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**Executives:**

Jennifer Gillette - Staff Social Worker at National Bone Marrow Transplant LINK

Julie Larson - Psychotherapist and Speaker-Educator

Stephenie Perry - Survivor of Hodgkin lymphoma

**Operator:** Hello and thank you for standing by. At this time, I would like to welcome you to The Practical Needs Before, During, and After Transplant with the Focus on Self-Care and Self-Awareness Conference Call.

All lines have been placed on mute to prevent any background noise. After the speaker's remarks, there will be a question-and-answer session. If you would like to ask a question during this time, simply press star followed by the number one on your telephone keypad. If you would like to withdraw your question, press star one again.

I would now like to turn the conference over to Jennifer Gillette. Please go ahead.

**Jennifer Gillette:** Thank you so much, Jericho, and thank you, everyone, for joining us today. We appreciate you tuning in, and we really hope this program helps you today. Again, my name is Jennifer Gillette, and I am your facilitator, as well as the Staff Social Worker at the National Bone Marrow Transplant LINK. I'd like to welcome you to this Lunch & Learn with our special focus on The Practical Needs Before, During, and After Transplant with a Focus on Self Care and Awareness.

A special thanks to our generous sponsors, the Leukemia & Lymphoma Society, Johnson & Johnson, and Incyte. We also like to thank our esteemed LINK partners because we could not do what we do without them.

Just so everyone has a basic outline for today's program, I'm just going to introduce the National Bone Marrow Transplant LINK to any of the callers who are not familiar with us. And then, I'll introduce you to our health professional, Julie Larson, who's a psychotherapist and speaker-educator who's spent her entire career working with survivors and families. And then, we'll have our Survivor speaker, Stephenie Perry, a survivor of Hodgkin's lymphoma, who underwent both an auto and allogeneic transplant with her story and her best tips. And then, we'll open the floor for questions and comments.



So, for those of you who may not be familiar with the LINK, our mission is dedicated to helping individuals and their families from diagnosis through survivorship. We provide resources, support, and education. Some of the resources we provide to help families navigate through the transplant journey are our Lunch & Learn programs like you're on today. These feature a variety of health professionals and survivors, and they can be disease-specific, they might be coping related there. We have a variety of titles, and all of these are housed on our website [nbmtlink.org](http://nbmtlink.org). So, if you want to listen to other programs that have been recorded, feel free to check them out.

We also have our Marrow Masters' program that has over 30,000 downloads on all things related to bone marrow transplants, whether it be survivorship, chronic graft versus host disease, and that can be found on many platforms wherever you listen to podcasts, but you also can check that out on our web page as well.

We have our two webinars we host a year, usually in the fall and the winter months. We have our Coffee Klatch program, which is a Zoom-based support. We have our peer support programs which we can hook both patients and caregivers up to talk to those that have been through this.

We have our celebrate second birthdays program where we acknowledge that second birthday you get each year on your transplant day and our Survivors Drive Book Club, which is a Zoom-based program as well.

We also have other programs that we come up with during the year. So, if you stay tuned in to our Facebook page or check out our webpage@[nbmtlink.org](mailto:webpage@nbmtlink.org), you can keep informed on all of that.

We also have award-winning books and information on our site that you can download and also order and we provide emotional support and referrals from a licensed social worker. So, if you need more support, please reach out.

Before we begin today's program, I'd like to review just a couple of housekeeping things. First of all, when we get to our question-and-answer portion, which will be after our speakers complete their programs, we will ask you to ask one question at a time and then get back in the queue. We also ask that you try to be concise just so we can get to as many questions as possible today. Also, please know that the information provided in this program is meant to stimulate conversation with your own healthcare team and is not meant to replace your individualized medical plan.

So, now on to the educational part of our program. Julie Larson has spent the entirety of her professional career in oncology supportive care. She's a graduate for Columbia University, and she began her career at CancerCare, where she developed and directed the Adolescent and Young Adult Program. She's a trusted advocate for mental health



care throughout the cancer trajectory. And she has contributed to initiatives from the National Cancer Institute and Lance Armstrong. Julie currently sits on the Medical Advisory Board for Stupid Cancer, Cactus Cancer Society, and the MercyOne Richard Deming Cancer Center. And her private practice Julie meets with survivors of all ages and diagnosis combining her training and cognitive behavioral therapy and mindfulness, she helps her clients strengthen inherent strengths and strategies for navigating hardship. She is a sought-after speaker, educator, educator for cancer conferences, professional organizations and corporate groups, and a frequent contributor to coping and cure magazines, as well as a guest on numerous health and wellness podcasts. Julie's Ted talk living in and is based on 17 years of clinical work bearing witness to the resilience of individuals facing an unexpected medical diagnosis. Julie maintains a private practice in Des Moines, and she and her husband are the proud parents of four children. Thank you for being with us today, Julie.

