Creating a Survivorship Care Plan with Your Health Care Team

National Webinar Transcript

January 5, 2022

Presented by:

SHARSHERET®
The Jewish Breast & Ovarian Cancer Community

This webinar was made possible with the support of:

The cooperative agreement DP19-1906 of the Centers of Disease Control and Prevention

The Sigmund and Edith Blumenthal Memorial Fund

Melissa Rosen: It's very interesting that almost half the people on this webinar were diagnosed in the last couple of years, but definitely a significant amount were diagnosed more than 10 years ago as well. This group is almost equal in whether or not the term survivorship is a word you want to use, with a little edge to ‘no I don't use the term survivorship’ and the majority of you believe that survivorship starts on the day of diagnosis but there's definitely some strong opinions in either direction and what's most interesting is that a full 75% of you were not provided or given access to a written or electronic copy of a survivorship care plan. So I am so glad that we are doing this webinar today.

Let's get started. My name is Melissa Rosen. I am the Director of Training and Education at Sharsheret. Thank you for joining us for an important conversation about survivorship and creating a care plan specifically for this part of the cancer experience. Thankfully, more and more cancer patients are living long and meaningful lives, so it makes sense that in the last decade or so, more and more time and resources are being devoted to healthy survivorship. And Sharsheret is here to help you with that transition.

Before we begin, I have just a couple of housekeeping items to share. I would like to thank our sponsors for today's webinar, which enable us to continue to offer meaningful programs. The cooperative agreement DP19-1906 of the Centers of Disease Control and Prevention and the Sigmund and Edith Blumenthal Memorial Fund. This webinar is being recorded and will be posted on Sharsheret's website along with a transcript for you to use as a resource. As always, participants' names and faces are not included in that recording, and you do have the option to be anonymous today if you would like to be and instructions on how to do that are being posted in the chat box right now, thank you Bonnie.

We received many questions through the registration process and as questions arise during the presentation itself, please use the chat box to ask those questions and we will have a dedicated Q&A period at the end. As a reminder, Sharsheret has been providing telehealth services to the breast and ovarian cancer communities for now more than 20 years, because cancer is so much more than simply a physical experience. And I do want to highlight one particular resource that Sharsheret has. Sharsheret understands that treatment and survivorship are different for everyone and that's why our Thriving Again Survivorship Kit is customizable, based on each person's distinct needs and interests. You can order your free survivorship kit through our website link, which is being put into the chat box right now. Our Thriving Again Kit, of which we have three versions, breast cancer, ovarian cancer and metastatic cancer serves as a much-needed tool to ease transition beyond active treatment. And if you are interested in finding out more about Sharsheret's free, confidential and personalized services, please email us or visit us at our website at sharsheret.org.

As we move into the webinar itself, I want to remind you that Sharsheret is a national not for profit support and education organization and does not provide any medical advice or perform any medical procedures. The information provided by Sharsheret and by today's speaker is not a substitute for medical advice or treatment for a specific medical condition. Always seek the advice of your physician or a qualified health provider with any questions you have regarding your specific medical conditions.

We are so very fortunate to have our speaker with us today. Rachael Lerner is a board-certified nurse practitioner specializing in women's health. She is the current president of the Nurse Practitioners of New York and previously served as their co-chair of advocacy and policy. Ms. Lerner is also an experienced speaker in health policy on the national, city and state levels, and she has also been a prior member of the health policy committee of the Public Health Association of New York. She has over 17 years of clinical practice and has practiced in breast oncology and breast health for over a decade. Her areas of interest include health promotion and education to help her patients become empowered partners in their own healthcare. You'll see that as she talks.

Welcome, welcome Rachael, and thank you so much for being with us today. Today's topic is such an important one. To begin, we know that treatment plans are created for every cancer patient, but what is it about survivorship that necessitates its own care plan?

Rachael Lerner: Well Melissa, thank you so much for having me today. I'm so excited to speak with so many people about survivorship and I just want to, before I go into everything, I did want to just put it out there that I know that survivorship is such a complex topic, and a lot of people have a lot of feelings about it and conflicting feelings about it. So I will use today both survivor as a word to describe a person with a history of cancer, as well as a person with a history of cancer to be inclusive, because I don't want anything to trigger people or to raise concerns.

