

Living Longer with Cancer: Rethinking Survivorship
SWW Season 6 Episode 4
Transcript Script FINAL

TINA DEIGNAN:

It's like this ongoing battle with cancer. We're improving our screening, we're improving our outcomes, we're improving our treatments. But cancer's trying to beat us. It's increasing in numbers, it's going younger and making it more challenging.

RAVEN: All season we've been talking about the efforts and innovations that have changed the way we define, test for, and treat cancer – and we've gotten a glimpse at what the future might hold.

Right now, we are witnessing the intersection of great achievements, but also new challenges in oncology—and doctors, researchers, and organizations are rising to meet the moment.

TINA DEIGNAN:

We now have a whole other set of issues and complications to deal with from a patient perspective, because it's now about a longer term survivorship. And how do you navigate that journey on the long term for patients?

RAVEN: Tina Deignan is the Commercial President of Pfizer Oncology.

TINA DEIGNAN:

Every year we hold an annual event where we bring together patients and patient advocates across many different types of cancers.

RAVEN: During an advocacy event Pfizer hosted last year, Tina found herself sitting at a table with a group of patients and patient advocates, talking to them about their experiences and long-term survivorship.

TINA DEIGNAN:

I was really struck by how they described how a patient journey has evolved from 20 years ago.

RAVEN: Twenty years ago, a diagnosis of metastatic cancer — often called stage IV, carried few effective treatment options. Metastatic cancer means the disease has spread from its origin point to other parts of the body, usually making it more complex to treat.

TINA DEIGNAN:

The community rallied around them, their family rallied around them, everybody came to help that patient because it was almost like an emergency.

RAVEN: But as Tina listened – and as the conversation unfolded – it became clear that this experience has changed. For many with cancer, the journey looks very different.

RAVEN: For certain cancers, the experience has shifted from a short-term emergency response, to a much longer journey. People are more likely to be diagnosed earlier, treated earlier, and then go on to live longer.

TINA DEIGNAN:

Roll the camera forward, we're now talking about a 70% five-year survival rate.

This is an incredible shift. In the 1970s, the five-year survival rate across all cancers in the U.S. was 50%. And today, as Tina mentioned, it's 70%.

In fact, more people are living with and beyond cancer than ever before. And that's a sign of progress – driven by real gains in survival.

But with that progress comes a new challenge: When cancer becomes something you live with longer, finding the right support becomes harder - not easier.

TINA DEIGNAN:

It's now 5, 6, 7 years on, and it's just hard to sustain that level of support. And so they struggle, they struggle with being able to maintain the level of support that they still need on their journey because they're often still going through treatment, still dealing with complex issues and now maybe dealing with newer issues that they didn't deal with in the early stages because of the longer term journey and the emotional and mental health implications of being on that journey for such a prolonged period of time. And I found it really humbling because it really just struck me how much more we have to do and how many different ways we now need to think about supporting patients.

[theme music in]

RAVEN: That word – humbling – really stuck with me. Because living longer with cancer shouldn't mean navigating it alone.

RAVEN: I'm Dr. Raven Baxter. a.k.a., "Raven the Science Maven!" I'm a molecular biologist and science educator, and I'm the host of Science Will Win.

This season, we're exploring some of the most urgent and complex topics in cancer today. The innovations, new frontiers and big unanswered questions.

In this episode, we're talking about what cancer survivorship – the process of living with, through and beyond a cancer diagnosis – means today, and the holistic support that is needed to help patients continue to live longer and better-quality lives after a cancer diagnosis.

[theme music out]

We often think of cancer as a thing to "fight" and "beat". Of reaching a finish line: ringing the bell, closing the chapter, moving on. But that isn't really the end for all patients. The effects of cancer – physical, emotional, and even societal – can linger.

I want to be clear that when we talk about survivorship, we're describing a multitude of different experiences that can look very different from person to person.

Some people who identify as cancer survivors are living with long-term side effects from their cancer treatment. Some are still in treatment, managing it like a chronic illness. Others are in remission, with no

detectable disease, though they still face the possibility of recurrence. And for others still, the word “survivor” doesn’t fit for them. It’s not how they want to define their experience.

