your patients and get on our distribution list! Email Zac at patientinfo@fightcrc.org.



KNOWLEDGE is POWER

I joined Fight CRC in May 2022 as the Director of Patient Education and Research. Prior to joining the team, I worked at the Colorado Department of Public Health and Environment as the Comprehensive Cancer Program Manager.

For the past six years I have worked with providers, health systems, nonprofits, advocates, patients, caregivers, nurses, social workers, navigators, and many others to reduce the burden of cancer and improve the quality of life for those living with cancer. Through this work, it became clear just how complicated it can be to navigate our healthcare system, and when you add in a scary cancer diagnosis, it can be paralyzing and overwhelming.

There are many people in our communities working tirelessly to help ease this journey and to

improve quality of care. But what has become abundantly clear to me over the years is that the more knowledge a patient has about their disease and the more options and services available to them, the more tools they have in their toolbox to advocate for themselves, know what questions to ask, and have a better idea of the path to take.

My first real, personal experience in the “cancer world” was in 2006 when my brother-in-law was diagnosed with a rare eye cancer at age 34.

Little was known about the disease, even amongst the medical community. This led to a disjointed, discouraging, and frustrating experience for him. By learning as much as he could about his biomarkers (genetic mutations), available clinical trials, and treatment options, my brother-in-law took a more active role in his cancer journey. He asked his doctors critical questions and crafted treatment plans that were often seen as “outside the box.” I believe this contributed to him surviving for six years longer than originally expected. I saw how powerful it can be when patients use their knowledge to fully advocate for themselves. The medical team is truly a TEAM, and my brother-in-law was a part of his. It extended his life.

The phrase “knowledge is power” isn’t new. In fact its origins go back to the 1500s when Francis Bacon first coined the concept. Generally speaking, having knowledge can sharpen skills like problem-solving and reasoning, and with this, we become more self-empowered. We can understand what’s happening and look after ourselves to make informed decisions for both

ourselves and our families. This will lead to a better quality of life overall.

Patients with knowledge tap into their power, and this can lead to regaining some control over their lives, values, and goals. From the day of diagnosis and into survivorship, knowledge is important. Patients and caregivers must always advocate for themselves.

This is where my team and I come in, and we’re here to help you. I’m excited to create resources to guide you through this fight. We want you to have knowledge because we know that will reveal your power.

BECKY SELIG, MSW
is Fight CRC’s Director
of Patient Education
and Research

FOLLOW BECKY!

@Becky_fightcrc





Survivorship Trials

Did you know there are clinical trials for cancer survivors who have reached no evidence of disease (NED) and are not in active treatment?

We asked Maia Walker, Lead Curator for our Clinical Trails Finder, to tell us more.

Wait—there are clinical trials for patients who are NED?

A YES! There are always trials for survivors who have reached NED/ are no longer in active treatment. They're happening in different locations in the U.S. and around the world. I know a lot of survivors who reach NED or maintenance want to be "done" with cancer, but there are a lot of trials that can help them.

Can you give us some examples of these trials and benefits of participating?

A There are trials with immunotherapies (often, therapeutic vaccines) given to prevent recurrence after surgery with curative intent in patients with lower stages (I to III), but considered at high-risk; also, in patients with stage IV that achieved NED (with ablations or chemo), who are known to have great risk of recurrence. Those survivors might achieve a cure/durable response with that intervention, instead of relapsing.

There are trials that use ctDNA tests to monitor recurrence. Those survivors might catch a recurrence at an earlier stage, making it more treatable (with an ablation, for example), obtaining more time to find the next treatment (another clinical trial, for example; in this case for active treatment).

Other trials aim to help survivors (or survivors and their couples/families) to manage lasting side effects from treatments, like if they're related to physical, mental, or sexual health. They could offer a lifeline for many.

A survivor should consider participating in a clinical trial to prevent recurrence, ease side effects, help family members to prevent CRC, advance science so others won't face cancer, or will have better treatments available.

How do patients find these trials?

A Ask if they are happening at the facility you're being treated, or if your doctor has knowledge or direct access to these trials. You can try to use advanced search on clinicaltrials.gov, playing a bit in the search bar with the terms "NED," "recurrence," and "maintenance." This isn't easy though, only by staying on top of what is being researched will you hear about those. You can regularly read about these trials in our Clinical Trials Conversations Blog on [FightCRC.org](https://fightcrc.org) where I regularly post about them. Patients can also use our Fight CRC Trial Finder at [TrialFinder.FightCRC.org](https://trialfinder.fightcrc.org).