With that said, survivorship and the concept of survivorship began back in the 1980s in trying to encompass the large group of people that had a history of cancer but were no longer in active treatment. In 2006, the Institute of Medicine had a landmark publication called From Cancer Patient to Cancer Survivor, and this document addressed the oncology community in recognizing and addressing the needs of people with a history of cancer. It presented 10 different recommendations, also including a survivorship care plan. The areas it addressed relating to preventing, detecting and providing surveillance of cancers, coordinating care between the oncology team and primary care providers, and ensuring that patients were given information on both late and longterm effects of cancer treatment and also health promotion.

In 2015, the American Cancer Society and ASCO created a breast cancer survivorship care guideline regarding breast cancer. The areas it recommended are regarding how frequently seeing a care provider is for screenings, recurrence or new breast cancer screenings and risk evaluations, also evaluating for genetics and when to screen, also addressing the physical and psychosocial longterm effects of cancer treatment. A lot of times people with a history of cancer at the beginning of their treatment or in their first diagnosis do not have any family history of cancer, and all of a sudden, through the years, people's family history changes and so kind of visiting back to family history and then referring to genetics at some point later on and not just ignoring that part of it.

It's also evaluating lymphedema, cardio toxicities, cognitive impairment, distress, depression, anxiety, fatigue, and also bone health, and nutrition and other various health promotion areas like smoking cessation and healthy weight and things like that. In addition the NCCN also provides a guideline regarding symptom-specific survivorship care. That document is over 100 pages long. NCCN is a great resource. You have to develop a username and password but once you do there's a whole resource for patients as well, so we think that's a great resource.

It is very clear that throughout which organization is creating these guidelines or reviewing literature, survivorship is a multidisciplinary approach in order to help people with a history of cancer and improve their quality of life. The goal of a survivorship care plan, also depending on which organization is discussing it, includes the area that we discussed, but it also can be regarding transitioning people to their primary care provider so that the primary care provider has a history of what's going on as well as empowering the patient in various areas to address their needs as well. No matter where the lines of the different guidelines are discussed, again, they're all overlapping.

Melissa Rosen: Thank you. It's good to understand how this came about. Let me ask you some specific questions. So what about longterm side effects, such as cognitive issues that so many people have been through cancer treatment have, or late occurring but non-cancer problems such as lymphedema or perhaps even cardiopulmonary problems that result as a certain treatment? Are those integrated and how are those addressed as a patient goes out of active treatment?

Rachael Lerner: Sure. So a lot of times it's a very common thing and as people age a lot of times they have cognitive changes in their life and so we tend to see that, it's a very common thing. Regarding that, a lot of times we refer people to a neuro-psych consultation, where they do specific measurements to see what functioning is going on and then also address and given recommendations to improve any cognitive impairments that people are experiencing. So sometimes that's related to memory, sometimes that's related to ... Again, like where did I leave my glasses, what's going on, or what did I do today, I don't remember anything regarding today. And then there's things that you can really help to fix it, which is creating lists. Just very tangible things in improving memory, so sometimes they'll say like, "Just do crossword puzzles everyday," and just kind of flex different muscles that you haven't maybe flexed for a long time.

Then other times when they do the consults, they'll see that there wasn't really a huge change, or it wouldn't be categorized as a huge deficit, but that there is a change for the individual and again can give very straightforward recommendations to improve that. Lymphedema, as we know it can happen at any time after having surgery, depending on how many lymph nodes were removed or if radiation was provided or things like that. And so a lot of times after someone has gone through active treatment, and kind of gone through and things have calmed down regarding the rush of all of those interventions at the beginning of diagnosis, people then settle down and they realize and they can process, they have the ability to process everything that's going on and so these other symptoms will come up. So for lymphedema, there are lymphedema specialists that are wonderful that work with patients, and it's a wonderful resource for people and people have very positive experiences with that.

Regarding cardiopulmonary problems, every provider that you see will always ask, "Do you have any shortness of breath when you're walking upstairs," and other straightforward questions, and then depending on what's going on with that, will advise different testing that's going on, as well as just areas to improve our health.

