“Navigating Cancer Survivorship" (Caroline Knudsen and Chasse Bailey-Dorton, MD) [#140]

Brad Power
April 25, 2025

“Nobody knows what it's like to hear the word ‘cancer’ or go through treatment unless you've been there. I've been there. Most times in life, you feel bad, you go to the doctor, they do something to make you feel better. For cancer, the treatment we get makes us feel worse than when the whole thing started.” – Chasse Bailey-Dorton, MD

“Survivorship has changed. We now have folks who are going to be on treatment for the rest of their life. Sometimes they feel like they don't fit in this paradigm that we have, but they're still dealing with a lot of the issues – these issues are not dealt with enough in our clinics and for our stage 4 patients.” – Chasse Bailey-Dorton, MD

“Cancer-free doesn't mean healthy.” – Caroline Knudsen

“My job is to load the boat with everything possible to help you without sinking the boat. Meaning: there's a lot of misinformation on the Internet. There's always somebody trying to sell you something. You face all your family and friends saying, ‘Well, I read this. You should do that.’ We have to make sure we're not interfering with the treatment that you have.” – Chasse Bailey-Dorton, MD

Meeting Summary

Cancer patients and caregivers face the often-overlooked challenges that survivors face, from lingering treatment side effects to emotional and lifestyle adjustments. In most cases, patients feel abandoned once active cancer treatment ends and lack guidance in their post-treatment journey.

Chasse Bailey-Dorton, MD, and Caroline Knudsen are uniquely qualified to talk about the challenges of cancer survivorship. Dr. Bailey-Dorton is the Co-Founder and Medical Director of The After Cancer. She's a 22-year breast cancer survivor, and has a background as a family practitioner and completed a fellowship in Integrative Medicine. She led the Integrative Oncology Department at Levine Cancer Institute (in Charlotte, North Carolina) for over a decade. She currently guides The After Cancer's clinical approach and is the Director of Survivorship at First Health in Pinehurst, NC. Caroline Knudsen is the Co-Founder and COO of The After Cancer.

Why do you need to pay attention to cancer survivorship?

Cancer patients and their loved ones face numerous challenges after treatment that are often overlooked. These include physical side effects like neuropathy and fatigue, psychological challenges such as fear of recurrence, and emotional struggles like feeling isolated or losing trust in one's body. Cancer-free doesn't mean healthy. Survivors need ongoing support to manage symptoms, address mental health, navigate life changes, and develop strategies to cope with the long-term impacts of cancer treatment. Paying attention to survivorship helps patients and their loved ones regain a sense of control, improve quality of life, and effectively manage the ongoing "elephant in the room" of cancer in their lives.

What are the main issues that cancer patients and their loved ones struggle with post-treatment?

- **Fear of recurrence**: the "elephant in the room" that never completely goes away.
- **Physical side effects**: neuropathy, fatigue, and changes in body function that persist after treatment
- **Emotional and psychological**: feeling isolated and lonely, loss of trust in your body, anxiety between medical scans, processing the trauma
- **Relationships**: changes in relations with partners, family, and friends, and difficulties in communicating about your experience.
- **Lack of ongoing support**: feeling abandoned after intensive treatment ends, with reduced medical team contact and limited resources for continued care

What knowledge and tools can help you navigate cancer survivorship with confidence?

- Curated, expert-reviewed information sources
- AI that is transparent (including sources, confidence, and limitations) to help filter and contextualize information
- Healthcare professionals and credible experts
- Peer support, group sessions with professionals, one-on-one chats
- Managing automatic negative thoughts

What are practical strategies to engage with cancer survivorship?

- Join groups that encourage discussion of practical coping strategies, empowerment, and problem-solving
- Involve your partners, as they may be more willing to attend and can help encourage participation
- Try journaling and gratitude practices
- Find safe spaces to discuss sensitive topics like sexual side effects or emotional challenges without feeling vulnerable

How can you learn more about supporting cancer survivorship?

- Find support groups focused on cancer survivors' experiences and specializing in cancer survivorship support
- Review related Cancer Patient Lab discussions:
    - “Healing the Cancer Journey: Tools for Emotional Wellness” (Savio P. Clemente) [#87]
    - "Palliative Care for Advanced Cancer" (Tom Smith) [#32]
    - “Navigating Cancer with the Mind as Your Ally” (Sheryl Anjanette) [#124]

“Navigating Cancer Survivorship" (Caroline Knudsen and Chasse Bailey-Dorton, MD) [#140]

    - “Navigating Relational Health Through the Challenges of Cancer” (Jason Binder) [#127]
    - “More than 60% of the Cancer Journey Happens at Home; Why No Comprehensive Support?” (Katie Quintas) [#115]
    - “Palliative and Psychosocial Services for Cancer Patients” (James Tulsky) [#85]
- Go to The After Cancer website, explore their services, and see how they might fit in providing services to meet your needs.

For the video recording of this conversation, please see here.

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Meeting Notes

KEYWORDS

Cancer survivorship, integrative oncology, fear of recurrence, patient support, integrative medicine, emotional adjustments, treatment side effects, non-profit organization, evidence-based therapies, virtual survivorship programs, patient isolation, scan anxiety, peer support, complementary therapies, healthcare system.

SPEAKERS

Rick Davis (30%), Chasse Bailey-Dorton (26%), Caroline Knudsen (17%), David Wheeler (12%), Raj Aji (5%), Alen Amini (5%), David Plunkett (3%), Brad Power (2%)

SUMMARY

The discussion focused on the challenges of cancer survivorship, emphasizing the emotional and physical impacts beyond treatment. Dr. Bailey-Dorton and Caroline Knudsen from The After Cancer highlighted their platform's role in providing personalized support, educational resources, and group sessions to address survivorship needs. They shared a six-week study showing reduced symptoms and depression, and increased normalcy. The conversation also touched on the importance of integrative oncology, the challenges of misinformation, and strategies to engage men in support groups. The After Cancer team expressed interest in collaborating with peer support groups to enhance patient care.