Today, we’re going to explore how these different types of survivorship are becoming more common. And what doctors and support organizations are doing to help people through this phase and address their new and complex needs.

RAVEN: As survival rates increased, and more people began living with cancer – and beyond it – our care systems were forced to catch up to a new reality.

SHELLEY FULD NASSO:

The phrase I like to use is, it's not over when it's over. So the treatment is over, but cancer's not over.

RAVEN: That’s Shelley Fuld Nasso, the CEO of Cancer Nation — the oldest cancer survivor-led non-profit organization in the United States.

We hear about the five-year survival mark all the time. But it can be deeply misleading. A five-year survival rate doesn’t mean cancer is cured, or that there won’t be recurrence. The five-year benchmark dates back to the 1930s, when surviving that long was rare. Over time, it became a major clinical benchmark for cancer research studies – but culturally, it took on a meaning it was never meant to carry.

SHELLEY FULD NASSO:

Survival rates are also dependent on how advanced a cancer is, when it's detected, and how well we're treating it. Somewhere along the line, we've had this idea that if you hit this five-year mark, you're home free. And that's not the case.

RAVEN: This is one of the reasons Cancer Nation believes that survivorship doesn’t begin when treatment ends. Instead, they define survivorship as beginning the moment someone is diagnosed and lasting the rest of their life.

When Cancer Nation was founded, it was called the National Coalition for Cancer Survivorship – or NCCS. It began in 1986, when a group of people from different walks of life - doctors, nurses, lawyers - got together for a weekend in Albuquerque, New Mexico. They all had one thing in common: they had survived cancer. At the time, they were considered to be “victims” of cancer by the general public, the media, and often by the medical community. But this word didn’t feel right to them... it didn’t encompass how they felt about their cancer journey.

SHELLEY FULD NASSO:

There was no help for life after cancer at that point because people weren't living after cancer, and they decided they didn't wanna be considered victims. So they decided to create the organization, National Coalition for Cancer Survivorship, and to coin the term survivor.

RAVEN: At the time the founders coined the term “survivor”, cancer had a certain stigma. The language shift contributed to a larger survivorship movement that took away some of the societal fear of talking about cancer and how people who’d survived cancer were viewed.

SHELLEY FULD NASSO:

And they thought about how do we wanna be perceived? How do we perceive ourselves? And they knew they'd been through something really difficult in terms of their cancer treatment, and

they decided that Survivor was really the best way to describe it. But they also recognized, we don't wanna say you have to finish treatment to be a survivor. And that's why they said, we're going to consider someone a survivor from diagnosis through the balance of life.

And they really started the survivorship movement.

At the same time, we know that not everybody loves that word. And we believe everyone should identify however they want.

RAVEN: Language is powerful and it drives cultural change. The term “survivor” helped transform how people talked about cancer. Bob Riter experienced this shift:

BOB RITER:

In general, it's much more open than it was 30 years ago. People are much more open about sharing cancer, their own cancer stories, and to say that they've had cancer, i think that's probably due to the fact that people are living much longer. When I grew up, you know, I knew kind of distant family members who probably had cancer, but it wasn't discussed much back then... And today a lot of people survive cancer. They live with cancer as a chronic disease.

RAVEN: Bob was diagnosed with breast cancer in 1996.

BOB RITER:

My initial reaction was simply being stunned. I was shocked that I had cancer, but to have breast cancer was even more stunning. And when I would tell my family and friends, you know, they all had kind of the same reaction.

RAVEN: Only 1% of breast cancer cases are men — although rare, it still happens. About 2,800 men in the U.S. are diagnosed with breast cancer each year.

BOB RITER:

I had this very, very surreal moment when I had my date book and I wrote down mastectomy. And I remember, you know, August 30th, 1996, mastectomy.

At the time of his diagnosis, Bob taught healthcare administration at Ithaca College.

BOB RITER:

Actually my mastectomy was scheduled for the very first day of classes that semester... and I knew I'd be out for about two weeks.

RAVEN: His diagnosis put everything on pause. Once Bob recovered from his surgery, he spent six months in chemotherapy all while still teaching.