Melissa Rosen: So it's good to know that these things are addressed as they arise. But is there any indication on a care plan that these are things to look out for or does that tend to be more worrisome and it's just as things arise?

Rachael Lerner: So on written care plans when providers are giving that to patients or giving it to other providers, it does go through what treatments were received and so based on those things, a provider will know, "Okay, this person received radiation in this area, so we're going to look out for this." Or, "This person received chemotherapy, so we're going to look out for cardiac toxicities." A lot of times providers will remind people down the line, "Okay look, you had this specific treatment. We know that you should look out for these things. We don't want to alarm you, but we want you to be aware of the possibility for things that are going on." And I always told patients if it's a change for you and it's persistent for a certain amount of time, then it's definitely an important thing to raise. I would say that if it happens over 24 hours, and it's not short of signs of a heart attack or having difficulty breathing, life-threatening things, then just observe and see what's going on with your body and know when there is a change.

Melissa Rosen: Okay, that's very helpful. You mentioned there might be a referral to a neurologist or a PT person for lymphedema. So let's get a question out of the way that I'm sure a lot of people are asking or thinking which is once someone transitions away from active treatment, and they are healthy, who manages their care? Is it the oncologist? Is it a primary care physician? Is it someone else entirely?

Rachael Lerner: That's a great question, and it depends. It depends on where you are. It depends on your care team and what resources the care teams have. It depends on geographic location, if someone's traveling two hours to treatment, then you will be seeing your primary care or a local provider more frequently and there will be communication going on. I don't think any provider wants to impose stress to a person because we know that with cancer treatment immediately, there's a lot of time for medical leave and there's so many things going on. So your providers want to make it convenient for people and so there's a lot of teamwork that happens behind the scenes but it's important to know that you have a primary care provider, they are experts in normal and they will know when something is not normal. I think it's really important to continue that relationship and start one if you don't have one. Because they really can look at the whole person and what's going on.

Melissa Rosen: Oh I was going to say, I actually think that's very comforting. Like they're supposed to know specifically what is normal and what isn't. Because for many people who have faced cancer, the thought of leaving a specialist is a very scary thought, but the way you just phrased that really resonates with me. So thank you for that and when we talked earlier, you mentioned if you don't have a primary care physician or if your primary care physician is uncomfortable taking on a person who has just finished treatment, then ask your oncologist if he or she works with someone that is good and get yourself a new PCP.

Rachael Lerner: Yeah. And you'll notice that through treatment, that at some point if you have a radiation oncologist, they will transition care and not see you as frequently. If you have a surgeon, then they will also at some point refer you back to your primary care or for you to continue seeing your medical oncologist at some point, and so there is a lot of making sure that someone is covered but not necessarily seeing so many providers when it's unnecessary. It might be comforting, but sometimes it's unnecessary and it can be a burden for someone that is constantly having to take off of work or taking care of other needs going on. So I think it's just important that you have communication with your providers and feel comfortable what's going on and knowing what to do for next steps.

Melissa Rosen: Makes sense. What about this. Is the patient involved in the creation of a plan? Do their specific concerns get factored into that plan?

Rachael Lerner: So there's various plans and when I was looking at the various plans going on, there is OncoLife, which is associated with Penn Medicine. They go over some guidelines and what's in your care plan and they kind of go over guidelines as to what should be in the care plan or what areas to question and to make sure that you know about, and then the NCCS which is the National Coalition for Cancer Survivorship, they also have an example of a care plan and then things to discuss and what you should know after finishing active treatment. So some of those things are regarding screening for various other cancers, diet, exercise or other health recommendations, any physical or emotional concerns that may occur after treatment and also healthcare. So how do you discuss options for rehabilitation therapy to proactively manage and overcome potential side effects like range of motion and being referred to a rehab medicine provider? Also, if there is concerns regarding FMLA or your insurance changes, we all know that especially in the United States that insurance is constantly changing and can change annually, and those are concerns for people because providers are in a network and so there might be shifting of that, and so there are providers and there are teams that can help with that piece as well.