**Julie Larson:**

Oh, thank you for having me. Hello, everyone. It is my pleasure to be able to spend my lunch time with all of you, as you contemplate and want to sit and kind of learn more about your needs before, during, and after the transplant. This word “Practical” within our title kind of it is something that I'm thinking about in a very different way today. Sometimes when I think of the word practical, I think of you know those very, very concrete tasks and things that we do to take care of ourselves. Like what's in your fridge? What do you need to stock in your home or have ready for you as you walk into a Medical Center? But I think maybe what I'm going to just begin with today is for us to start to consider our emotions and the needs that we have. Also, concrete things that we are going to be navigating and managing throughout the transplant journey, whether this is you are meeting us today before transplant, during or after, how do we begin to conceptualize the dots and the feelings the bubble to the surface as concrete and practical that we need to care for and think about in very specific way.

As we begin, if you have a pad of paper and a pen or pencil, grab that and get it with you right now because I am hopeful that some of the things that I say today are things you can jot down and come back to later are down the road as ways to kind of structure and the way we think and the way we kind of approach caring for ourselves.

So, first of all, I'm just going to lay a very just kind of basic foundation for our wellness and for just a sense of how we feel and take it back to basics, sometimes we get pretty kind of complex or abstract when we think about caring for ourselves and that oftentimes our worry and our fear and our uncertainty can come from, you know, things that we feel a great deal of loss of control and that we don't even know where to begin. And sometimes people say to me “I don't know. Do you know what I can actually do to take care of this restlessness or this unsettledness within me?” And I often begin with people by saying “Let's take it back to basics” and what I mean by that is sleep, eat, move, and connection. So, those four kinds of legs of the stool, that really when



we think of “I’m not feeling a feeling of out of control.” “What can I do?” if we can think about your sleep, what you're putting into your body. How you're moving your body and connection, those might be four areas where you might have something that you can actively do that 100% changes how you feel or even the outlook of our perspective. We all know that we kind of approach a day differently when we're well-rested or when we're not hungry right? hungry. So, kind of just beginning to experiment and to pay attention to what contributes to sleeping well, what contributes to kind of feeling good when we're eating and putting things in our body moving even if we're feeling tired or fragile or weak. How do we move our body and then the other piece of connection? Where are those others in our lives that help us to feel like we're not alone? And maybe that's not necessarily talking or doing something with somebody else, but just the presence of another person in our day-to-day? So, I'm just going to lay those four things out there: sleep, eat, move, and connection as very tangible basics of general well-being that may give us some ideas for things you can do to feel like you have some control.

Okay, now let's step away from that, and let's go into kind of my wheelhouse, and let's say I'm a therapist. I work with people in my office every day around the mental and emotional stress of a cancer diagnosis. And when I sit with people in my office, I often say to them, and this is another thing for your notes that are distress shows up in our bodies there it shows up to us in three ways. Okay, it shows up in the way that we're thinking. Right? So, the narratives and the thoughts and the things that are sitting in our mind, it shows up our distress can show up in our emotion, what we feel. So, it can be you can might be very teary. You might feel very overwhelmed. There might be a great deal of dread or worry or fear. There might be impatience or irritability. So, those are all feeling words, feelings. And then, the third way that our distress shows up is in our body. Right? We might feel a buzz of like this thing, like, of anxiety and unsettled. That's right. We might feel just a heavy gut-punch feeling in our gut, right? Just that that heaviness that sits there with dread or anxiety, we might feel an overwhelming sense of tired that isn't necessarily physically tired, but mentally or emotionally, just heavy and tired. You might feel it in your shoulders to pants. You might feel headachy, and it's kind of related to distress, right? So, think about that. Your distress can show up in your thinking and your feelings and in your body. So, if we think about it in that way, then the good news, we have three entrance ramps to taking care of ourselves, right? So, we can address the way that we're thinking. We can address the way that we're feeling and how do we comfort and soothe our emotions, and we can think about our body. How do we bring calm and ease to our body, right? So, that might be one way to kind of begin to think about “what do I do when I am not feeling at my breast?” Okay. So, let's begin by our thinking. “Can you begin to identify where your thoughts are going?” “What is that narrative?” “What's the spin in there?” And sometimes I find that many, many of our worries and our fears and our anxieties. If we dig, dig, dig