BOB RITER:

When I finished the chemo, that was actually my hardest time, which is a little bit counterintuitive because you think when you finish treatment, it's a time of celebration. Like you finished the hard part. But when I finished the chemo, they patted me on the back and said, Bob, you're doing great. We'll see you in three months. And they kind of thrust you back into the world. And you have to make that transition from being a cancer patient back to your regular life. And that, that doesn't happen overnight.

RAVEN: This transition back to “normal life” is challenging and can feel sudden, because cancer is an experience that can completely *change* someone’s life.

At Cancer Nation, they know intimately the ways that going back to day-to-day life isn’t always possible. Here’s Shelley again:

SHELLEY FULD NASSO:

Our former CEO Ellen Stovall was a three-time cancer survivor and an incredible advocate. And she would describe it as being dropped into a foreign land without a map and no way to navigate. And she was really one of the leaders who helped, uh, work with the Institutes of Medicine at the time. Now called the National Academies of Medicine, in a report that came out in 2006 called “Lost in Transition”, that really underscored the problems that cancer survivors faced in making that transition from treatment to post-treatment life.

RAVEN: In 2006, the Institute of Medicine released a landmark report called *Lost in Transition*. It highlighted how many people were left without guidance once treatment ended.

One of its key recommendations was that every patient should receive a survivorship care plan. A survivorship care plan is meant to serve as a roadmap - summarizing treatment history, outlining follow-up care and guidance on things like exercise and rehabilitation, and flagging long-term risks that may not appear right away.

The goal is to make sure care doesn’t end when treatment does, and that patients aren’t left to navigate what comes next on their own. But survivorship isn’t one-size-fits-all. Ideally, each plan is customized to the patient and their medical history.

In Cancer Nation’s annual survivorship survey, patients who received survivorship care plans tend to report feeling more confident about navigating long-term care.

SHELLEY FULD NASSO:

The experience of having cancer and having to confront your mortality, even if you have a very good prognosis. From every cancer survivor I’ve talked to, it just changes your outlook on life overall. And there’s a lot of positives that come out of it in terms of gratitude, maybe rethinking priorities, appreciating life more, but also a lot of challenges that can cause issues with relationships, isolation, and loneliness and fear and... that fear of recurrence can really be debilitating for some people.

RAVEN: People who have had cancer experience higher rates of anxiety, depression, and post-traumatic stress than the general population. There are also cognitive effects, financial strain, and chronic fatigue, all of which can linger long after treatment ends. For Bob, it took six more months after treatment to get back to feeling “top speed” as he said.

BOB RITER:

My biggest side effect was just fatigue.

I was still working about three quarters time. You know, I’d go to bed early at night.

RAVEN: At the time, perhaps these side effects weren’t visible to his students or colleagues, but they were constant, and they followed him back into a part of life that many people living beyond cancer are expected to simply resume: work.

RAVEN: Work is often treated as a practical concern - income, insurance, benefits. But it's also about purpose and normalcy.

REBECCA NELLIS:

There are so many additional reasons that people work.

It is part of their identity. It's how they contribute to the world. It's how they feel whole, it's how they have an escape from being a full-time patient.

RAVEN: Rebecca Nellis is the Executive Director at Cancer and Careers, the only US-based organization that focuses on the intersection of work and cancer.

That intersection can be especially complex for younger people impacted by cancer.

BOB RITER:

When you're diagnosed makes a big difference. And if you're diagnosed at 40, it's very different than being diagnosed at 70.

And how you deal with it depends so much on, you know, the biology of the cancer, your own age, your own family situation.

RAVEN: Bob was 40 when he was diagnosed with breast cancer. This is typically an age when many people are building careers, raising families, and planning decades ahead... when a diagnosis abruptly changes everything.

For Bob, cancer reshaped how he thought about time - and how he wanted to spend it. His diagnosis was a catalyst for deeper reflection about the kind of work he wanted to do with this new perception of time, which eventually led to a career change.

BOB RITER:

When I was first diagnosed, it really did change that time perspective. And one thing that sort of solidified that was when I took a new job and I had a retirement account and had options like where to put my retirement funds and should I invest in the long term, which I always did, but suddenly my future was less certain. So maybe I should invest, not for the long term, but for the short term. And that was like such a concrete illustration of my changing timeframe.