So it is specific to what a person needs and what they want, but there's also some standards as well. Regarding the poll that said 75% of people do not recall receiving one. So because we saw that some people are zero to two years after first ... Like when they first diagnosed, it doesn't surprise me because a lot of times, that does occur later on, depending on how many years someone was first diagnosed and things like that. But that being said, it is one of those things that it might not be a written document that you receive depending on where you are, but those areas that are going to be addressed and going to be asked are going to be continuously asked down the line. They might be addressed down the line when things come up. But it is on a lot of people's radar.

Melissa Rosen: So what you're saying is someone might not physically get a piece of paper but if the same issues are being addressed in the oncologist's office by either the oncologist or a nurse practitioner or a social worker in that office, then that serves the same function.

Rachael Lerner: Exactly. In a perfect world, it would be beautiful that all AMRs would bring everything, old medical records together and then it would come in one specific piece of paper. But unfortunately there's still a lot of nuances to making it streamlined. There was a couple of studies that showed that the time it takes can be over one hour, just to create one for a patient. And so I think that once someone is completing active treatment, I think it's important to always get a copy of your records. Some people are great at using their EMR, but I think making sure -

Melissa Rosen: Define EMR for the audience.

Rachael Lerner: Sure. So the electronical medical record. So you'll notice sometimes now when you're seeing any provider that a lot of times they're listening but they're on the computer typing away, and so that is what we're typing into a lot of times is an EMR. And regarding that, so I always tell people, "If you've had surgery, making sure that you get a copy of your pathology report. If you've had a radiation, getting a copy of what radiation you had and how frequent it was. If you had any kind of endocrine therapies or oral medications or chemotherapy, getting a copy of those reports as well." And then any imaging that you've had done recently. Getting copies of those as well. If you have that record, it makes it sometimes a little bit easier if you haven't received either a treatment plan or a treatment record or a survivorship care plan.

Melissa Rosen: So what I'm hearing you say and please correct me if I misunderstood, but that theoretically, or in an ideal setting, the survivorship care plan should include an analysis or a listing of what the diagnosis was, tumor behavior, what the treatment was and things like that, in addition to what's being done moving forward.

Rachael Lerner: Exactly, yes. So it will talk about what surgeries you had, what radiation, all those specifics. But then also possible late and longterm effects that might occur regarding certain issues that patients with a history of cancer might have had, regarding smoking history, fatigue, insurance, weight changes, sexual functioning, and areas like that. As well as health promotion, so how frequently should you receive a colonoscopy or if you were a smoker, a low dose chest CT screening. It can incorporate all of those things in addition to the primary cancer treatment that was done.

Melissa Rosen: So it can be quite comprehensive. I noticed earlier that there's so many directions we can go in now, so let me just pick one. I noticed earlier that you were talking not just about the physical things we might expect, like screening for recurrence or things like that but you talked just now about sexual functioning, you talked about reconditioning to get someone back to their physical shape that they were in prior to treatment which can often be debilitating. You mentioned even a little bit about emotional health, that kind of thing. So if the doctor, if your oncology office doesn't have all of those people and they won't have all of those people within their office, then it seems to me like there are likely a lot of referrals that come as a part of this plan. Can you talk about that a little bit?

Rachael Lerner: Yeah. So we live in an era where there are so many specialists and so many people that are part of your healthcare, and so when things come up, you can really refer to a physical therapist that can help again with range of motion. You can refer to sexual medicine regarding sexual function and areas of concern there. The social workers that I work with, the psycho-oncologists that I've worked with, they're all such an important component and genetic counselors are super important, and there are so many parts of people's care. Nurses, licensed practical nurses, medical assistants, just that whole puzzle of people that are involved in bringing everything together. Each is such an important component, and I think that oftentimes, cancer is kind of this traumatic event that happens in someone's body. But I also think in how we approach it and how we look at it and how we improve our quality of life, those are things that we can really feel empowered by and make active changes in our life, and I think that that's just such an important thing to remember is that we do have control over certain things and feeling empowered by those things that we are in control of.

Melissa Rosen: For those of us who have a little bit of fear associated with moving beyond our oncologist, what I just heard you say is really the best option is to have lots of people involved so that you're meeting all sorts of needs beyond your oncology needs specifically.

Rachael Lerner: Yeah, yeah, absolutely. Again, I'm not saying refer to everyone.