under it, we discover an unanswered question. So, can you sit face-to-face with what you're thinking about and really listen closely to the narrative in your mind? And do you discover questions? Put them down on paper because of some of these questions, we may be able to get answers to with your medical team, with other peers. So, when I use the word peers, I'm talking about other survivors or support groups, you know, places where you can connect with others who've been there and are walking the same path. Can you underneath fear and worry, find questions and then use those questions to direct the conversations that you have with other people? And when we begin to answer those questions, we might begin to feel a bit more in control and may begin to kind of color in the spaces of what we're not understanding ourselves and is leading to a great degree of worry. We may discover worst-case scenarios, catastrophe thinking or what if, what if, what if? Right? And when you discover those what-ifs in your mind, we can do a lot of different things with what-ifs. One of the things we might do with a what if "What if this happens?" "What if this..." is to begin to recognize that most of our what-if thinking is throwing us way into the future, right? It's "What if this happens on the road?" "What if I discovered this when I'm on that journey?" And how do we begin to kind of say, okay, that is for my future self-bucket our thinking, I call that kind of bucketing or thinking. So that's a future. Oriented thought and how do I bring myself back to what's right in front of me? What's happening right now? What my very next step is. So, in that thinking, if you begin to discover that a lot of it is throwing you way out into the future. Can notice that you can see that for what it is, and then bring yourselves back to where we have a bit more control about what's happening right now, right in this here and now. Sometimes that's hard, so we can turn the "what if into what is." You know, that's kind of bringing it back to right now. Sometimes I just chat with people and like, you know, Julie, that's hard. That's hard to do. I'm having...I just kind of find that my mind is kind of he continually pulling me back again and again and again. And I need something else, and I said, well, what else are you doing? If that's hard, how did you make it to make it and commit today? You know, how are you sitting in front of me? And sometimes I've had many people say to me, "well, I found that there was something kind of helpful and maybe following my what if." So, maybe another way to address that thinking we're still kind of in that thinking path is "What if that happens? Can you take yourself down a journey of your worst-case scenario?" That might sound scary, but "what if I have these reactions? Or these symptoms?" or "what if I'm and then what would you do?" And sometimes there can be something very settling and very calming to coming up with responses are concrete their actions that we would do if some of our what ifs were some of our worst-case scenarios came to pass. So, sometimes when we come up with a concrete plan for a worst-case scenario, our for a catastrophe in our mind, that can be settling. It can be like, "Oh, I would talk to the doctor." "Oh, I would rather these things around me. I would explore what the next steps would be if that were to come to pass." And then, in doing that, we begin to identify, oh, goodness gracious, that's not at all where I am today. I've now



created a scenario that is very far away from where I am in my present and that helps me to get back to my here and my now. So, that is kind of what if, what if to what then, or what's next, right? So, you can do a lot of different things without “what if” thinking in your mind bring it back to the present. What is it, what what's right in front of me? Follow it and come up from a for a plan that helps you feel prepared. Our worry serves a purpose, right? Your worry is your both your minds best way of trying to prepare you or trying to help you to feel prepared. So, then you can use that and then come right on back to what it is right now. Okay, so that's one path that thinking.

Now, our thinking can also drive emotion. So, that my second path was that your stress or your stress distress might show up in your emotions, you feel fear, you feel worry, you feel overwhelmed. What is it that you know has historically are always helped you when you are feeling distress? Is it connecting with other people? Is it getting outside into the day and kind of getting perspective? Is it crying? Are journaling or what is it that you do that helps you to find comfort and ease when you are feeling emotional? Different feelings require different things. So, I always tell my clients in my office and the audiences that I speak to that maybe one of the first things that I would give you is homework is to cultivate a practice of noticing yourself. And just ask yourself, how am I doing? Like, what am I feeling right now? And then alongside that practice of noticing yourself, can you grow your feeling, words, vocabulary, you know? And right now, I'm feeling irritable and feeling really impatient. Okay? What is it that I need? So just a second ago, when I said if you pay it start to pay attention to your thinking, you might discover an unanswered question. Similarly, over here in the lane of feeling, when we begin to pay attention to what we're feeling, sometimes underneath a hard feeling or an uncomfortable feeling, we discover an unmet need. So, when you look at those feelings that you're having, I'm feeling impatient, aren't feeling overwhelmed, aren't feeling lonely, or I'm feeling scared. Is there a need? Do you have a need underneath that? Okay, I'm needing connection. I'm needing more information. I'm needing to slow down and to kind of paste this. I needing to kind of get organized. And to kind of prepare and prioritize what's ahead of me. And so, all of this feeling of overwhelmed is because I need to slow things down, and I need to kind of organize my next steps. All of this feeling that I'm having of kind of loneliness and dread is I'm needing a connection with other people. And I'm needing perspective and I'm needing some comfort. So, that's another thing to kind of when you're in this lane of feeling, do you discover an unmet need what you have, and then what are some things you might do that can maybe meet that need? Okay.

