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**Executives:**

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Michelle Bishop, PhD - Clinical Health Psychologist

Janice Chabros - Acute Lymphoblastic Leukemia (ALL) Survivor

**Operator:**

Hello and thank you for standing by. At this time, I'd like to welcome you to the National Bone Marrow Transplant LINK 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 the 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 being on this call today. Yes, my name is Jennifer Gillette, and I am the Staff Social Worker at the National Bone Marrow Transplant LINK.

I'd like to welcome you to our Lunch & Learn with the LINK. This month's program will focus on "You Look Great, What do you Mean You're Tired and Still Struggling with Post Transplant Issues." I'm sure it's something that everyone on this call has experienced.

A special thanks to our generous sponsors, the Leukemia & Lymphoma Society, Johnson & Johnson, and Incyte. We also thank our esteemed LINK partners.

Just so everyone knows how our call will go today, we're going to have a very brief introduction of the National Bone Marrow Transplant LINK for those who are not familiar with it, and then I will introduce our health professional, Michelle Bishop, who is a Clinical Health Psychologist who will focus on how survivors handle well-meaning friends and family, especially during the holiday season, who want them to get over their illness and just get back to normal. And then, we'll hear from survivor, Janice Chabros, an Acute Lymphoblastic Leukemia (ALL) Survivor. She will share



her story and how she manages these types of situations. And then, we'll open up the rest of the call for questions.

So, for those of you who are not familiar with the LINK, our mission is dedicated to helping individuals and their families from diagnosis through survivorship. We provide resources, support, and education.

We do this through the following:

- We have our monthly Lunch & Learn calls like you are on today. And that's on a variety of topics. It could be survivorship issues, GVHD, disease-specific issues
- We have our Marrow Masters podcast program. We have 15 seasons to date with more than 34,000 downloads
- We have our annual webinars. One is actually happening next week, so if you're interested, go to our website and sign up. It's on GVHD
- And then, we have our popular award-winning resource books on all things bone marrow stem cell transplant
- We have our healing arts program, a four-week series of journaling, watercolors, and craft sessions
- We have our peer mentor support program where we buddy up newbies with post-transplant survivors
- We also have our celebrating second birthday program
- We have our Survivors Thrive Book Club
- Our Coffee Klatch, which is a support Zoom for survivors and caregivers
- And we have an active Facebook, Instagram, and Web page to inform on our supports and resources from many organizations
- We are also part of the GVHD alliance, which is uniting more than seven recommendable like-minded organizations to raise awareness, education, and support for those facing the disease

For more information, you can go to [www.gvhdalliance.org](http://www.gvhdalliance.org) as well as you can go to our website at [nbmtlink.org](http://nbmtlink.org). So, feel free to reach out to us if you are interested or are needing any of those services.

Before we begin today's program, I would like to review a couple of housekeeping items to maximize the experience of all on the call today. First, I ask that you please try to be mindful and concise with questions when we get to that section of the call so that we can answer as many as possible. You'll ask for one question at a time and then your line will be muted, and you can get back in line if you have additional questions. Also, please know that the information provided in this program is meant to stimulate conversation with you and your own healthcare provider and is not meant to replace your individualized medical plan.



So, now on to the educational part of our program. It is an absolute pleasure to have Michelle Bishop back with us. Dr. Bishop is a Clinical Health Psychologist who has worked with cancer survivors and caregivers, including those treated with HCT for 30 years. She has spent the first half of her career at the University of Florida. First, as a clinician providing inpatient and outpatient care to HCT families and later as a research faculty studying HCT survivorship and quality of life and HCT caregivers' health care. In 2009, Dr. Bishop moved to private practice to provide direct clinical care to cancer and transplant survivors and their care partners, which she remains today. She served as a consultant to NMDP on their caregiver companion program as a speaker and chapter author for the National Bone Marrow Transplant LINK and is a speaker and consultant for BMT InfoNet. She currently is working on several projects with BMT InfoNet to address the unmet mental health needs of HCT survivors and is the program lead and a facilitator for the chronic Graft-Versus-Host Disease support group program.

Michelle, thank you so much for being here today.

**Dr. Michelle Bishop:** Thank you, Jennifer, and thank you to Peggy and to National BMT LINK for inviting me to participate in this month's Lunch & Learn. I am so glad to be here with you and Janice. I love the programs you do, and I think it's so important to do one related to the holiday season since this time of year can bring unique joy, as well as particular challenges. And thank you all patients, survivors, care partners, and support people for calling in today and being part of this discussion. I really look forward to hearing your questions and ideas later this hour.