Rachael Lerner: It's a balance, but I think that when you have an issue coming up that you can go to that provider, you can go to that professional addressing that specific issue if that makes sense. Yeah.

Melissa Rosen: So there are a couple of questions that came in just now that I think are relevant for right now, so you had talked about ... Since 45% of the people on this call are within the zero to two since diagnosis timeframe, then it doesn't surprise you that more people haven't received a formal care plan. So the question came in, ‘what does the end of treatment look like’? What if somebody's gotten through the chemo, the radiation, any surgical interventions, but they're on hormone suppression for 10 years. Like do they not expect a care plan, a survivorship care plan until they're done with Tamoxifen or an aromatase inhibitor?

Rachael Lerner: So there are a lot of people that after being on a medication for a certain amount of time, even an aromatase inhibitor or Tamoxifen, that they will see their PCP and a lot of PCPs feel comfortable managing that and managing the DEXA scans or bone health scans that are monitoring certain side effects. And then there are other practices where you're seeing an oncologist or your oncology team throughout that whole treatment, and then there are some again that it might be that you're seeing a lot of oncology providers through that. It depends I think on both the needs of the patient, it depends a lot on location and the availabilities of the medical system and how they can accommodate it.

And resources involving all of that, so it really does vary, and I think that as long as the person who is receiving the treatment feels comfortable and understands what is going on, then I think that it's definitely a reasonable thing. I think providers sometimes feel very hesitant to say, "Okay, at this point, we want you to see your primary care provider for this," and people feel scared or nervous, which is totally a natural feeling because you've been so involved in seeing your oncology team and then you're now back to seeing a primary care, or you're creating a new relationship with a new primary care provider, and that can be really, really scary. But again, I think that as long as there's an understanding and again, the survivorship care plan is a great document or a great tool to use in order to make that transition as seamless as possible.

Melissa Rosen: Okay. So one of the questions that I have for you was actually seconded by someone in the chat box right now. Someone noted that they believe that everyone deserves a written care plan, especially in a time where we're told we should be advocates for ourselves. That's what even the healthcare team wants and especially in a time of COVID where doctors have limited resources, the most valuable one being time, that everybody deserves one. So here's a question. If someone does not receive one, whether that's an electronic one, a print one, a lengthy conversation that serves as the plan. So if someone doesn't receive one, is it appropriate to ask for one and how might people go about doing that? Because sometimes it's hard to call out our doctors who you're so grateful to and so what's the best way to go about doing that?

Rachael Lerner: So I think it's completely reasonable to look at one of the examples that we kind of discussed and we can again provide those resources for people and websites for people -

Melissa Rosen: Well, on the follow-up email.

Rachael Lerner: Yeah, exactly, that they can refer to, and I think it's totally appropriate if you have not received one or are questioning it to bring it up and see what the provider's response is regarding it and then depending on, "Okay, we do that," or, "You know what? We don't really do that right now." And then you would feel empowered and you can say, "Well look, these are the areas that I'd like to address or I'd like to know about, what should I be looking out for? And then you document what's going on and you can document what to look out for, side effects and things like that. I think that if you don't feel comfortable with the response, I think that calling the office and speaking with the nurse in the office or speaking with another person in the office, I think that they can also be tremendous resources. Because it sometimes can be tricky and uncomfortable to ask one person in your oncology team for that information, and I think that there's no silly question. It's really important I think to feel comfortable and so if you don't get the answer, you can always ask it again, and you can always make sure that you feel comfortable with the next steps and with the plan.

Melissa Rosen: That's actually very helpful. I have heard others say, "If you have questions specifically about this or any sort of weighty topic, let the doctor know at the beginning so that they plan to spend the time. Don't do it as you're walking out or the doctor is walking out. Even email ahead of time and say, "I want to talk about this day and I just wanted to make sure we have enough time." That can be an important thing to do.

Rachael Lerner: Absolutely, and I always ... If you have a calendar, however you document things, the weeks coming up to your appointment or in between the time period, writing those down and then having them available and if someone is taking your blood pressure or doing your weight and you're seeing anyone ahead of time, you could always say, "These are the questions that I have," so that way the provider that you're seeing will also be prepared for that as well. So I don't think you can say it enough to people that you're seeing.