And then now, let's go over into that third lane, which is our body, right? So, you notice, this is, there's a buzzing fence and my body is just restless and I can't fall asleep because I'm just like there's a there's a buzz to my body or there's, there's just this heaviness in my shoulders and thigh or there's a knot in my stomach. Okay. Yes, that distress is also related to whatever is spinning around in your mind. We just talked



about that. And yes, your body is also feeling all of those feelings because you have emotions of sadness, are overwhelmed for sure. But what else can we do to just very simply, attend to your body. And sometimes, dissecting our thoughts can be complex, and it can kind of lead us to feel more intensity in our body. And sometimes our emotions are so big that it's hard to even uncover what that unmet need is because we're just so activated. So often, the very first step is attending to your body and finding some calm, and so that might be practicing what it feels like to just slow your breathing are to get your feet on the ground and begin to just find ways that you can quiet and calm your body and it can be really, really powerful to think that if your body is calm, often our mind follows and our mind feels calmer. So, begin to kind of explore ways that you can quiet and calm your body and there are techniques like breathing is very powerful. Sometimes when we say the word breathing, people find that very abstract like inhale, exhale and it's helpful to kind of have a strategy around breathing that you can kind of do or actively do. So, if you find that your body is activated or you're feeling kind of stressed in your body. There is a technique called square breathing where if you think about drawing a square in the air with your finger in front of you and then think of the two vertical lines of that square as inhale on the left and exhale on the right, and then the two horizontal lines, top and bottom as holding. So, if you draw that square, we're going to draw up and inhale for four counts. And then, we're going to go across and we're going to hold for four counts, and then we're going to go down and then square. We're going to exhale for four counts and then across the bottom and hold for four counts. And when we do that square, it kind of gives us a way to conceptualize or to actively think about that breath and slow our body down.

Another way of finding calm in your body and this is one that I think is incredibly helpful is a hug. So, maybe you're with another person that you care about and it feels that you can be you can be connected to, or maybe you're on your own and you can just tightly grab and hold on to your shoulders and give yourself a hug. But we know that when you're in a hug, whether that's with another person or yourself, it activates your parasympathetic nervous system, so that's the rest and restore part of our nervous system that helps our body find calm. And I find that not only a hug, but a gentle like sway like a slow dance, you know, kind of thing also helps to kind of slow and quiet our body. And so, when we think about this lane of tending to your body, how do you calm and quiet? So, might be breath. It might be that kind of tight hug that you do. It might be just standing up if you're sitting down. And going to see outside the window, it might be taking a drink of water and feeling the way that that cold water goes all the way down your system and really noticing your body. But that when we tune into our body and find some rest and some calm that shockingly or surprisingly, in my opinion, not surprising at all, our mind that starts to slow down and our emotions start the edges of our emotions start to feel a little smoother. So, I've kind of can structured this way of kind of practically or thinking about your emotion and your mental kind of stress as



something to think about as thinking, feeling, and body. Right? And if you can think of those as three different options, you have for attending to the swirl of anxiety or the storm of uncertainty and worry and fear and “okay, I’ve got options I can think about my body and how do I find calm?” “I think about my emotion and what does my what does that feeling?” Say to me, “what am I meaning in that feeling?” And then, my thinking, how do I kind of combat that thinking, think about those narratives and come back to the present or give myself permission to give that thought and that worry to my future self. So, how can I think about all of those things? So much more can be said goodness to only have 20 minutes to talk about this is just really not enough time and so I’m sure that we’ll hopefully in your questions in the things that come up as we talk later in this hour, we can share even more about how you’re going to navigate this terrain of your mental and emotional distress as you go through transplant. But before we get into questions, I would love to turn this conversation over to our other guests today. I’ll let you take the floor, Stephenie.

**Jennifer Gillette:**

Thank you so much. That was a wonderful presentation, Julie. We really appreciate you. And yes, I would like to hand this over to Stephenie Perry. Stephenie is a survivor of Stage 3B Hodgkin's Lymphoma. She was diagnosed in 2015 at the age of 26, during her last month of Graduate School. Through chemotherapy, radiation, immunotherapy, clinical trials and an auto stem cell transplant, and then an Allogeneic stem cell transplant, she reached her remission in 2018. Stephenie currently works part-time and lives in Northwest Georgia with her husband, Justin, and two beagles. She's been on a rough road but has an amazing story of strength and love, so prepared to be inspired. Thanks for being here, Stephenie.

**Stephenie Perry:**

Thank you so much. Excuse my voice. I'm getting over a cold. So as Jennifer said, my journey began back in 2015. I was in my last semester of graduate school. I had no genetic history of cancer in my family. I had just turned 26 years old, and I was considered to be in good health. I kept up with my annual primary care checkups on top of school and working part-time. I was going to the gym five days a week. I was notorious for going to class with a kale smoothie instead of snacks and a bunch of candy. So cancer was not on my radar at all.