So, we typically think of the holidays as a period of joyful gatherings, pretty lights and decorations, fun celebrations, and traditions. But frankly, this time of year can also be pretty stressful. One can feel overwhelmed with all the expectations, activities, and obligations. It can be wonderful to see family and friends, but sometimes those gatherings can also bring tension or conflict when we don't always see eye to eye. And the season can bring feelings of sadness, grief for those we've lost and memories of time gone by. These stressors are amplified and become even more challenging for survivors of cancer and transplants. Having low energy, experiencing pain, not feeling well, or being immunocompromised make it difficult or impossible to participate in activities you used to enjoy. One can feel down, frustrated, lonely, and socially isolated. And social isolation is often made worse when others don't understand why you need to wear a mask, or why you can't attend an event, or why you need to cancel at the last minute because often you don't know how you're going to feel from one moment to the next. To add insult to injury, folks may say things like, "Hey, you look so great, I thought you were done with treatment. What's the problem?" or "Why are you still wearing a mask? The pandemic is over" or "What do you mean you're tired and you have to leave early? You look fine." Unfortunately, very few people



understand that the effects of treatment, particularly the high dose treatment used with stem cell transplant, often have lingering late and long-term effects that continue for months, even years, sometimes after transplant, long after one's hair has grown back. And often these lingering effects like pain or fatigue, are invisible as well. Making it even harder for others to know that you're still dealing with challenges even though you "look normal". Or you might be dealing with a new complication of transplants, such as chronic graft-versus-host disease, which the majority of folks have never heard of and really don't understand. So, the question becomes, "How do you cope with all of this?" And so today we're going to talk about some of the specifics in terms of what people say, but also in general, how to manage some of those stresses of the holiday.

So, fortunately, there are lots of things we can do to make it more manageable and enjoyable, and I'm only going to highlight a few here and I have to confess I literally cut my presentation in half last night when I realized I had way too much material, as there's so many different ways of coping, but I'm excited that we have about half an hour for the Q&A. So, we'll be able to talk about lots of other examples at that time.

So, the first suggestion I have is to start off by giving yourself space and grace. So, what do I mean by that? Well, all the thoughts and feelings, the expectations and frustrations, the hopes and fears you're experiencing can be overwhelming. All of it can build up and create a lot of inner tension and pressure and anxiety inside. So, it can be really helpful to just stop for a moment, step back, and take a breath (inhale, exhale). Like, just slow everything down. Give yourself space, room to breathe, and the grace to let go of any expectations you have of yourself or of trying to do it all. We put a lot of pressure on ourselves this time of year, we should on ourselves. We feel like we should do things in a particular way, or we should feel a particular way. We can even get down on ourselves for feeling down, pressuring ourselves to be jolly this time of year. If you think about it, would you ever say to a friend or a loved one who had just been through all you've been through? "You really should get going on those holiday cards." "You really should run to the store and plan all those meals." or "What do you mean you're tired? You should just be grateful to be alive." Of course, you wouldn't talk to someone else that way. That would be terribly mean. But often, that's how we talk to ourselves. If you were talking to someone else, you will encourage them to take it slow if they need to, and to not feel like they have to do everything.

So, one practice is to try to talk to yourself as you would a friend with empathy, understanding, and self-compassion. You can recognize with kindness all you've been through. Perhaps appreciate your poor body who's been through the ringer, but still here and needs a little extra loving care. Perhaps acknowledge that things might be different this year, and that's okay. You're still adjusting to changes and you're doing your very best. Also, recognize that you likely will be feeling a lot of what makes seem like contradictory feelings, such as feeling grateful to be here for another holiday, but



also tired, perhaps or sad, and that's okay. It isn't an either or. It's a both ends. What I mean is that both those things are true at the same time.

So, in terms of creating space for yourself, there are lots of ways to do this. Could be quiet reflection, prayer meditation, going for a walk, doing art, writing or journaling. Basically, give yourself time to reflect on what's most important to you. What's most meaningful to you about the holidays. And then, check in with how you're feeling and doing in the same way that you would check in with a friend. You check in with your mind, your body, your emotions with curiosity and care, without judgment. So, as you would ask a friend, you'd say, "How are you feeling?", "What do you need?", "What's your energy level today?", "Where do you feel pain?", "Where do you feel ease.", "What can you do to make things better?", "What would feel good today?" So, we could call that tending and befriending yourself.

So, the first suggestion was space and grace, and the second is to tend and befriend. So, when you do this, you check in and really listen. Now, this is the key. Really listen to what your mind and body are telling you and not override what it's saying. You'll be in a much better place to use your wise mind in planning the season so that things will go more smoothly. Having checked in with yourself with curiosity and kindness, you should have a good sense of what your energy level is like these days, how long it lasts, what times of day are better or worse for you, etc. And you can use that information to prioritize where you put your energy and how best you want to use it. Can you keep it simple this year? So, for example, looking over the entire holiday season, you could be really intentional and planful, which is suggestion number three. It might make sense, for instance, to only schedule one activity a day or one every couple of days. It will likely be important to schedule in downtime, to rest and recharge in whatever ways work for you. Give yourself permission, or even better, encourage yourself to say no to things. Be discerning and selective with your precious limited energy and time. Remember, you'll get more from being fully present for a few things, than stretching yourself so thin that it's hard to not be present at all.