Melissa Rosen: That's great. By the way, our Thriving Again Survivorship Kit does have some places where you can note questions or symptoms or things like that. So that's a great tool to use there as well. One thing we haven't addressed at all today, what about someone who is facing metastatic disease? Does someone with metastatic disease benefit from a care plan and how might it differ from a standard, or you know what, let me rephrase that. What I'm really asking is how do the elements of a survivorship care plan benefit those who are dealing with advanced or metastatic disease?

Rachael Lerner: That's a great question, Melissa. So regarding that, again, a lot of organizations say that survivorship begins the day of diagnosis. So that is a very well-accepted definition, and that said, there are a lot of treatments that are ongoing and a lot of surgeries that have been done that create side effects and create symptoms, and so the elements of a survivorship care plan addressing those various aspects of treatment are very applicable to someone with metastatic cancer, and so looking at those pieces and again asking about them and how they affect my quality of life and what provider can I be referred to for this is very important. I think that there are so many elements of survivorship care plans that are very applicable to metastatic people, patients with that, and so I think it's important to look at those things, and again, feeling like you're improving your quality of life and feeling empowered by those providers that are involved in your life positively. Those are reassuring.

Melissa Rosen: Okay, so thank you, that was helpful. So clearly, many aspects of a survivorship care plan are applicable. Have you ever heard of a care plan, like an ongoing longterm care plan with a metastatic patient or it's more like we just need to take the pieces out and apply them to these patients?

Rachael Lerner: Yeah, so I haven't personally seen a written care plan for someone with metastatic disease. That said, it's not unheard of and again, there's a continuum of how care plans are implemented. So unfortunately I don't have personal experience with that, yeah.

Melissa Rosen: Okay. Have there been any studies that prove that having a care plan improves longterm outcomes?

Rachael Lerner: That's a great question. So there's been a lot of reviews of all the literature out there and studies that are out there, and some of them have actually found out that as long as certain issues, so for survivors, some specific areas of concern are regarding the signs and symptoms of recurrent cancer, but fatigue, cognitive changes, depression, anxiety, relationship changes, work changes and financial areas and concerns. And with that said, if those areas are addressed, it doesn't matter if you've had that written piece of paper or have that available to you. It's a matter of feeling like those areas are addressed and if they're addressed, it's fine. Yeah.

Melissa Rosen: So studies show that whether it's a digital or written or conversational care plan, as long as you feel like your needs are being addressed, then it actually does improve longterm outcomes?

Rachael Lerner: Yes, exactly. So that said, there are studies that show that survivorship care plans as far as everything that is addressed and ensuring that, it definitely is very helpful and it can also very much optimize healthcare and so there's a lot of research out there that varies. But what I found interesting is that there were studies that also showed that it didn't affect outcomes as much, because again, if you're seeing a primary care, you're seeing an oncologist or whatever other providers you're seeing, those areas are all being addressed.

Melissa Rosen: And I guess the reality is in the scheme of things is it's still a pretty new aspect that we're addressing of the cancer experience.

Rachael Lerner: Yes, definitely.

Melissa Rosen: Yeah. Okay. So I'm mindful of the time. I do want to say that lots of questions came in about the organizations that had information about care plans on their websites. I just want to confirm that when a follow-up email goes out to anyone who registered to this, there will be ... Those will be named and there will be links. When you and I talked earlier Rachel, we noted that some won't be appropriate for everyone and some will be and they are just examples and none of them are the right way to do it, but they are great examples of things you might be thinking about or should be thinking about and things you can ask questions of your healthcare team about.

Rachael Lerner: Exactly. Yeah.

Melissa Rosen: Okay. So I'm going to encourage ... I'm going to start with some caller questions, some participant questions, but I want to encourage anyone who still has questions to put it in the chat box now. So a lot of the questions that came in were about specific survivorship concerns. But let's talk about a more general one first. What surprised me in the poll at the beginning was that 38%, it was almost evenly split, but the majority of people, 38% of people didn't even use the word survivor. Which really does surprise me. Another 31 said yes they do and another said, "Yeah, but I'm not so comfortable with it." So a question came in, how can we even use the word survivor or survivorship with patients who have a highly likelihood of recurrence? And I guess that question can be answered from both a medical and a psychosocial perspective.