The first symptom I noticed was my shortness of breath. I had just run my first half marathon and now I couldn't even walk to class without losing my breath. I attributed it to the high Georgia humidity and a flare-up in my asthma. The next symptoms I noticed were some small lumps in my neck. I didn't know much about lymph nodes, but I knew that they swell up when you're sick. So after a few weeks of taking over-the-counter cold medications, my sister insisted that I have the lymph nodes checked out by a doctor. Everything began to move rather quickly after that initial visit. There were so many appointments and tests that had to be done before I finally received my official diagnosis from an oncologist on April 28th, 2015. Twenty-six days after I





turned 26 years old, I was diagnosed with stage 3B classical nodular sclerosis Hodgkin lymphoma. At the time, the first line of treatment for this type of cancer was to do six months of chemotherapy. My oncologist told me that I was lucky because this was a very treatable form of cancer with a high survival rate. He assured me that I was young and healthy and living back to my normal life after six months of chemotherapy. That was not my experience. After arranging makeup finals with my professors, I was able to graduate alongside my classmates. I had my port placement surgery two days before the graduation ceremony, so I wasn't very coherent for the actual commencement. I had my friends physically holding me up while I was walking, but while I was waiting to walk across the stage. I watched my friends and classmates start their new careers as I started chemotherapy five days later.

Despite what the oncologist told me, my treatment did not end after six months. After multiple regimens of chemotherapy, immunotherapy, and clinical trials, I still needed to have a stem cell transplant. So we began the process for an autologous stem cell transplant that would use my own stem cells. I was introduced to the transplant clinic and did all of the testing for the preparation. We began high-dose chemotherapy, and I had to do self-injections of Neupogen to increase my stem cell production in the week before collection.

On transplant day, my own stem cells were transfused back into my body, and although many autologous transplant patients are able to go home the same day, I have to stay in the hospital for my first 100 days post-transplant because of my lack of transportation to and from the hospital. My port ended up getting infected a couple of days after my transplant, and I had to have an emergency port removal. So for the rest of the hospital stay, we had to run blood tests through my veins, which also eventually began to give up. I waited for weeks until my blood counts would return to normal so that I could finally be discharged. Unfortunately, shortly after I was discharged, we found that my cancer had actually been metastasized to my spine.

I began my first radiation treatment, specifically targeting my spine. I was put back on immunotherapy until my body was strong enough to move on to the second transplant. I was not happy with the results of my first transplant, knowing I would have to have an allogeneic transplant this time with a donor. I wanted to get a second opinion. I went to another cancer clinic and was able to find another doctor I felt comfortable with. We moved my treatment to the new cancer center and that was probably the best decision I ever made for my treatment. I continued my treatment with the new clinic and was declared in remission in February of 2018. My doctors were confident that we could finally move to transplant. My allogeneic transplant began with testing my family members to see if they would be matching donors and in a stroke of good luck, my one and only sister was a perfect match. So I began another round of high-dose chemotherapy and total body irradiation. My sister was also getting prepared, getting



a central line placed so that she could start her stem cell collection. Finally, it was transplant day, and again, I stayed in the hospital for the 100-day post-transplant quarantine period. I had my ups and downs during my stay, including trying to get my graft versus host disease under control, but my numbers came up faster this time and I was just charged before my 100 days were over.

The at-home recovery was difficult with all the restrictions, and I still had to go to the clinic several times a week for checkups and blood work, but those check-ins eventually became less and less frequent. I was officially discharged from my transplant center after five years. However, I'm still in communication with my team in case I have any issues that arise.

My cancer journey definitely came at an unexpected time. I thought I was going to graduate with my master's and go on to start building my career. Even with the curveball of cancer, I was still able to accomplish so many things. I met my husband during treatment. We got engaged the day after I found out I was in remission, and I planned my wedding from my hospital bed. And we just celebrated our five-year anniversary last week. I was able to keep a full-time job in my desired career field for a year. However, the long-term side effects of treatment made me realize that I was not ready for a full-time job just yet. I persevered and was able to find a flexible part-time position within my career field and this has now been the longest job I have ever had, and I continue to excel in my role.

I continue to work with my doctors, my therapist, and my chiropractor, in all of my goals. I continue to work on my physical strength to combat the fatigue so that I can eventually start working full-time again. I began working with a physical therapist at first, but I wasn't seeing much progress, so I switched to a chiropractor. That was a critical point in my recovery because, after a few months with my chiropractor, I was able to completely stop taking opioids for my pain. After years I'm finally able to take my dogs on walks again. I can stand long enough in the kitchen to prepare and cook a full meal. I'm able to carry my niece and nephew. I remind myself that these things that seem like small wins are actually large steps forward in my recovery.