OUTLINE

Introductions, Challenges of Cancer Survivorship

- There are overlooked emotional and physical challenges faced by patients and caregivers, including treatment side effects, fear of recurrence, the impact of treatment on daily life, and emotional adjustments.
- Dr. Bailey-Dorton and Caroline Knudsen are experts on cancer survivorship.
- The concept of an "iceberg" illustrates the visible and invisible challenges survivors face.
- Integrative oncology is presented as a comprehensive approach to address physical, psychological, social, and spiritual aspects of cancer treatment.
- Addressing survivorship issues is required to minimize side effects, maximize recovery, and decrease the risk of recurrence.

The After Cancer

- The After Cancer was born to focus on the gap in support for cancer survivors.
- The organization aims to provide evidence-based answers to day-to-day questions and address issues like fear of recurrence, loneliness, and relationship changes.
- The After Cancer platform offers virtual survivorship programs, personalized support, educational resources, group sessions, and one-on-one chats.
- A six-week study measuring the impact of The After Cancer program is presented, showing reduced symptoms, decreased depression, and increased normalcy.

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- The After Cancer program has a subscription model which is also accessible through sponsorships and insurance.
- AI is having a big impact on getting and interpreting information. Navigating online information can be challenging, and ensuring that information is evidence-based.
- Patients and their loved ones have concerns about misinformation and a dose of skepticism is needed in navigating online resources.

Support for Caregivers and Families

- The After Cancer platform offers expert-led resources to help survivors navigate the evolving dynamics of relationships with family members and caregivers. Our focus is on supporting survivors through guidance from professionals in family therapy and relationship coaching. Please note that we do not currently provide services or support specifically for caregivers or family members.

Engaging Men in Support Programs

- The "Men Speaking Freely" group avoids the term "emotional" to attract more male participants.
- Journaling and keeping short notes can track treatment experiences and manage anxiety.
- The use of gratitude journals can help survivors focus on positive aspects of their lives.
- Ongoing support is needed for dealing with scan anxiety and recurring cancer.
- There are strategies for managing automatic negative thoughts and the importance of resiliency and cognitive restructuring.

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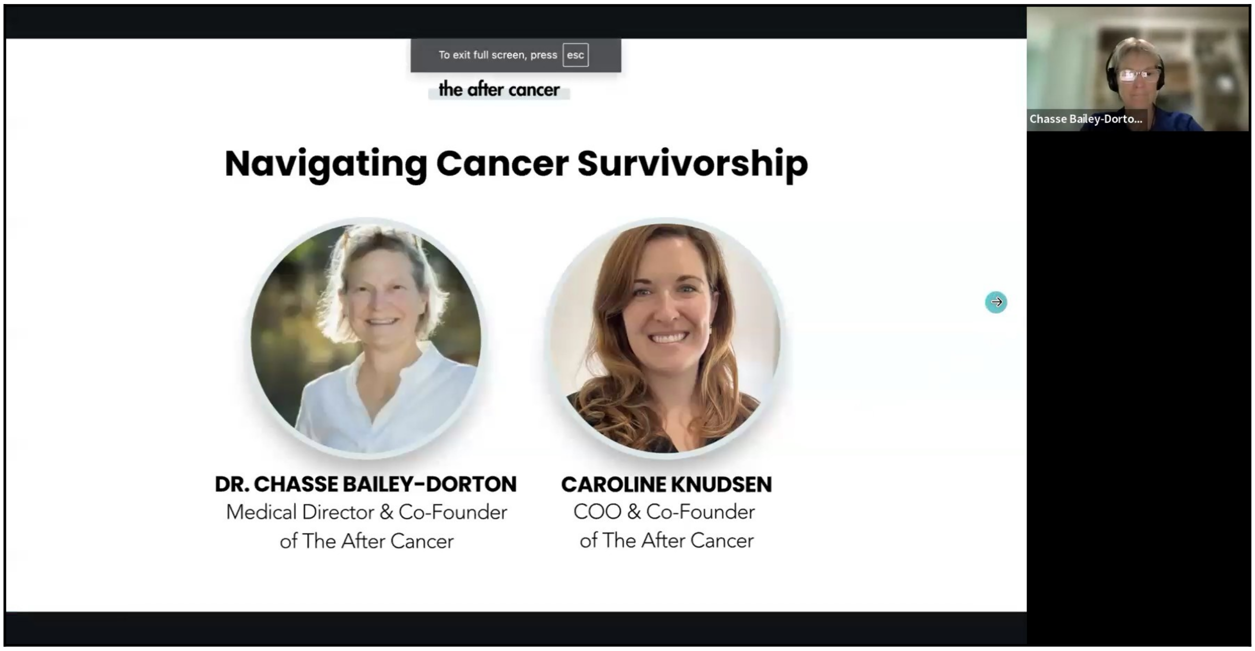
TRANSCRIPT

Alen Amini
We're really excited for the discussion that we'll have today, as I'm sure it's no secret to all of you, both patients and caregivers face often overlooked challenges, from treatment side effects, emotional lifestyle adjustments, and oftentimes, what that ends up doing for patients and their loved ones is invoking a feeling of abandonment. So we're very excited to have Dr. Bailey-Dorton and Caroline Knudsen here today who are uniquely qualified to talk about the challenges of cancer survivorship. Dr. Bailey-Dorton is the co-founder and medical director of The After Cancer. She's a 22 year breast cancer survivor and has a background as a family practitioner and completed a fellowship in integrative medicine. She led the integrative oncology department at Levine Cancer Institute for over a decade, and she currently guides The After Cancer’s clinical approach, and is the director of survivorship at First Health in Pinehurst, North Carolina. Caroline Knudsen Is the co-founder and COO of The After Cancer. So we're very excited to welcome them.