MAIA WALKER

Lead Curator of the Fight CRC Clinical Trial Finder



LEARN MORE

Scan to read Maia's Clinical Trials Conversations Blog

TOP 10: PAYING for

CANCER

Cancer's expensive— even if you have insurance.

Patients often tell us the financial burden of colorectal cancer is one of the hardest aspects of it, and the most long-lasting. Here are 10 stories from survivors or caregivers who have tackled mountains of medical bills.

① **Shiray Berry**

STAGE IV SURVIVOR | *Clovis, New Mexico*

I've been incredibly lucky to have a great insurance plan. Because of very low deductibles and copays, we've been able to afford treatment with very few changes to our lifestyle. When we moved to Phoenix for nine months because of a second opinion, our parents were incredibly generous and helped us pick up some bills. We also had a few family members who sent us cash or gift cards for groceries and fun stuff. I wish everyone could have our experience with finances.

② **Tim McDonald**

STAGE IV SURVIVOR | *Tampa, Florida*

I was so fortunate to have a friend who put me on her company's insurance. The cost was high, so a friend set up a GoFundMe page. We raised over \$20k in less than two months. It helped with out-of-pocket amounts and deductibles. We still have enough to hopefully offset any non-covered expenses for my liver transplant.

③ **Stephanie Adler Lex**

STAGE III SURVIVOR | *Salt Lake City, Utah*

I was very fortunate to have an excellent insurance plan, and I had supplemental insurance that paid 12 weeks of short-term disability and a lump sum. My final chemo treatment was in January, and it was going to cost around \$2K, but the office manager helped me get a grant from the American Cancer Society. I didn't actually need it, because she also resubmitted the bill to my insurance company, and they paid it! That said, I also have a husband who was able to support us on his salary without making too many changes to our lifestyle. I would have had to dip into my savings if I was single.

④ **Heather Hardecop**

CAREGIVER | *Plano, Illinois*

Oof. We had a baby and were in the second year of my husband's career as a Lutheran school teacher when he was diagnosed. All our savings had gone to paying for the birth of our baby. Insurance was awesome, but we were so young and made some critical errors like putting chemo on credit cards. Friends had fundraisers for us (this is before GoFundMe). We have been paying for cancer ever since. We were finally able to purchase our first home 18 years after cancer. To be fair, we didn't have a lifestyle we were accustomed to before cancer, so all we've ever known is cancer debt. And if it wasn't the direct cost of surgery, chemo, radiation, it has been follow-up appointments, scans, hospital stays due to complications, and long-term side effects of cancer. I feel like I have a weird financial form of PTSD.



⑤ **Paula Chambers**

STAGE I SURVIVOR | *Houston, Texas*

Cancer set us back at least 10 years. We are in medical debt every year because of our high deductible.



8 Sharon Parrett
SURVIVOR & MEDICAL PROFESSIONAL
Hot Springs, Arkansas

I had insurance, but the deductible and copays were still high. I used savings, cut expenses where I could, and used some retirement money. My radiation center was not in-network and that bill was a huge sticker shock. I negotiated with the hospital for them to write off a large amount, and paid some using my credit card. I used a payment plan for the rest.

9 Kristi Holcomb
STAGE III SURVIVOR
Chattanooga, Tennessee

My husband and I had to file bankruptcy after I finished treatment.

10 Denelle Suranski
STAGE II SURVIVOR
White Oak, Pennsylvania

Before the Affordable Care Act (ACA), I was kicked off my mother's insurance because I was 19 and had to drop out of college when I was diagnosed. The only way I could get insured was to move to my sister's house and get a bill put in my name to get medical assistance. Being diagnosed with cancer is one thing, but there are so many other burdens that come with it.

6 Beth Palcher Kornegay
STAGE III SURVIVOR | *Shawnee, Kansas*

Although I had insurance, the deductible was still high. Thankfully, I was able to set up a payment plan and paid a certain dollar amount each month (minimum payment was \$125), and I paid that plus a bit more until it was paid off. The cancer center never called me to ask for payment, but I ensured I always made at least the minimum payment. It took between two and three years to pay it off, and it was a great feeling to finally see that ZERO balance on my spreadsheet!