There is no end to my cancer journey. It is teaching me new things about myself and the world every day. And throughout my treatment, I learned that I had to be selfish. I had to put myself first. I found reputable sources to do my own research. I asked questions and I spoke up when I wasn't comfortable with something. And I realize you have to take control of your own treatment. I began seeing a therapist during my treatment and I continued to talk to a therapist to this day. There are so many thoughts running through your head before, during, and after treatment. It helps to have someone to talk to you about it. A lot of my friends and family members don't understand what having cancer is like, so I sought out places where I could talk to other survivors. I



started going to local support groups and joined several Facebook support groups as well. One of the biggest lessons I've had to learn was how to give myself grace. Recovery takes a long time and it's different for everybody. I've had to learn to listen to my body. I know that when I'm feeling more pain and fatigue that I have to take it easy because my health comes first. I still have good days and bad days, and I let myself have the bad days so that I can let out all of my emotions, but I don't let them take over. I keep moving forward and I keep living.

Thanks for having me today and I look forward to your questions. And I turned it back over to Jennifer.

**Jennifer Gillette:** Thank you so much. We appreciate you being here and sharing your story, especially with the cold. You are a trooper

Jericho, can you please let our callers know how they can ask questions today?

**Operator:** Yes, thank you. We will now begin the question-and-answer session. If you have dialed in and would like to ask a question, please press star one on your telephone keypad to raise your hand and join the queue. If you would like to withdraw the question, simply press star one again. We're going to pause for just a moment to compile the Q&A roster.

**Jennifer Gillette:** While we're waiting for the queue to get a couple of people in line, Stephenie, I have a question for you. As far as if you would have had any understanding that this was coming your way because I know a lot of times when people get diagnosed, things go very fast. Is there anything for those callers that are real new to the journey that you can share might help them prepare mentally, or even just practical things around the home that maybe they could do to get ready for a transplant?

**Stephenie Perry:** Well, one of the best things I did was creating an online calendar. We did a Google Calendar every time I had an appointment, or I needed a ride somewhere or there was some something happening, I would put it on the calendar. And I shared it with everybody in my family and any of my friends who wanted to be involved. So if they ever saw a time on the calendar where like they just saw that I came back from chemo, they would know to check in on me. Or they would see that I'm going to the hospital one day, so they'd ask me if I needed a ride. That also helped me stay organized because multiple people had access to the calendar like your memory kind of comes and goes, so it helps me as well so that other people can take a look at the calendar. As far as around the house, we just made sure that everything was kind of comfortable and quiet so that when I did come home from treatment that there wasn't too much going on. Luckily, it's like my house doesn't have a lot of little kids or anything, we just have two dogs, so it was easier for us. But if there's any way to prepare your house, to just make it more of a calming, soothing environment, I think that really helps as well.



- Jennifer Gillette:** Great. Thank you so much. Jericho, do we have anyone in the queue?
- Operator:** There are no further questions as of this moment. Just wanted to remind you again if you would like to ask a question, please press star one.
- Jennifer Gillette:** Okay. Well, as we are waiting for anyone that might have questions, I'll throw this next one to Julie, but then also, Stephenie, if you have thoughts too. I am curious to both of you knowing that going through the hospital stay can be so challenging. Is there any tips that either of you, and we'll start with you first, Julie, might recommend to help people get through those tough days being in the hospital?
- Julie Larson:** I think I might maybe beginning with knowing who's all on your team. I mean, I think we obviously know our doctors and the people that have kind of helped us to figure out treatment planning and prepare. But when you're in the hospital, who are the different nurses that are walking in every...or touching base with you, not necessarily walking in but touching base, who is available to you as far as other complementary alternative care options, for comfort and for management of side effects, is really understanding all the players who's there and what supports you have. And then in the hospital, I've had patients talk to me about all kinds of different things that they found helpful to them, bringing their own, some of their own things from home so that it felt comforting and familiar and nice for them. Getting activities that that they could do that didn't require a lot of intense thinking, but somehow occupied their attention. So things like knitting or coloring or crossword puzzles or Sudoku, or watching a show that they could kind of turn their attention to that and it and it occupy...so their mind wasn't always spinning or thinking. Things that were Stephenie already said, but just very restful, just calming and soothing. So ways that you can create a space for yourself that feels nice too. I don't know, Stephanie, what would you have to add?
- Stephanie Perry:** Yeah, pretty much all the same stuff. I know since I was in the hospital for so long, I had my own pillow. I brought my own sheet. I had like entertainment things like you said, so I really like scrapbooking during my second transplant. I had my friends bring me a wedding planning magazine, so that really kept my mind off of it. I had my Nintendo Switch so I could play games, and I wasn't feeling like doing anything else. There was even...I remember my neighbor in the next room, he had brought his guitar. Playing music that really helps and sometimes like his family would come and they would have a whole jam session, and I would just kind of listen in and in the hospital. Yeah, it was really fun, actually. But in the hospital, they do, they encourage you to do laps around the hospital floor just so that you can get moving and stuff. And there's other people walking the floor, other patients and they're in the same situation as you are. So don't be afraid if you're passing somebody in the hall, just start up a conversation like you're probably the only person other than nurses and doctors that they've talked to all day. So just whatever makes you comfortable. I even had a friend.