Brad Power 1:16
This conversation is for information purposes only. This is not medical advice.

We are a non-profit, 501(c)(3), and we depend on the kindness of people making donations. So if you're so inspired to make a donation, we would greatly appreciate it. It's easy to do if you go to our website and click on the Donate button.



the after cancer

Navigating Cancer Survivorship

DR. CHASSE BAILEY-DORTON
Medical Director & Co-Founder
of The After Cancer

CAROLINE KNUDSEN
COO & Co-Founder
of The After Cancer

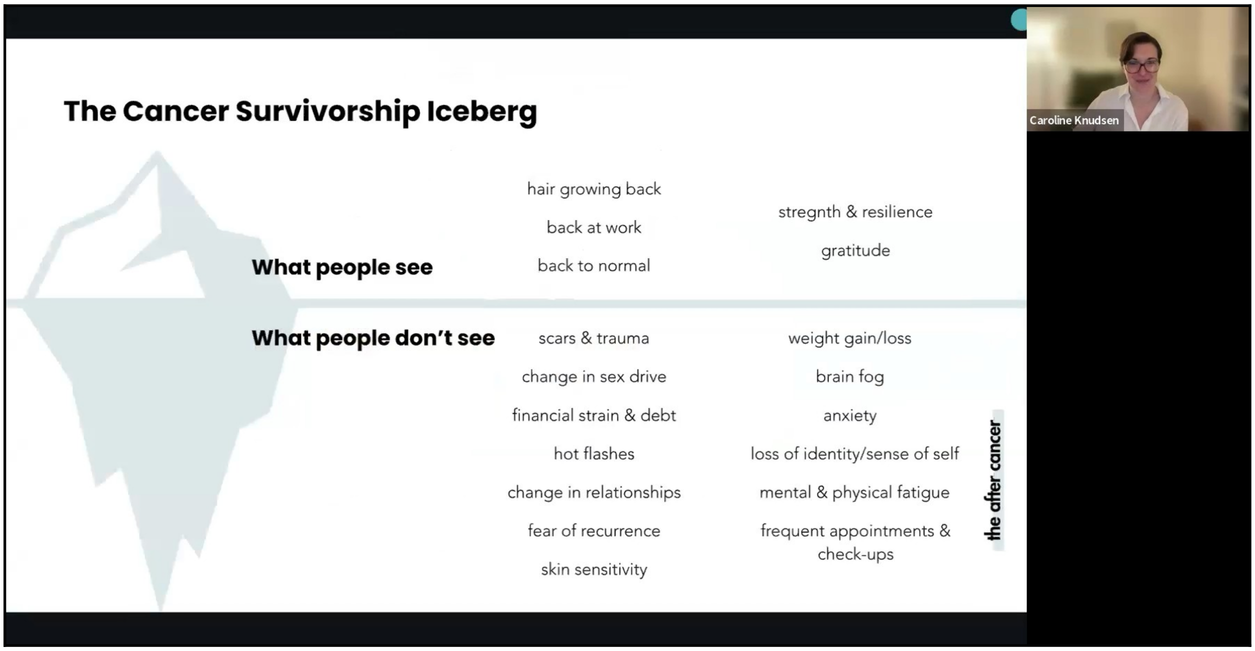
Chasse Bailey-Dorton 1:58
Nobody knows what it's like to hear the word “cancer” or go through treatment unless you've been there. I've been there. Most times in life, you feel bad, you go to the doctor, they do

something to make you feel better. For cancer, the treatment we get makes us feel worse than when the whole thing started.

We're always wanting to know, “What can I do? Is there anything I can do to decrease the side effects? Is there anything I can do to help my body fight this?”

As scary as it was at diagnosis, it's even worse when we get towards the end of treatment, the thoughts are: “I didn't know I had this.” “Is it going to come back?” “Why did my body fail me?” “Will I know if it comes back?” “Can I do anything to keep it from coming back?”

I went through those things myself, and that's what led me to an integrative medicine fellowship. When I meet with patients now, I tell them, “My job is to load the boat with everything possible to help you without sinking the boat.” Meaning: there's a lot of misinformation on the internet. There's always somebody trying to sell us something. They face all their family and friends saying, “Well, I read this. You should do that.” We have to make sure we're not interfering with the treatment that they have. We want to put that plan together.



The Cancer Survivorship Iceberg

What people see

hair growing back
back at work
back to normal
strength & resilience
gratitude

What people don’t see

scars & trauma
change in sex drive
financial strain & debt
hot flashes
change in relationships
fear of recurrence
skin sensitivity
weight gain/loss
brain fog
anxiety
loss of identity/sense of self
mental & physical fatigue
frequent appointments & check-ups