7 Karla Thompson
STAGE IV SURVIVOR
Carlsbad, New Mexico

I am very fortunate to have insurance that covers my chemotherapy 100%, plus a large amount toward my two major surgeries and regular scans. Still, having cancer isn't cheap. Early in my treatment, I shared my "sticker shock" with my oncologist who (I think) took that to mean I was having financial difficulties and referred me to a local charity (didn't connect the dots until much later). I met with them and they offered to cover any and all outstanding costs regardless of my family income. I protested it, and they said it was their mission to help. They truly did not consider income, or whether I could "afford" treatment and tests or not. I was humbled to say the least and gratefully accepted. Finally, when I had to wear a pump after each infusion, my insurance paid for the 5FU drug but not the pump itself (go figure, right?). My husband called the company who made the pump and asked what our options were. They decided to cover the \$2,000 cost and canceled my balance. Never hurts to ask.



Fight CRC Project Coordinator, Melissa Frantz, chatted with Madison McMahon Ward from Triage Cancer on Instagram Live about creative ways to manage your medical bills. Check it out!

1. TALK IT OUT

Talk with your healthcare team about expected costs for treatments and procedures. Ask if there are any programs to help you cope with the costs.

2. PAY PROGRAMS

Ask the hospital if they offer any "ability to pay" programs or financial assistance. Some may wave a portion of the bill.

3. CASE MANAGERS

Insurance companies have case managers who can help you. Keep in mind: They work for the company. But, it can be comforting to talk to the same person each time you call.

4. SHOP AROUND

Shop around for tests. For example, if you know you have upcoming lab tests, you can get a printout of what they will be and shop around for a fair price. Use healthcarebluebook.com to understand the fair market value of tests in your area.

5. GROUP YOUR VISITS

If possible, group appointments together so you only pay one copay for an office visit.



WATCH MORE

Scan to watch the full interview and see her advice for building an emergency fund when you're surrounded by debt, facing cancer if your insurance sucks, and more. For resources about cancer finances, visit triagecancer.org.

IT HAD *never* **BEEN DONE BEFORE:**

*thousands of blue flags waving
on the National Mall for
colorectal cancer awareness.*

Fight CRC is known for pushing the boundaries—like taking over Times Square and hosting parades and marches. But in 2022, we made a shift.

We set our sights on Washington, D.C., and we planted ourselves in front of the Capitol.

Literally.

From March 13–18, more than 27,000 flags representing the number of lives that could be saved sent a clear message: Act Now. Why wait until people are dead to make change happen? Surrounded by toilet seats, each lifted lid explained, state-by-state, how many cases and deaths are expected in the United States. The installation told a grim story:

Nationwide, colorectal cancer is estimated to be the No. 1 cause of cancer deaths in people under age 50 by 2030 if things don't change.

So, we designed an installation to get attention. Members of Congress looking out their windows and walking to work couldn't miss it. Passerbys stopped to learn. Survivors and caregivers came to volunteer, to educate, and to mourn. United in Blue both celebrated those who are surviving and honored those we've lost.

If we all act together, we have the opportunity to save the lives of more than 27,000 people through prevention, research, and better treatment options. We are obligated to fight for that.

WE HAVE NO PLANS OF STOPPING.



JOIN US *in*
MARCH 2023



WATCH

Watch President Anjee Davis and Fight CRC advocates tell the emotional story about United in Blue.



The Fight CRC Advocacy Team (from left to right): Olivia Welch, Advocacy Program Manager; Molly McDonnell, Director of Advocacy, and Erin Darbouze, Health Policy Manager

SMALL STEPS LEAD to **BIG THINGS**

On July 25, 2022, **Fight Colorectal** **Cancer went to the** **White House.**

We brought together leaders in colorectal cancer screening from the patient advocacy and business communities to meet with staff for the President's Cancer Moonshot effort, as well as multiple federal agencies about ways we can work together to increase colorectal cancer screening.

The meeting was an opportunity for us to explain the challenges and opportunities before us when it comes to getting more Americans screened for colorectal cancer, while also showing this group's commitment to bold action to reduce deaths from this disease.

The President and First Lady have set ambitious goals as part of the Cancer Moonshot effort.

They want to jumpstart the more than 10 million cancer screenings missed due to the pandemic and ultimately reduce cancer deaths by 50% over the next 25 years. We are excited about being a part of making these goals a reality.