At Cancer and Careers, Rebecca Nellis sees people living with cancer consider changing jobs often and she attributes it to two main causes. The first is a search for work that feels more meaningful. The second is to accommodate a change in the person's capacity.

REBECCA NELLIS:

The cancer experience is a moment to ask themselves, is this how I wanna spend my time? Is this the most meaningful thing to me? I have a different appreciation for what my time means now than I did before my diagnosis. What do I want to do with that? We caution people not to assume that immediately means go start a or work for a charity or work for a cancer organization. That may be what you decide, but meaning comes from a lot of different things for people.

RAVEN: That was the case for Bob. Returning to work wasn't about pretending nothing had happened... It was about deciding *what mattered now* – and letting that guide what came next. For Bob, cancer advocacy, community, and education became the center of his work.

BOB RITER:

After I was diagnosed, I got involved in cancer support. I was a client and a volunteer, and then a board member of the local Ithaca Breast Cancer Alliance. But then I began to work there and I joined them as the associate director. And I was the executive director for like 18 years, that was my work, was really local cancer support. And I love that work. I loved working with people who were newly diagnosed, um, to make them a little bit less scared. I really enjoyed kind of sharing what I've learned and kind of translating information and getting the right information to people in the right way at the right time.

RAVEN: Bob's story shows one possible path - finding new meaning through work. But for many people, the challenge isn't meaning. It's capacity - and how that capacity is perceived at work.

Rebecca says that long-term side effects can change what work is possible, at least for a time. But that doesn't always mean leaving a career behind. Often, it means rethinking how work gets done.

REBECCA NELLIS:

One of our big cautions with employers, with healthcare providers and with individuals in their families is don't fall prey to the misconceptions. Get underneath it and figure out what the issue is, what the job demand is that can't be done anymore. Can it really not be done? Could it be accommodated? Is there another job in the same sphere that could be done?

RAVEN: To explain what that can look like in practice, Rebecca often uses a helpful example.

REBECCA NELLIS:

Is that firefighter, uh, an urban firefighter or a forest firefighter? Does that firefighter drive the truck or does that firefighter go into the burning building? Is there a piece of equipment that has to be driven to every fire call, but 95% of the time isn't used? Can that person drive that piece of equipment? Like that's the level of granular.

RAVEN: It can be about accommodations, adjustments, and reimagining roles rather than abandoning them.

But before any of that can happen, many people living with cancer face an even harder question: what do I tell my employer?

Disclosure can be one of the most anxiety-producing moments people can face at work.

REBECCA NELLIS:

My hope is that systemic change is possible as more companies want to be more supportive work environments, they want to have cultures that feel safe enough to disclose that information.

It needs to be a much more infused conversation in a company how we support you, where you might get access to something. And managers need to be trained because at the end of the day,

the manager is the person who's going to be the frontline of how the company culture gets interpreted to its employee base.

RAVEN: Trust is key to feel safe about disclosing a personal diagnosis. When cancer interrupts a person's life, work can actually become a refuge. A place where they can focus on something normal, even in the middle of treatment.

But sometimes, you may encounter an awkward conversation with a coworker. For those moments, Cancer and Careers teaches a specific technique called the swivel.

REBECCA NELLIS:

The example we use, and it comes up in a lot of different variations, is someone who has disclosed being in the office one day and someone coming up to them and saying, you know, my uncle Greg had cancer too.

And what are you supposed to do with that? You're at work to be away from it potentially, right? Like, that might be your frame, but you can't ignore that and you don't wanna have a long conversation about Uncle Greg either. And you don't wanna be the all-knowing cancer person.

So the swivel's really handy for something like that too because you can say, wow, I'm so sorry to hear that. I'm sure it was really difficult. While I have you, I'd like to talk about the part of the meeting that we're presenting together because I have a couple of ideas for how we might build our slides. Now it's gonna be really hard to go back to Greg because you've moved the conversation on to work. But if you don't do the rest of the swivel and you just say, I'm so sorry to hear that, that must have been really quite hard.

What is that person gonna do? They're gonna tell you how hard it was and you don't wanna carry that necessarily, right? Someone else might be fine with it. Like everyone is different. These tools are for the people who don't want to sit in that space.