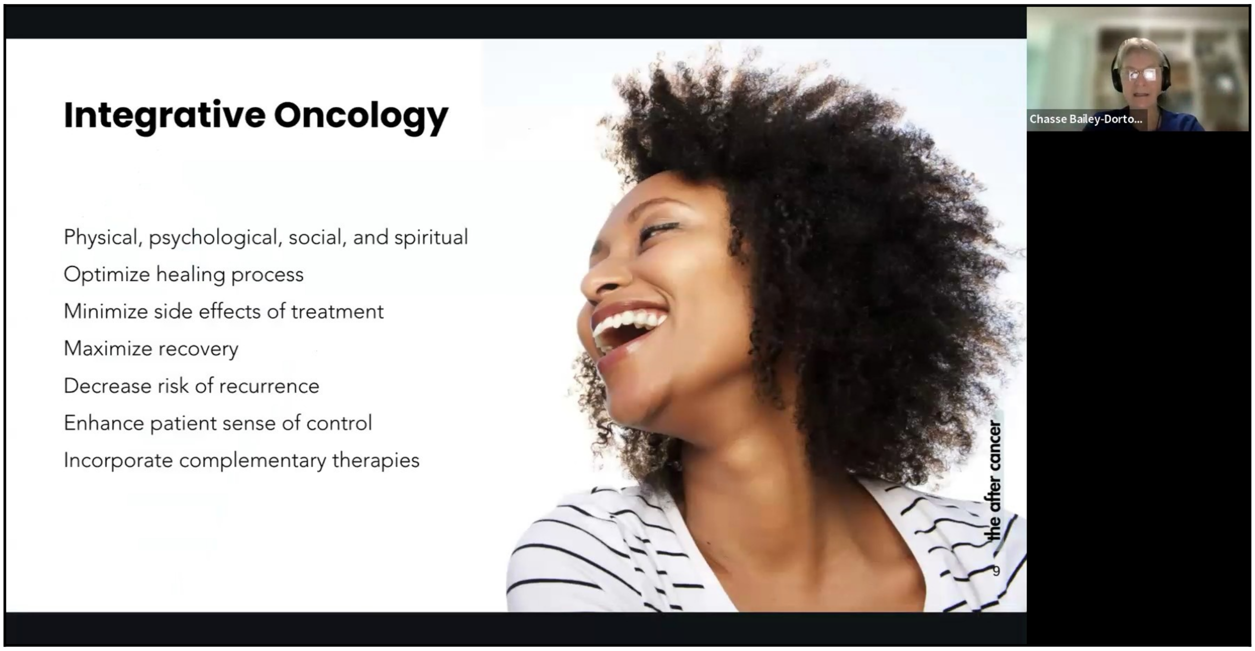
the after cancer

Chasse Bailey-Dorton 3:59
This is something we modified that I found on the internet. This talks about this iceberg. We get to the end of treatment, and what people say is, “Oh, your hair is growing back. You're able to go back to work. You're back to normal. You're so strong. Aren't you great?” But what they don't see is what we're dealing with underneath the water, underneath that iceberg, that fear, that feeling, where we'd been seeing our oncology team every four to six weeks, and now it's, “Well, I will see you back in three months or six months.” The neuropathy, the fatigue, the change in our body, the loss of trust in our body, and then this overwhelming fear of recurrence.

“Navigating Cancer Survivorship" (Caroline Knudsen and Chasse Bailey-Dorton, MD) [#140]

I always describe it as “cancer is the big elephant in the room”. I'm 23 years out, and the elephant is still here. It's small, and it's in the corner, and there are times it wants to grow, and a lot of survivorship is learning how to control this elephant when it wants to grow, and we've got to process through what we've been through.

Survivorship has changed. We now have folks who are going to be on treatment for the rest of their life. Sometimes they feel like they don't fit in this paradigm that we have, but they're still dealing with a lot of the issues – these things that are under the water and the iceberg – that are not dealt with enough in our clinics and for our patients.



Integrative Oncology

- Physical, psychological, social, and spiritual
- Optimize healing process
- Minimize side effects of treatment
- Maximize recovery
- Decrease risk of recurrence
- Enhance patient sense of control
- Incorporate complementary therapies

We mentioned integrative oncology. This is how we deal with survivorship. This is where integrative oncology starts, at diagnosis, getting in there and really addressing the physical, psychological, the social and the spiritual aspects of this patient. Many times when there are significant others in the room, I'll turn to them and say, “How are you?” They're like, “Well, no one's ever asked me that before.” How do we optimize that healing process? How do we minimize the side effects? How do we maximize recovery? How can we decrease the risk of recurrence?

There's a great analogy of mold in a basement. You cut the mold out, you radiate the basement, you maybe put chemicals on the basement, but if you don't change the basement, mold is more likely to come back. How can we help decrease that risk? How can we give some control back to that patient so that they know they're doing something? How do we incorporate evidence-based complementary therapies? This gap is where The After Cancer is able to come in and address some of these issues.

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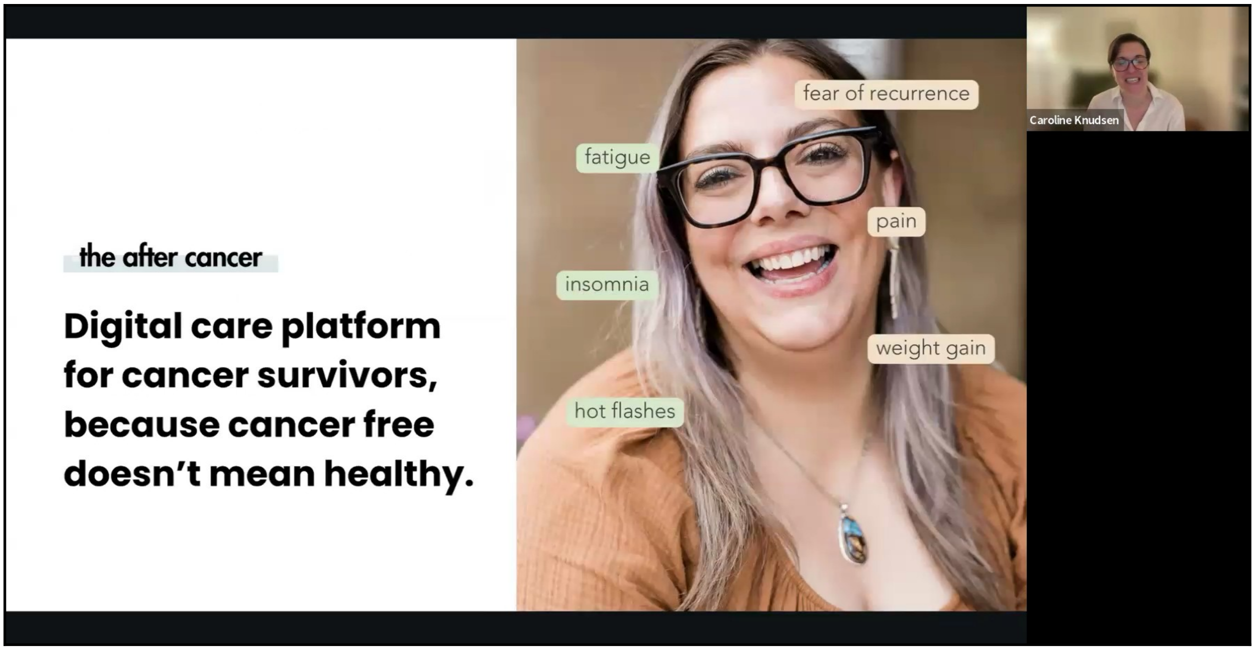