You may be thinking: How did this happen? How did we get to the White House? The answer is simple: Through the power of you, our advocates. Survivors, caregivers, and loved ones have tirelessly shared their stories, raised their voices, and our government officials are taking notice.

This is an effort our community has been building toward for years. Each Call-on Congress when you shared your stories with your members of Congress, each March when you secured proclamations from your governors, and throughout the year when you raised awareness in your communities about colorectal cancer—it all helped lead us to the White House. Each step may have felt small, but it led to big things.

This was exemplified by rockstar advocate and stage I colorectal cancer survivor, Paula Chambers Raney. She joined us at the White House to share her story and be a voice for colorectal cancer survivors. She put a face to the statistics and reminded the group that while data and measurable goals are important, at the end of the day, this is about real people, real lives.

When it comes to talking about advocacy, one of my most-used phrases is, "If we don't raise our voices, no one else will do it for us." Colorectal cancer survivors have raised their voices, and we now have the attention of the White House. Thank you for being relentless.

Perhaps the most exciting part of this meeting was the commitment by all participants that it would not be the last. If we are going to reach the Cancer Moonshot goals, it will take all of us working together. More to come!

MOLLY MCDONNELL
is Fight CRC's
Director of Advocacy

FOLLOW MOLLY!
@MollyFightCRC



BEMIS IS A PROUD SUPPORTER OF FIGHT CRC



We manufacture toilet and bidet seats that provide wellness for all, regardless of your life or health stage. Bathroom issues can sometimes seem “taboo,” so we want to encourage conversations about colorectal cancer and support the fight to find a cure.



INNOVATION
FOR EVERYDAY LIFE.

FACING FEARS*Coping* **AND** *Conquering*

Life with and beyond a cancer diagnosis is often an emotional, spiritual, physical, and social roller coaster ride of unexpected twist and turns.

No two rides are the same. Each person's cancer experience is influenced and affected by their personal characteristics, beliefs, history, and culture. Nonetheless, fear is highly likely across all cancer experiences. Here are common cancer-related fears and ways to cope with them.

Fear of recurrence and/or fear of dying

Cancer brings uncertainty and can also bring a loss of control of health, schedule, and sense of immortality. Human nature seeks to find order in our environments (1,2,3); a cancer diagnosis disrupts this. Therefore, feelings of fear and anxiety, and urges for a reclaimed sense of control, are common. Here are some ways to address these difficult emotions:

- 1. Name the emotions and the fears (to yourself, loved ones, or professionals).**
- 2. Do things that give you a sense of empowerment, health, and wellness.**
- 3. Discuss and understand surveillance and survivorship plans with your healthcare team.**
- 4. Accept that fear of death is a hard-wired survival mechanism.**
- 5. Recognize that cancer is often a traumatic life event, and trauma results in anxiety responses.**

Fear of passing hereditary risks

As a parent or grandparent, the safety and health of our children is top priority. It's common for cancer survivors with, or considering having, biological children to fear passing down a cancer risk. Speaking with genetic counselors and your oncology team about the reality of these risks is an important first step. Even when armed with reassuring information, learning to live comfortably with uncertainty is an essential task of both parenting and cancer survivorship.

Fear of new relationships

Countless changes occur to a cancer patient's body, functioning, and identity following treatment. Accepting and feeling compassion toward oneself can be challenging, and even more so, in a new relationship. Grief and loss about your prior appearance and sense of self is a common and expected experience. Allow yourself to acknowledge your sadness and grief (and possibly anger) about your body's changes. Be gentle with yourself. Focus on the positive aspects of your body and find gratitude for your resilience; you'll more likely be able to adapt effectively to the changes. (4)

When and how to seek help

Cancer does not happen in a vacuum, nor in the absence of other significant life stressors. Often, a cancer diagnosis is a life-altering curve ball that causes you to reprioritize your life to make meaningful and, at times, difficult changes. Fears and emotional distress are common; however, suffering does not need to be a part of survivorship. For some people, individual and/or group psychotherapy can be a form of prevention before intense, difficult emotions lead to major problems. Wellness activities, mental health, and psychiatric treatment can also help address the trauma and losses associated with cancer.

What are the signs that anxiety or depression are more serious?