She printed out pictures and she put them all over my hospital room. So I had pictures of all my love. I put up a poster in my room that said, like everyone who's visited room, whatever was in and everybody who came to visit me, you know, it was like a little yearbook. Like they would write me a little message. Those days that I didn't have somebody who came to visit me, I would still have that poster board there reminding me of all the people who had been there. So just there's a lot of things that you can do to keep the mind occupied, yeah.

**Julie Larson:** Alright. I love that and somebody as (indiscernible). Oh, sorry. Go ahead.

**Jennifer Gillette:** No, go ahead, Julie. I just thought I loved that.

**Julie Larson:** I do too, and in so many concretes that we're talking about practical things, Stephenie, you just brought up so many really thoughtful and intentional ways that you kind of used to get yourself for that long period of time. I love the yearbook poster board. I mean, what a cool thing. Yeah, and you know...

**Stephenie Perry:** Yes. And I still have it.

**Julie Larson:** What?

**Stephenie Perry:** And I still have it, so I still have it in my house.

**Stephenie Perry:** Of course, you do.

**Julie Larson:** You know, so many of my clients, I don't know about you Stephenie and those who are listening, but so many of my clients talk about so many people wanting to be of support and wanting to help but not quite knowing exactly what to do. And some of the things you said are beautiful things to direct other people to do like, "hey, bring me craft things or write me a letter." I've had so many people that I work with say that what's the most helpful thing for you? People have said to me the caregivers in my life, the friends and family in my life, who wrote me cards because I could reread them. I could look at them again and it kind of makes me think of that yearbook poster board that you have. You know that when people are asking what to do, write my card, give you something that you can go back to again and again.

**Jennifer Gillette:** You know what? I just want to piggyback on that and share with everyone too. And this is done, I worked at a hospital system for years and years and there was this wonderful lady who eventually ended up teaching a class about making a scrapbook with like those cards and things. Because we were talking in one of our support groups about how sometimes on this journey there's very lonely spots, and it's hard because the people around you are also trying to still work and trying to maybe help with kids or help with different things. And so those moments where you're more alone, if you have those cards or you take pictures of the flowers that were sent or you make a note



of a nice gesture or something someone did for you, you can take that little book out and remind yourself I'm not alone on this. Today just might feel a little more lonely, but I have a lot of people that love me right now and care about what I'm going through. And so I just want to add that because I loved that when she did that class, I think it helped a lot of people.

But anyway, Jericho, is there anyone that wants to ask us a question?

**Operator:** Yes, there is. And the first question comes from Melissa. Your line is now open.

**Melissa:** Hi, everybody. Thank you so much. My mom is going to be having a bone marrow transplant pretty pretty soon. Unfortunately, the donor backed out and she was supposed to go into the hospital this Saturday. So we're just getting prepared for during hospital and after hospital. So my question is around when you're home and animals, right. She's got two small dogs. Stephenie and the other lady, I'm just curious, how important is it about the cleanliness around these animals? Because I know sometimes animals are therapy as well. And I know they are going to be her therapy. But I've been reading a lot of things about, like, don't let him jump on you, don't let him kiss you, don't let him scratch you. How to...if somebody can kind of talk to me about that a little bit.

**Jennifer Gillette:** Stephenie, since you have two dogs, let's start with you.

**Stephenie Perry:** Yeah, I do have two dogs, and during my recovery, when I went back home, I actually had...so my husband, he was just my boyfriend at the time, I actually had him take the dogs to his house so that I could recover without them. And that's just because my dogs are so active, and they love to lick my face. They love to jump on me, and I just couldn't even walk them. So he just took on that responsibility. And I think it depends. I think the restrictions are less now than what it was when I had my transplant. So your clinic should give you all the instructions. But I would say if they're a very licky active dog, maybe just for the first few weeks at home, maybe just separate for a while until your mom's more stable, and then try and introduce her back slowly.

**Julie Larson:** I would echo that that sounds like a really important and not at all trivial conversation for the medical team to understand that you are kind of just keeping her safe and wanting to make sure that she stays healthy especially when immune compromised. But I do hear you on the piece that a pet...and especially a really very well-loved pet is comfort and a type of self-soothing option as well. So where are those limits? Maybe that animal can be in a specific space but not in the bedroom or somebody else is helping with general hygiene and care of the animal, but this is just for cuddle moments. I don't think that those kinds of your figuring out boundaries.