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Digital care platform for cancer survivors, because cancer free doesn’t mean healthy.

Caroline Knudsen 6:31
Cancer-free doesn't mean healthy, and that's what the birth of The After Cancer was from that realization and personal experience. And a clinician for Dr. Bailey-Dorton, as well as our co-founder and CEO, Marianna, who was a four time, eight times over, now cancer caregiver. So what do we do in this space after cancer, and how can we support in that gap? Because the consequence is, all of us know of better cancer treatment, which is brilliant, but it does mean that there's more diagnoses, there's younger patients who are being identified earlier, and there's longer and higher survival rates. And so there's an increasing population of patients with all those needs we talked about, what's kind of under, under the surface there in the iceberg image, and our healthcare system hasn't caught up to really support in that space, and so that's the gap that we're trying to help fill at The After Cancer. So this is a use case Mary, a 31 year old breast cancer survivor, but is just as true of all of the users who come to our platform, and this quote is really indicative of that experience as well. Is I'm more scared now than the day I was diagnosed, and it's really because in that space after treatment that really strong multidisciplinary team and support is gone, and patients are often having to navigate that alone. So what we're trying to do with The After Cancer is help patients like Mary find evidence based answers to those day to day questions of all of the things we just saw earlier, but here, more specifically, in this use case, questions about drugs you're taking post treatment, so things like tamoxifen, and the impact that that has on patients, what to eat, nutrition, what's safe, what's not safe, questions about feeling isolated and lonely. Loneliness is huge for people, and changing dynamics within relationships, and how to manage that. We talked about fear of recurrence, how to manage fear of recurrence and really help patients live in between scans, and manage scan anxiety when those moments of monitoring come up, and then to manage those frequent questions that come up around both the physical as well as the psychosocial things that that are sort of day to day needs for survivors. So we do that with our virtual survivorship programs I mentioned a little bit earlier. It's available in all 50 states. For us, it's really important increasing access to this kind of support. And so that digital first approach was was fundamental for us,

and these are sort of the core resources. So there's personalized support to give guidance to patients on what they should be exploring in their own journey and also based on their interests and their own concerns that they self report. There's educational resources that are sort of available asynchronously, so they can do this whenever and wherever is convenient to delve in and learn more. There are group sessions. So this works just kind of like a gym membership. There is something every day for them to attend in a group setting. And these are both complementary therapies and practices that promote well being, but also chats with experts. So we try to bring experts in as much as possible so that they can have that direct impact. And we're trying to manage also some of that, that fatigue around appointments, but still get those answers. Circles. There's what we call our communities. So we have patient communities on topics, and then finally, one to one chat. So really trying to help people stay away from the WebMD and the going to Google when they have questions and come to us where we have a group of 14. Between practitioners who are experts, who can get the answers they need in real time. So just important to note for us that measuring that impact has been something that's important for us as well. So this was a six week study we measured patients before and after participating and having access to these group based integrative approach resources, and the results are on the left. We presented this at SiO last year. Dr. Bailey-Dorton did, and in just the six week period, saw, saw this impact. So reduce reduce burden in terms of overall symptoms, decreased reported symptoms of depression and increased sense of normalcy. But really important is really the quote on the right from one of our patients, Lauren, who spoke to exactly what we saw earlier in the iceberg, you may look better, and there's an expectation that after treatment, you're really done, but that's just not the case. And so what we're really hoping to do is support patients in that in so many different ways, reported outcomes and otherwise. So that's really kind of what The After Cancer does. Dr Billy Dorton and I are here for questions and answers, and then just know that you can always reach out to us as well. We're thrilled to engage with this community and this ecosystem.

Rick Davis 11:50
What is the cost of the program?

Caroline Knudsen 12:07
So that is a good question. We have kind of two models right now. One is direct to patient, so it's available as a subscription model on a monthly basis, so 1499 to access to all of the resources, or an annual at 99 a year. But we've also been working a lot with nonprofit organizations and other organizations that are willing to sponsor groups of patients, because for us, sort of accessibility is fundamental, and so the more we can explore that, the better. I'd also mention we're really looking into ways that this can be included in terms of insurance. So are there ways that we can and find billable codes as well? So that's that's on our 2025, goals as well.