RAVEN: If a hiring manager or recruiter asks about a resume gap, Cancer and Careers suggests using the swivel technique as well.

REBECCA NELLIS:

The way the swivel works is you acknowledge the question so that you're not just ignoring the fact that someone says, "oh, I see you have a gap on your resume."

You know, "what's that about?" And it could be something like I was dealing with the family issue. It could be I realized that my last role wasn't really what I wanted to do. But the trick of the swivel is you don't stop there. You, they then say, 'and' you move the conversation to something that shines a light on your skillset or the job or your interest in the job or something that would be relevant. Because for most people, they're gonna pick up on the last thing you said, not the first thing you said.

RAVEN: For some people, disclosure is a choice they want to make. It can help normalize cancer – and reclaim control of the story.

Bob decided to disclose his breast cancer diagnosis to his students during the semester he was going through chemotherapy.

BOB RITER:

I was very open with my students because I wasn't sure if I'd lose my hair or how I'd be at teaching that semester. So I thought, well, I'm just gonna be open with them. And it was fun because even those people who sat in the back row with their baseball caps pulled down, they kind of perked up and they listened. And they were very engaged. Many of them may not remember what I taught them in terms of the content of that class, but they probably remember my cancer journey.

RAVEN: What Bob was doing, maybe without even realizing it, was making a choice about how his cancer showed up in the room.

Cancer and Careers encourages people to think about disclosure as narrative control.

REBECCA NELLIS:

There's very little of a cancer journey that you control that's yours. One of the things you can control is your story.

Who you share that with, who gets to know that about you, what you want them to know, how you wanna frame it, that's yours. And I think in circumstances where you don't feel like you have much control, owning your narrative becomes even more important. And it is part of your identity whether you wanted it to be or not. And so how you let that influence your identity and how you present yourself to the world is a place that you get to decide.

RAVEN: Survivorship support looks very different depending on the kind of job someone has. Remote flexibility, paid leave, and accommodations are far easier to offer in some industries than others.

That's why these issues aren't just the responsibility of an individual – they're societal and systemic. Cancer Nation has been working on partnering with patients to share their stories with their members of Congress and advocate for policy changes that can improve the cost and quality of patient care, which includes survivorship care plans. Here's Shelley again:

SHELLEY FULD NASSO:

We have long advocated for reimbursement for survivorship care, including survivorship care plans, and that is part of the work that we do on Capitol Hill and advocating for cancer care planning.

RAVEN: The Comprehensive Cancer Survivorship Act is a federal legislation that was introduced in 2023. It's meant to improve long-term care for cancer survivors, from treatment planning and follow-up care to transportation, childcare, and employment assistance. The Act is an effort to make long-term survivorship care more standardized and supported by the health system. This would expand access and address the holistic needs of people beyond diagnosis and treatment.

There are some cancer centers that offer robust survivorship programs, but they often rely on philanthropy to fund their efforts. This means that access to this kind of care depends on where someone is treated and what resources exist there. Shelley gave me an idea of the type of care a well-rounded survivorship program can include.

SHELLEY FULD NASSO:

So diet, nutrition, exercise, mental health support, support groups, reiki and acupuncture and, you know, a lot of supportive services that help people during and after treatment. And that kind of thing really only happens with philanthropic support. And that's the kind of thing that all cancer survivors could benefit from. But not everyone has access to.

RAVEN: The factors that influence whether someone has access to comprehensive survivorship care are likely the same ones that determine who even gets access to early screening or treatment for cancer. We know this because the 70% five-year survival rate across cancers that we're seeing today is *not* equally distributed.

Here is Tina Deignan, Commercial President of Pfizer Oncology, again:

TINA DEIGNAN:

Racial factors, geographic factors play a significant, contributing role. And that's often associated with the access to care and the likelihood of screening, like the likelihood of screening is so critically important. And that is not consistent across all populations, both from a racial perspective and ethnic perspective, from a geographic perspective, and also sometimes from a gender perspective.

RAVEN: When it comes to racial disparities, it can mean that people are getting diagnosed too late.

TINA DEIGNAN:

So Black women and men are more likely to be diagnosed with breast and prostate cancer. They're also more likely to be diagnosed at a later stage of their disease and therefore have poorer outcomes, and therefore more likely to die from cancer.