**Jennifer Gillette:** Thank you, both. Jericho, do we have any other calls?



**Operator:** Yes. Our next question comes from Sandy. Please, the line is now open.

**Sandy:** Yes, good afternoon, everyone. Can you hear me?

**Jennifer Gillette:** Yes, good afternoon. Welcome.

**Sandy:** Good afternoon. Yes, thank you. I don't have a question per se. I just want to say that I was very inspired by the two ladies, especially Stephenie. Your journey through your transplant. I had a transplant, bone marrow transplant, November of 2022. And what she was saying about getting yourself involved. I just want to put like a little spiel. When you're in the hospital, yes you feel very vulnerable. You're lonely at times and nobody's there. I just took myself out of the bed and got up every day. Got dressed, walked the hallways, and I met everybody on my floor. Talk to them, became friends with everybody. I got to see a little boy; we became friends. He bought me a little stuffed animal. I bought him a little fire truck. We played with each other every day. I had my journal there. My daughter gave me a photo blanket with my grandkids on the blanket and everything, their pictures. I took pictures. I have my bible. I was involved in everything. I get set up lives every day and I really like...even though, yes, I had the anxiety and whatever and I had to stay in the hospital too because I was more than 60 miles from the center. But I was very...I kept myself to be busy and try to just encourage myself. And therefore, I encouraged others. Like I said, I met everybody, and when I didn't get around for a couple of days, the people would ask the nurses, "Where is Sandy?" Whatever. But it's just you take yourself out of it at times, even though you may not feel like it, but you just have to keep pushing. Just keep pushing and just realize and maybe somebody else going through something worse than what you are going through. And as far as the animals, my oncologist told me when I got home, I didn't have any, he said, but I advise you not to be around any animals at first. But like the previous lady said, they were very effective. Of course, they're going to lick you and kiss you and all that stuff. And your immune system, you don't have an immune system after you had the transplant. So you don't want to get any type of infection from anyone. But I just want to compliment the two ladies that spoke. I really was inspired by your words, your inspiration, your journey. Just keep on fighting. Just keep on going and you'll get through it. That's all I have to say.

**Jennifer Gillette:** Thank you, Sandy. You're voicing inspiration too.

**Sandy:** Thank you.

**Jennifer Gillette:** Jericho, do we have any other callers on the line?

**Operator:** Yes, we do. The next question comes from Anna, please, your line is now open.



**Anna:**

Hi. I didn't have a question. I just wanted to just actually maybe even echo some of the things that were mentioned before. After...you have to try different things. And maybe on lavender I was very nauseous and nausea was a big thing for me. And one thing a nurse did was he had these little packets, I mean, tiny, not sachets, little quarter-sized packets that he would put near my pillow. And it wasn't overwhelming like peppermint or lavender. Sometimes it helps, sometimes it didn't help. So if you...I don't know, nausea was a big thing for me. Also, I think that overall, you have to give yourself some grace and allow your feelings like one day you might be very upset about something and another day you're like, oh, this is not so bad, and kind of go with the highs and the lows. I tried after a while sort of temper things out, temper things a bit because I felt like once I got over one hurdle, there would be another issue. But if I just took it kind of in stride instead of saying okay now, I'm cured or now I don't know this infection is better so that's it, now I'm better. But then there would be something else down the line. I think your kind of just go with the flow instead of...it was easier for me to keep things tempered as opposed to being at either extremes of emotion, either very happy because I had overcome something or very low because I was in the midst of some issue. And so for me, it was better to be somewhere in the middle most of the time rather than be very happy or very sad. That helped me sort of like just to keep a better perspective on things and I want to thank you both for this presentation.

I agree with so many things you said. And somebody asked about preparation. I know you touched upon it. I also had to stay at a residence across the street from the hospital because I lived about two hours from the hospital. And one of the things I did was I left everything packed so that when I got out of the hospital, I didn't have to tell my husband, my kids, "Ohh, I need this and this and this," and pack them. I was too weak to do that. And I was so grateful that...I don't know somewhere I had read or heard that to leave everything as much as you could leave, pack if you weren't going to bring it with you to the hospital. And that was very helpful, but I don't know where I heard it, but it was one of the best things.

**Jennifer Gillette:**

Thank you for that tip. We appreciate that and I appreciate your comments and sharing.

**Anna:**

Hi there.

**Jennifer Gillette:**

Hello. Hello. Well, thank you. Thank you. And I know we need to start wrapping up, but such a great presentation and thank you everyone for being a part of it. Thank you to our wonderful speakers, and those wonderful people that gave additional tips. And I just want to remind everyone, this will be on our website if you want to share it or relisten. It usually takes a few days, but it will be there. Make sure to stay tuned, you can go on our Facebook page or on our website for future programming. But if anybody else needs additional support, please feel free to reach out. Thank you again all, have a wonderful day.





**Operator:** This concludes today's conference call. Thank you for joining. You may now disconnect.