Rachael Lerner: Yeah. So using the word survivor is a really loaded question on many ends, right? Because some people, if they have a recurrence, they feel as if they failed, and in other areas, people feel really empowered by the word survivor. They were diagnosed, they got through it and feel super empowered by that word. And it's just a highly emotionally charged word. I think that it's important for people to see what they feel comfortable with overall and I think that it's totally okay if you don't feel comfortable using that word, and it's okay if you feel comfortable using that word, and I think it's just a matter of again how someone feels and if you feel like a survivor on day one, then that's a great thing. As long as the person, but I think there's definitely a continuum of how people feel towards it. Yeah, and I think it's just a matter of what you're comfortable with and just like every person, right? Every person has a different temperament. So every person is going to have a different feeling about the word survivor and what that is, and that's totally okay. I think if you say I have a history of cancer, that's fine too, and it's just dependent on your comfort level and also what word choice you feel comfortable with.

Melissa Rosen: Right. So there is no right answer and whatever word you choose, embrace it and be proud of that title. The webinar that we had where that actually ... There were so many questions, it happened over the summer in June, was really a webinar about the word survivor and we had different people sharing their perspectives on that word and the condition of survivorship. I think because there were a few questions today on that, in the follow-up email, we'll also put a link to the recording of that webinar if anybody wants to explore that differently or additionally.

So we got a couple of questions about ... These are things you've touched on, but maybe a little bit more. So somebody says, "It's been difficult to build a medical team who is interested in survivorship. At this time I'm still at a crossroads. If my team isn't interested in that, how do I actually go about finding physicians who are comfortable and totally fine with taking care of a cancer survivor?

Rachael Lerner: So I think it goes back a little bit to having a primary care provider, and what's interesting I find is that when people transition from their oncology team or they see a new provider for the first time and are still seeing their oncology providers, that that person has a fresh lens on what's going on and can also take a step back and ask all of those history questions and all of those side effect questions that they might not have been looked at in depth before, and so I think that having also ... When you come across different providers and feel uncomfortable, that said, if you have a great physical therapist that you see, you can always ask them. Any kind of care provider that you're seeing, or a social worker, there's also so many organizations that have tips and information on how to find providers too.

Melissa Rosen: Sharsheret.

Rachael Lerner: So there's a lot of that. That said, I mean I've also had personal experience where you see a provider and it just wasn't a great match and so you find someone else and no one takes it personally. So I think if you're not getting what you need from one team, then it's totally fine to keep going on and find what you need.

Melissa Rosen: Yeah. I think that's great. Somebody actually just put in the chat box with regard to the word survivor that her team uses the phrase NED, no evidence of disease, and that's a word that they're comfortable with, right? It's more of a technical word but I've heard people say I'm a friend of NED, and that meant that they were a survivor. So you can find whatever feels comfortable to you.

Okay, another person asked ... And this is more ... Less about plans, but more about one of the symptoms that the plan hasn't been able to manage yet. So what about longterm fatigue? Still suffering, for people still suffering longer than anticipated, where the doctor, the oncologist has no more resources to share, has no answers. Let's generalize it. If a survivorship care plan can't address something that's going on, what's the next step?

Rachael Lerner: So you want to have a medical evaluation to evaluate if it's a thyroid function issue, if it's anemia, if there's something going on at the base, but if it's something that is discovered to be an effect of cancer treatment, exercise has been really shown to help improve fatigue, and we're not saying you have to spin every day to find an effect, but even starting out with a five minute walk a day or taking the stairs, little things that you can do and we know that physical activity helps so many things. And so I would start there. If it's persistent, I would again refer to other providers and see specifically what is going on and have them look at that as well. But like nutritionists, like every provider has a different lens to look at things, and so if you connect with those providers, it's just more tools in your toolbox, and again like I said, sometimes a provider or a team is not a great fit, and again, you won't use their tools. But you take what's helpful to you and you just leave the rest.

Melissa Rosen: Sounds to me very similar to the discomfort some people have getting a second opinion. My doctor won't think I trust them, things like that. So again, a solid doctor is happy for you to get a second opinion and if your longterm oncologist can't meet a particular need in survivorship, if you ask for a recommendation or if you find somebody else, they will be grateful that you found a person who can help you with a particular need or concern.