Rick Davis 12:48
So let me take let me take this off so you can see who you're talking to. Hello. This model. It's an interesting model, and obviously we'd love to learn more about it, at least. And can we'd love to know more about it, because it really complements a lot of what we're doing. We have a we

have a poster coming up. It isn't really we, I should say, one of our moderators, Ben Nathanson, was invited to the AACR conference in Chicago, which I think starts this weekend, on Sunday, and he was invited to present a poster, and the poster precisely hits on what you're talking about, which is the value of peer support. Well, not precisely, but it hits on the value of peer support in patient decision making, and it dovetails very much into what you're talking about, because a lot of integrative discussion exists in our groups, as well as a lot of really good technical information. An ex president of the AU a recently attended and sent us a quote and said we were comparable with with a tumor board at the center of excellence. That was his experience. But it's not just about the technical stuff. It's about supporting nutrition, exercise, stress reduction and all the integrative all the other integrative aspects complementary medicine that we're really committed to. So we really get what you're doing. Our model is free and drop in, because it was very important to us to create a peer support model. That have the lowest barriers to entry, because it's very important in our view, to get people to step over the threshold the first time, because if you can't get them in the first time, you're not going to get them back, right. And so and, of course, money, money and time are the two things that prevent that. So I really, I love what you're doing, and maybe there's a way that we can work we're a 501, c3, so maybe there is a way that we can work with you. We We cover a lot of different conditions and situations. We do a lot of mental health programming, so we should talk. So I will send you my email and you can reach out to me and and I love what you're doing.

Caroline Knudsen 15:53
Thanks. Looking forward to

Alen Amini 15:55
thanks. Rick David,

David Plunkett 15:59
you mentioned information and misinformation that patients find on Google and WebMD. Are you also seeing the same sort of thing from people who are exploring with AI? How

Chasse Bailey-Dorton 16:14
do you experience with that? That's an interesting concept. Is AI any better?

David Plunkett 16:23
It's I would say no. It depends on the questions you ask and how you ask and and how you use them as a starting point. But we've had at least one presentation on this group giving some examples of how people have had some success finding out new treatment ideas and exploring using AI. There's also a recent post where someone who is exploring using AI was able to make contact with some researchers of another type of cancer that turned out to share something in common with the cancer they were researching, and so they made a connection they probably would not have otherwise. So it's it's a wild and crazy online world out there, and finding guardrails and finding thoughtful and skeptical, and I'm running out of adjectives, but finding a way to navigate those tools is is something that is difficult for most of us. So guidance on that is helpful. That's

Chasse Bailey-Dorton 17:35
interesting concept. You know, from my experience to going from or even just introducing integrative oncology and survivorship in a large Cancer Center, and now trying to do it in a community hospital, this interesting road to travel that's uphill.

David Plunkett 17:53
The phrase that I like is that the quality of the answer depends on the quality of the question. I like that.

Raj Aji 18:13
From what David said, the misinformation and information that you might have on the internet, if you go to your oncologist, who are often associated with larger medical institutions, you get the standard of care types of answers. But then there is this information out there about off label drugs and those sorts of things. How do you manage questions like that, and work with inquiries like that?

Chasse Bailey-Dorton 19:02
For me, it's interesting, because I had a actually had a new patient last week who must have been on 40 different supplements, and just kind of going behind, how did you pick that? What's your reasoning behind that? And trying to find out what information they're basing those decisions on, gives me a good starting point, but it's tough sometimes.

Rick Davis 19:27
That raises a really good point, because we talk a lot about supplements. We had a pancreas cancer group last night, and a lot of the time the discussion was around Creon. We always, always say we're peer-led, although we do have some medical professionals who are usually peers. We say, if you take a supplement, run it past your practitioner. Run it past your quarterback. Don't just take a supplement. And your point, Dr Bailey, is that people don't do that. And they come in and they come in to see you, and they've got this list. Why? Because they saw this on the internet and that on the internet, and they can get it. They can get it, so why not add it in? Nobody ever thinks about looking at the Cross interactions. Nobody ever thinks that some of these supplements could stop another medicine work. Well,

Chasse Bailey-Dorton 20:37
exactly, exactly. Sometimes I used a simple one that everybody's heard about grapefruit juice and certain medications. Yes, you know it can make it is it making your chemo more toxic, or is it making it less effective? Yes, and we don't have the study. We didn't. We're never going to have a study on every supplement and every chemo medication out there, so we've got to use as much evidence as we can to try to make informed decisions.

Rick Davis 21:03
Yeah, and that CYPA 45 or whatever it is, pathway interferes with everything. And

Chasse Bailey-Dorton 21:11
then the problem is in a lot of the research, though, is done in a lab test, and then we know supplements or medications are differently absorbed by different people, so it's just so many layers of complications, yeah,

Raj Aji 21:24
Or the questions around fenbendazole And, oh,

Chasse Bailey-Dorton 21:33
I try to listen to as many podcasts and things that are out there, so when patients come in with these fringe ideas, at least have some idea what they're talking about. Can at least have a discussion with them? Because I think that's where the medical systems failed, is we've just said no, yeah, and not had an open discussion about why or what's out there.

Rick Davis 21:55
I don't know who that PR agent is for mebendazole and ivermectin. I sure would like to hire them for AnCan.

David Wheeler 22:08
Something in your presentation struck me, having been a caregiver to my son after a treatment, a lot of people were of the opinion that it was all over, and we could go back to normal. And I just wonder, curious. I love what you're doing for the survivors. Do you do any educational outreach to, I'll say the non-survivors in our in order to kind of educate people on this topic that, hey, this stuff doesn't just end, it doesn't go away. It’s always part of your life and how to maybe help people in that stage of their journey.

Chasse Bailey-Dorton 23:06
That's certainly a needed area. Right now, we're running a six week Mind Body course online for survivors, and one of the exercises we did last week and is called disclosure or journaling, where I have them write a letter to cancer, where they go through the anger, the sadness, the fear, the responsibility, and get all the way down to this, their love, wants and needs. And many times I've asked them to then take that letter to their family member or their partner who has been through this trauma too, to have them process because no one's there to help them process through what they've been through. They're often scared to say what they're really thinking to their family member, to the patient, and they need to process through this trauma just as much as the patient. But I think that is a needed area.

David Wheeler 23:56
Yeah, I'll just mention the fact that I have two other kids besides the patient and the area of siblings is a vastly underserved group of people. Yeah,

Chasse Bailey-Dorton 24:10
when I was in Charlotte, we did have one social worker who was trained to help those siblings in kid therapy, pediatric therapy, and I would fill her up. She went there. Was only there for a short

period of time, but I would fill her up with siblings and the other parents that had to deal with the siblings of what they're going

Alen Amini 24:32
through. Any other questions for Dr. Bailey-Dorton or Carolyn?