- **Your worry or anxiety gets in the way of relationships and daily activities.**
- **Your fear prevents you from going to your follow-up care appointments.**
- **You feel hopeless and/or apathetic about the future.**
- **You have difficulty sleeping or eating well.**
- **You don't participate in activities you used to enjoy.**
- **You have trouble concentrating or making decisions.**
- **You feel like there's nothing to look forward to.**
- **You're unusually forgetful.**

In these cases, seeking mental health care from a professional can be time consuming, but absolutely worth it. Life will change in many unexpected ways following cancer diagnosis and treatment. Living with uncertainty and loss of control often lead to fear and anxiety, but there are ways to adapt and cope.

CITATIONS:

- (1) Gilovich, T. (1991). *How We Know What Isn't So: The Fallibility of Human Reason in Everyday Life*. New York, NY: The Free Press.
- (2) Langer, E.J. (1975). The Illusion of Control. *Journal of Personality and Social Psychology*, 32, 311-328.
- (3) Patterns: The need for order (05/17/2016). <https://psychcentral.com/lib/patterns-the-need-for-order#1>
- (4) <https://www.virginiacancer.com/cancer-survivorship/mental-health/coping-with-your-changing-body-after-cancer-treatment/>

**JANA BOLDUAN LOMAX, PSY.D**

Licensed Clinical & Health Psychologist

Founder, Shift Healing | Health Psychology

Upcoming Events



**CALL
★ ON ★
CONGRESS**

MARCH 2023

United in Blue

Stay tuned for details at
FightCRC.org/UnitedinBlue



**THANK YOU TO OUR
BEYOND BLUE SPONSORS!**



A NIGHT *with* **THE STARS**

Friday, November 4, 2022

Springfield, Missouri

During this second-annual event, we will recognize the dazzling stars of the colorectal cancer community: patients, survivors, and caregivers. The collective light of these stars burns bright as we celebrate and remember our relentless champions of hope.



FightCRC.org/NWTS

Guide in the *Fight* Meetups

**SECOND &
FOURTH TUESDAYS**

Online

Whether you have just been diagnosed, are receiving treatment, or are supporting someone who is facing colorectal cancer, Fight CRC's meetups are a safe and compassionate place to talk to people who have similar experiences to yours while learning about resources available to you from Fight CRC and partners alike.

These free online gatherings are for people affected by colorectal cancer seeking access to resources and peer-to-peer support.



FightCRC.org/Meetups

Put a Blue Star on Your State

**BEGINNING
DECEMBER 2022**

Online

Get your state to participate in Colorectal Cancer Awareness Month this March by asking your governor to issue a state proclamation or letter of support! Proclamation materials will be available in early December.



FightCRC.org/Proclamations



ADVOCATE ADVICE

"Don't wait! Get your state's proclamation process started early, or you may miss the submission deadline. Fight CRC has made it easy to get started with their step-by-step toolkit."

Tim McDonald, stage IV survivor and Fight CRC Ambassador

Time to Flex a #StrongArmSelfie

Support Fight Colorectal Cancer by snapping a #StrongArmSelfie.

Each post, retweet, or share of a #StrongArmSelfie sends \$1 to Fight CRC!



Here's How it Works

Take a "selfie" while flexing your best "strong arm" pose. (If someone takes the picture for you, that's OK too.) Then, post it to social media using the hashtag **#StrongArmSelfie** and tag us **@FightCRC** so we can share!




Office of Cancer Health Equity
@WFCancerEquity

Thank you to Sean from the Office of @PatrickMcHenry for meeting with @FightCRC #NorthCarolina advocates, survivors, and #RelentlessChampions of Hope to increase @DeptofDefense and @theNCI funding to #PrioritizeCRC! @JJSingleton1 @jennyhg116 #StrongArmSelfie #CallOnCongress



CONNECT WITH US ON SOCIAL MEDIA

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Groups

Fight CRC's
Climb for
a Cure

ADVOCATES
at Fight
Colorectal
Cancer

“Not only are we relentless champions of hope, but no one ever fights alone. That’s who we are: We are Fight CRC, and we are a family. We are better together.”

—TERI GRIEGE, STAGE IV SURVIVOR AND BOARD MEMBER

Your support is essential as we relentlessly fight for informed patient support, impactful policy change, and breakthrough research endeavors.