Melissa Rosen: So. A couple more questions before we wrap up. So this one actually comes from a healthcare provider who struggles with their patient's anxiety. It's the fear of recurrence. Do you have any suggestions for anxiety reduction strategies and working with mental health professionals so that someone in an oncology office can help their patients reduce stress? And, if there's someone here on the webinar who was having these anxieties, they would take the same steps.

Rachael Lerner: Yeah. So I think amazing social workers, psychologists, hypnotherapists, there is so many areas that can help with anxiety and issues surrounding recurrence and how to manage that. I think that seeing a provider that specializes in mental health is very important, but there's so many resources out there. Some people find that they feel much calmer if they are doing exercise. Some people feel calmer if they do yoga three times a week. There's so many levels of what individuals feel comfortable with and what decreases people's anxiety, and I think that having a mental health provider, it should not be a stigma. It still somewhat is. I found it interesting that on New Year's Day, there is a physician that is in England and he said, "Take a pic of my pill," and he encouraged people for his mental health medications, he took a picture of his pills that he takes. And it's just like hypertension, and then everyone was sharing their pills and they took pictures of their pills, and so just de-stigmatizing that, and so I think that that's just a super important thing with mental health, to de-stigmatize it, and it doesn't mean that you're less of a person because you need assistance with coping with anxiety.

Melissa Rosen: Right, I mean you mentioned this is a trauma and so it's normal to need help getting through a trauma. You mentioned earlier an onco-psychologist. Can you say how that type of profession differs from going to see a regular therapist that you might find online?

Rachael Lerner: Yeah, so those providers ... I'm not sure if it's a special certification that people do, but it is additional training that healthcare providers can have. That said, I don't think that if someone's a member of that or they're not a member of that, that they do have a better experience in working with people with cancer. But I would ask the individual, if you're speaking with people, what expertise do you have in working with cancer, how frequently, looking at their bio and seeing have they done research with this, or do they put this on their website and are they talking about it frequently and then in the intake, again asking those questions and usually people get a feel, an intuition on their comfortability with it.

Melissa Rosen: Absolutely. So right, so there are a lot of different types of professionals one can go to for the emotional component of this, right? If you just need a little help then, it's great to reach out to either a social worker at your doctor's office or someone in your community. Of course Sharsheret has an amazing team of social workers that are available 9:00 to 5:00 in every time zone in North America, and they very often help people connect to additional resources, to listen to them on a difficult day, to help them work through a decision they are looking to make, and if someone needs ongoing support, they can make that recommendation as well.

So listen, this was the start of a much longer conversation, but a great start, and I want to thank you so much for sharing your expertise with us today. I learned a lot, I hope all of you did too. I want to ask everyone to take a moment to fill out a brief evaluation survey on today's program. That link will be in the chat box right now and you can actually click that link and still listen to the last part of today's webinar. During the next few days as we mentioned, you will receive a follow-up email with a link to the recording, the transcript, the organizations that talk about care plans that Rachel mentioned and a link to the last survivorship recording that we did, so please be on the lookout and again, please remember that Sharsheret is here for you and your loved ones during this time. We provide emotional support, mental health counseling, and other programs designed to help you navigate through the cancer experience including of course survivorship. All are free, completely private, and customizable. Our number is 866-474-2774 or you can email us and that email has been in the chat box several times, clinicalstaff@sharsheret.org. And of course we'd love for you to stay connected with Sharsheret through our social media where we post about events like this, program updates, fun ways to get involved.

And finally, I want to let you know that we have several exciting webinars on a wide range of topics planned over the next few months, including another Sharsheret in the Kitchen this Monday, a Cancer and COVID update, very relevant with the new Omicron variant, and one on genetics and genomics in gynecological cancer. So please check out our website regularly to see what topics are coming and we'll post that link in the chat box as well and of course you can always access recordings and transcripts of older webinars on that same link. Again, thank you so much to Rachel Lerner, who has spent the time educating us today and helped empower us to be advocates for ourselves. I hope that you all have a really wonderful rest of the day. Bye-bye.

Rachael Lerner: Thanks so much.