RAVEN: And if people do get diagnosed early enough, where they live or where they can travel to is also vitally important because most people don't live near a major cancer center with adequate treatment.

TINA DEIGNAN:

So geography plays a very important role, when you think about the fact that 20% of rural Americans live more than 60 miles from an oncologist.

So right there you have, um, a real block in terms of their ability to access the kind of care that they need to achieve an early diagnosis and then to get the kind of care they need throughout their journey.

RAVEN: That's why in 2024, Pfizer sponsored a program with the American Cancer Society. The program is called *Change the Odds* and it addresses these disparities. By expanding access to screening and care, it aims to improve cancer outcomes in underserved communities.

TINA DEIGNAN:

*This is an area where we have spent a lot of our time as Pfizer investing and in partnering with the American Cancer Society, for example, on our *Change the Odds* campaign. And that's what that's focused on, is trying to reach different groups that may not be accessing care to the same degree with education about screening, with information about how to navigate the situation. And this is also often connected to helping navigate their insurance pathway, which gets very complicated as you go through a cancer journey and gets very expensive. And helping patients figure out what are the tools and resources that are available to them.*

RAVEN: Expanding access to early screenings and care can help tackle the inequities we see in survival rates for underserved communities. More broadly, public education and guidance can help more people navigate their cancer with greater clarity and confidence.

When Bob was 65, he was diagnosed with cancer again – this time, it was prostate cancer. It had been over two decades since he had been diagnosed with breast cancer.

This time around, he was able to access more information that helped him understand his cancer, in large part thanks to resources available on the internet.

BOB RITER:

So it was much easier to track down information, also to have ready access to it. I remember 30 years ago during breast cancer, some of the information I found was in the form of paper. I mean, articles literally ripped out of magazines and put into a file. So you could go through, through files and find stuff. But today you can just go online and find so much information. Actually a lot of what I do is to help people find good information. 'cause you know, there's so much stuff out there on the internet. And yes, the majority isn't very helpful, but some resources are terrific. So you gotta guide people to the right ones.

RAVEN: Bob was able to receive radiation to treat his cancer. Through social media, Bob also met other men with different types of cancer. It's become another space of support and community for him.

BOB RITER:

And we meet every Friday for breakfast. And we've been doing this for about 16 years. And so we have, you know, different types of cancer. We talk about cancer, but now we talk about aging too. And we all have aches and pains, and sometimes it's hard to know what's normal aging and what's something else.

RAVEN: Today, Bob works to connect researchers in training with people living with cancer in order to help scientists understand their lived experiences. It's work that's so important, especially as their journey with cancer continues to evolve and bring new challenges to the forefront.

BOB RITER:

Through the last 10, 15 years, I've worked a lot with cancer researchers.

And I primarily worked with doctoral students in the basic sciences who were doing cancer research. My focus was to get them outta their labs to meet real people with cancer. And it's remarkable. I mean, it's really good for the students 'cause it exposes them to the human side of cancer.

RAVEN: Innovation in cancer care isn't just about extending life. It's about improving the quality of life at every step in a patient's cancer – from screenings, to diagnosis, to treatment, to what follows. For many, survivorship means living *with* cancer: managing side effects, long treatment arcs, or uncertainty about recurrence.

For cancer care to continue to improve and meet these new and ever-changing needs, it's important to remember survivorship doesn't belong to a single person, or even a single institution. It sits at the

intersection of the industries Tina, Shelley, Rebecca and Bob all touch: medicine, policy, work, and community. Success in cancer care can't be measured by survival alone. It has to include dignity, support, and the ability to live fully.

For our next and final episode of this season, we explore the future of tech and AI, and their role in the fight against cancer.

JEFF LEGOS: I think the potential and possibilities from AI are, are limitless, and I think we're really just starting to scratch the surface as to what those possibilities are. And while those possibilities are limitless, I think it's really important that we're focusing on very concrete solutions that can really enable practice changing breakthroughs in the way we think about kind of the next wave of innovation for our medicines.

You know, it's, it's the holy grail if we could figure it out.

CREDITS

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Thank you for listening!