Rick Davis 24:38
So I'd like just to comment on what David said, we just had a guy this week come into for the first time to our advanced, high risk recurrent advanced prostate cancer group, 61 years old, and he has. This local he has metastatic prostate cancer. 13 year old kid. He's reaching out to us right now. How do I talk to my kid? I don't know how to talk I don't know how to talk to my kid. And we're trying to come up with with ways to support him, to find sources. You know, Camp kessam, I don't know is comes to mind immediately, but, but it is support for in in some of these areas that are adjunct. Is really needed, and we don't think about that right away. I mean, how do you address how does after cancer address that?

Chasse Bailey-Dorton 25:51
We actually have one of our therapists who does family therapy and relationship therapy that can do some of that I've had, actually was a couple, both, both from our patients, both cancer survivors, had a child. The husband passed away, and he's been great in dealing with this remaining spouse and that child how to process it. So we do have a therapist that has some experience in that, and

Caroline Knudsen 26:17
then that's also part of the programming when we're considering those external experts that come in. So we also had someone who specializes in kind of coaching and re establishing relationships after cancer. He'd been a caregiver himself, and so is how do you start having those conversations again? This was much more in the context of with a partner, but he also does coaching with families as well, and so it's something that we regularly like try to have in our programming, because those are questions that come up frequently, both, both David and Rick. What you guys have mentioned is, is not uncommon.

Rick Davis 26:50
We've we just started a creative writing class. We have an art we have an art class that's been going probably two years now, which has been really, really successful. And it's, it's open to anybody with with chronic disease, any type of chronic disease, or anybody who's supporting chronic disease. So we get a variety of people the creative writing class, and we record that so people can come in later. We decided we don't record on other mental health offerings. We were wondering what to do with the creative writing class, but it's proved to be really triggering, so we're not going to record it. So it's be it's been a it's been an interesting experience. We just, and we just started this week one of these mental health groups just for veterans. Because we had a veteran, we have a veterans group for health care and benefits, which is very technical and alphabet soup sort of stuff. But the vet said, You know what, we can't talk about what's on our mind. So we said, Okay, we're going to start a group for you where you can talk about

anything except treatment, health care and benefits, because we have other groups for that, and we think that'll be pretty triggering too, so

Chasse Bailey-Dorton 28:14
that's great. I do find that the disclosure or the journaling is one of the most powerful exercises we do with survivors. So I have a question for you guys, how do we get men involved in our platform?

Alen Amini 28:30
Don't all jump at once? Yeah,

Chasse Bailey-Dorton 28:32
I suspected it was not going to be an easy answer,

Caroline Knudsen 28:36
so glad you asked it, though. Yes.

Rick Davis 28:38
Well, I have a lot of ideas, but that's because we face the same problem. So I'm going to stay silent for a moment and see who else wants to respond. David,

Alen Amini 28:48
saw your hand go up? Yeah,

David Plunkett 28:50
that is a question that hadn't occurred to me, I think because, at least in this group, we're self selecting, because we're the ones who have gotten involved in reaching out and talking to others, but finding the ones who don't want to do that or aren't interested in to do that or haven't thought about doing that, I don't know how to reach them, at least with the support groups that I monitor on Facebook. And there's not many of them, just two, well, three. Now, at least you know, somebody who finds who posts a question on Facebook will at least get a response, and that can include leads to other groups or other resources or whatever. But it's hard to filter the what led me to all this to begin with, is that the resources offered by my local Cancer Center in person, they were too far away and too infrequent and too hard to get to and and honestly, in person is a lot more intimidating than online. So. So the support groups that I found started out by finding as context on on Facebook, and I'm very fortunate that it worked out well for me. There are other platforms and similar but that's the one that that worked for me six years ago,

Chasse Bailey-Dorton 30:21
and also two comments, we found that to get men in, we couldn't label it a support group. If I labeled it a men's breakfast group, I'd have more participation if a support group. And the other area that I found specifically in regards to prostate cancer was it was the partners that needed the group to come together. I really found that that I had one social worker who would work with

that group, and it was more attended. The partner would come, the patient didn't necessarily come. Survivor wouldn't come. But the patient, the partners wanted to

Alen Amini 30:53
come. Rick, see your hands up,

Rick Davis 30:56
yeah, so you're exactly right, doc, you hit the nail on the head. I was diagnosed in 2008 with stage three after I was attending a physical virtual group, a physical group,

David Wheeler 31:19
and became

Rick Davis 31:21
involved in the moderation of that physical group, and we decided we should try and create some sort of an emotional support group, a psychological support group to and it, it attracted maybe two or three people, four people, we, we, we, we stuck it out for about a year, and then we closed it up. Now, when, when we started anchor? Well, it wasn't even anchor and then, but when we started anchor, and we started building groups, and especially in the area prostate cancer, we figured out that we probably needed a physical group, and we go through all the iterations, but ankan started a group called men speaking freely in 2018 that group has been tremendously successful in we now meet twice a month. We have an average attendance of probably around 20 guys with new guys coming in. The first thing that we, that I do, the some of the other mods are not so careful, is I avoid the word emotional. So you don't, you can't, you can't use emotional for men. So I needed, I needed a substitute. So I came up with men speaking freely. And they're allowed to speak. They're allowed to talk about anything except Except treatment that that seems to that seems to work quite well, and we've taken that speaking freely over to a women speaking freely, which is a women only group, and the veteran speaking freely, which is just for veterans. It is very much a challenge in terms of the technical groups. And we have, we have average attendance between 20 and 40 in all of our prostate cancer groups, probably about 5% five 5% or less of the women. Although what we find a lot of times is that the women sit behind the men, and they chime in and and they prompt because the guys don't know what treatment they're getting, but, but, but their care partners do know what treatment they're getting. But we are, but the prostate cancer groups are largely male at the same time. The guys are great. They have no problem talking about Ed or incontinence or any of the issues if there are women in the room. So we have to talk some more Caroline. I put, I did put my information in the chat window because it looks like we that we have a lot of common mutuality. Should I say, agreed?