ONLINE

Give.FightCRC.org or email **rebecca@fightcrc.org**

CHECK

Address your check to “Fight Colorectal Cancer” and mail to 134 Park Central Square #210, Springfield, MO 65806

CALL

(703) 548-1225 x10

STOCK & ESTATE

To learn about setting up estate planning and stock giving, please contact Michell Baker at (703) 407-7534 or **michell@fightcrc.org**

SHOP

Shop.FightCRC.org

IN-KIND

To donate products for our events and care packages, contact Natalie Keiser at (703) 548-1225 x17 or **natalie@fightcrc.org**

EMPLOYER MATCHING PROGRAM

Thousands of companies participate in employee matching programs. To learn more about how you can get your employer to match your donation, visit **FightCRC.org/Ways-to-Give**.

Fight Colorectal Cancer is a 501(c)(3) organization and contributions are tax deductible to the extent allowed by law.

Fight Colorectal Cancer has received high rankings for our streamlined, outstanding financial processes from several groups who watch for proper oversight of donations. To view our 990 reports, visit [FightCRC.org/Donate](https://fightcrc.org/Donate)



This past August, we hosted our seventh-annual Climb for a Cure.

More than 400 relentless climbers explored new terrain, and raised awareness and money for life-changing research.

Thank you to these champions who volunteered as Climb hosts and led an event in their local areas!



TYRO, VIRGINIA

Dwayne Coleman

Diagnosed with stage III colon cancer in 2020 at age 55.

ETLAN, VIRGINIA

Erin Darbouze

Fight CRC's Health Policy Manager. Lost both parents to colorectal cancer. Her mom passed away when Erin was 23 and her father died when she was 26.



ACCOKEEK, MARYLAND

Cheryl Alston

Diagnosed with stage II colon cancer in 2013 at age 56.



BOZEMAN, MONTANA

Michael Coleman

His father, Dwayne, was diagnosed with colon cancer (and he hosted the Tyro, Virginia Climb!)



BURNSVILLE, NORTH CAROLINA

Joe Bullock

Diagnosed with stage III colon cancer in 2018 at age 50.

JJ Singleton

Diagnosed with stage IV colon cancer in 2015 at age 27.



BAY AREA, CALIFORNIA

Mary Beth Kropp

Her husband was diagnosed for the second time with colon cancer in 2020; he passed away in 2021.

Jerianne Gerloff

Her ex-husband, Phil Gerloff, the father of their two sons, was diagnosed with metastatic colon cancer in 2018.

Natalie Mologne

She supported her boyfriend, Alex, and his family, as his father, Michael, battled colon cancer.



BAILEY, COLORADO

Ryan Vieth

Diagnosed with stage III colon cancer in 2019 at age 47.



OLATHE, KANSAS

Michelle (Mel) Harris

Fight CRC's Volunteer and Events Manager. She oversees Climb for a Cure and works with volunteers within the Fight CRC community.

Traci Bryan

Her husband, Kevin, was diagnosed in September 2016; he passed away in 2021.



HOUSTON, TEXAS

Paula Chambers-Raney

Diagnosed with stage I colon cancer in 2015 at age 44.



LAKE GEORGE, NEW YORK

Wendy Harpp

Diagnosed with stage III colorectal cancer, during a routine colonoscopy, in 2019 at age 55.



LEARN MORE

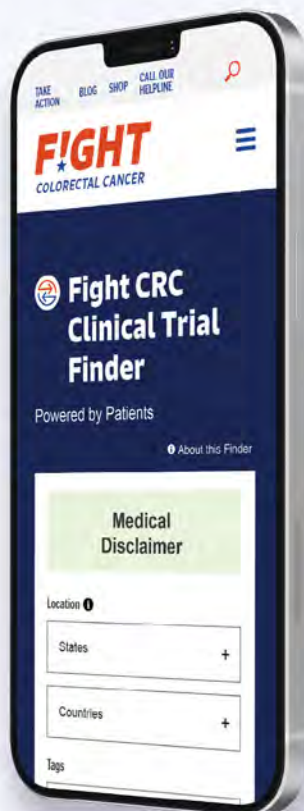
Scan to learn more about the Climb, how to become a Climb host, and how to start planning for next year's event.

46,500+

Searches for clinical trials and providers ... and counting.

The Trial Finder is a one-stop place to search for and learn about high-impact research studies for colorectal cancer patients.

One click away from the Clinical Trial Finder is the Provider Finder, a digital tool that helps patients find oncologists, radiologists, surgeons and gastroenterologists.



Search for Clinical Trials at
TrialFinder.FightCRC.org



Search for Providers at
ProviderFinder.FightCRC.org