David Plunkett 34:31
David, one point I would like to return to is your comment about journaling or keeping a diary. I found that is was tremendously helpful for me when I was going through treatment. I have suggested it to a lot of others. But the point I'll usually make for guys is it doesn't have to be paragraphs. It can just be short notes, just reminders. It's amazing what you don't. Remember

six months later, but going back and looking through those notes can make a huge difference, and you can, you can watch for the trends, and I find that's a lot easier to get across, even if I never share my notes with anybody. It's also made it easier when I came across people with similar cancers or similar treatments or similar experiences, to be able to go back and say, you know, I have these notes of, this is what happened, and this is what I did, and I can feel confident that it's an accurate memory, and not just wish I what I wish things had been. So I like that you're encouraging that in whatever format,

Chasse Bailey-Dorton 35:43
we've had some where we actually turned it into a gratitude journal, where they can only put something they're grateful for each day. Because I always say, you know what you focus on increases. If you focus on the negative, then you notice more negative things. But if you focus on something you're grateful for, then you notice more grateful things as a way to deal with some emotions, too.

David Plunkett 36:03
And sometimes we have just a place we swear Exactly.

Rick Davis 36:09
We have a board member who is also a co moderator of our men speaking freely group. And he does that, and he talks about it every says that we get sub every morning, and he writes down one thing he's grateful

Alen Amini 36:21
for That's awesome.

Raj Aji 36:24
Yeah, as question, you know, on your practice, as you said, cancer never goes away. There's always that scan anxiety. But then there's always, you know, with newer and newer technologies and treatment methods coming up, there is, you know, cancer recurs. You put it back in the box. You're dealing with it. There's an ongoing sort of engagement with with the cancer treatment, so to speak. It's not just sort of one and done as you, as you, as you know. I mean, there's and there are periods when you might be going through treatment. There might be periods when it's it's it's in remission, then it comes back. How do you do you deal with, do you work with patients like that, and how do you deal with, you know this especially around for men dealing with a sort of a lack of certainty, right men? Men struggle with a lack of certainty we want. We want solutions. We want, you know, answers to questions, you know, things like that.

Chasse Bailey-Dorton 37:27
I always joke that toughest patients that come in sometimes are either engineers or lawyers, because they're used to everything being black or white, black or white, there you go, black or white, and there's no in between. There's so much in between in cancer and medicine in general that is hard to get that across. That kind of deal with that. And you know, we we have done some work on resiliency or cognitive restructuring. How do we change these automatic

negative thoughts? How do we work around some of that? But it is hard, and that's as you mentioned, the elephant is always with us, and sometimes different things will trigger that elephant to grow a friend, being diagnosed, a scan or something, and it's gotta get that elephant back down and under control again. Or, you know, you get an ache, you get a pain, oh, shit, the cancer's back. You know, how do we deal with this mistrust, or loss of trust in our body too, when we get a symptom? I've taught the technique sometimes, stop, breathe, reflect, choose. You know, I get a headache. Oh, it's Candra. Stop, take a breath. Let's reflect. All right, you did go swimming. It's pollen season. You get a headache. Okay? If this is not gone in two weeks, that's how I'm going to handle it. So just stopping those automatic negative thoughts sometimes, but yeah, you lawyers and engineers make me work. Those

David Plunkett 38:46
thoughts are hardest at four in the morning. Exactly. Rick,

Rick Davis 38:54
how did you connect with the cancer patient lab?

Chasse Bailey-Dorton 38:59
That's a good thing. Marianna, somehow got connected?

Caroline Knudsen 39:03
That's a good question. So I think it was Marianna and Bradford connected. Yeah,

Rick Davis 39:10
Marianna is your other

Chasse Bailey-Dorton 39:12
co founder, their other co founder. Co

Rick Davis 39:14
founders? Yeah,

Alen Amini 39:18
we're very glad they did get in touch. Thank you both.

David Plunkett 39:22
I'll check out the website for some more details and see if I can forward that to some people who might be interested in it.

Chasse Bailey-Dorton 39:30
I've had a couple patients that I've given the Cancer Patient Lab info to, and I have a patient in mind that I'm going to do that for.

Rick Davis 39:50

We are not HIPAA compliant, because we are totally peer-driven. But we do have quite a few medical professionals, but they're all there as peers,

Caroline Knudsen 40:10
We're deeply passionate about being part of the ecosystem and helping to connect the dots. That's why we exist. It's already such a fractured space, and patients are looking to put the pieces together, and if we can be part of putting those and connecting those dots. That's our job. I’m thrilled to meet you guys and be part of this as well.

“Navigating Cancer Survivorship" (Caroline Knudsen and Chasse Bailey-Dorton, MD) [#140]

CHAT CONVERSATION

00:26:52 Rick Davis: Rick Davis rd@ancan.org https://ancan.org 415 505 0924 (AZ time) ..... fine to make public

00:36:05 David Plunkett: Do I have the right URL? https://www.theaftercancer.com/

00:36:23 Caroline Knudsen: Yes that’s correct!

00:36:33 David Plunkett: Reacted to "Yes that’s correct!" with 👍

00:39:55 David Wheeler: Apologize but I need to drop (not running away from the topic of getting men involved!). Thanks for the presentation and discussion!

00:40:05 David Plunkett: Reacted to "Apologize but I need..." with 😁