It will be really important in this process to try to openly communicate with your loved ones, so I'm going to call this one number four. Let them know how you're feeling and what you need. Sharing thoughts, feelings, and worries can lead to greater understanding with others. It can also lead to working as a team as you navigate the holidays together. If others know what you're thinking, feeling, and needing, they're more apt to be able to help you with those holiday plans and even come up with some creative solutions. Telling people how you are or how treatments are affecting you in advance can also help prepare family and friends if you're experiencing physical or cognitive changes. You can let people know ahead that you may not be able to participate in all or certain activities, or that you may need help with physical tasks such as cooking and decorating. You could also elicit the help of a loved one to run



quote interference for you and alert others of your current status and needs. You could plan ahead with your loved one to navigate social situations. For example, discuss beforehand how long you think you'd like to stay in an event, or perhaps agree on a cue to use to signal to your loved one when you feel tired and ready to go so, he or she can help you navigate the graceful exit.

Now, in terms of planning for seeing people and preparing for those darndest things that they say like “Oh, look so good” as we mentioned in the title of this Lunch & Learn. It may be helpful to prepare some answers ahead of time. Remember, if it isn't obvious on the outside, folks don't know how you're feeling on the inside. They may think in kind of black and white, or either or terms too. Thinking that you're either sick and in the hospital, or healthy and back to normal and not recognize those lingering effects of survivorship that we talked about. So, before you respond to others, first check in with yourself. Do you want to explain how you feel or not? Do you have the energy? Do you think this person really wants to know? There's really no right answer. You can actually create a menu of answers that you can have at the ready. For example, if someone says, “You look so great” you could say, “Thanks” and just leave it like that. Even if you don't feel great inside, you don't need to explain, it's okay. Or you could add, “Thanks, I wish I felt as good as I look.” Or if you want to give more information you could say, “Thanks, I know it can be hard to understand, but the treatment causes some ongoing problems that I'll probably deal with for some time. But you know what? I'll take it. I'd rather deal with those things and not be here at all.” Now, if you're interacting with someone you feel closer to, you could consider kind of coaching them up and letting them know more directly what would actually be more helpful or sensitive for them to say to you. So, for example you could say, “You know, I appreciate your words, and I know you mean well, but sometimes it's hard for me to hear from others that I look good when I don't feel well inside. Could you maybe say you're just glad to see me? That would actually feel really good to me.” So, I mean, hopefully just by saying it's been quite a year, and I won't be able to do things the same way this holiday, I hope you understand, people will get it. But frankly, if they don't, oh well.

So, this brings us to the last point. We can't control what others say and we may not be able to do things in the same way as we did last year. But we can practice being flexible and creative in order to get the most out of the holiday. So, I'll call this number five. So, flexibility and creativity are key ingredients for resilience, and they signify what we call a growth mindset, the willingness to bend and flex as things unfold focusing on what's most important and meaningful instead of a more rigid mindset which can actually create greater suffering for ourselves when things don't go exactly as planned or as we want them to. And by the way, I'll point out that you all are demonstrating a growth mindset to just by being here today, you're showing curiosity, a desire to learn and explore, and an openness to consider different ways you might approach the



holidays this year. So, some specific examples of flexibility and creativity, I know we could come up with a bunch together and we probably will share some ideas in the Q&A, but here are just some concrete examples. So, if you don't feel up to a particular tradition or ritual, could you find an alternative? Could you buy, let's say, a special bread or a holiday dish that you'd like to serve instead of making it from scratch? Could you send holiday greetings via e-mail or social media instead of sending cards? If being in crowds feels unsafe or uncomfortable, could you participate in a concert or religious ceremony via live stream, Zoom, or FaceTime? What about letting others help put up decorations, make food, shop, or wrap gifts? You could extend the holiday into January so you can enjoy the company of loved ones at a less frantic pace, or even consider doing Christmas or Hanukkah in July when you could celebrate outdoors. Remember the spirit of the holidays can be extended throughout the year. We can take pressure off ourselves. We can make it whatever we want it to be. And it's okay to try something new.

You know, I think about an example from my own life. When my dad died a few years ago, my mom couldn't bear to have Thanksgiving in the same way we'd had it for years. So, that year we decided to spend Thanksgiving at the beach. Now mind you, we live in Florida but not on the coast. But I'm originally from the Northeast, so even down here, Thanksgiving was always inside with all the traditional food and company. But I'll tell you spending Thanksgiving at the beach that year was actually pretty great. It gave us some space and grace to be with our feelings. We made a lot of the same food, but then we got to take a long walk on the beach to walk it off, which was pretty helpful and an added bonus, we didn't have to clean the house to get ready for guests. So, I'll tell you, it really shifted things for us and actually since then, the last five Thanksgivings we've spent at the beach, it's become our new tradition. It's not better or worse than before, just different. And just as lovely. So, you never know the changes you make could become new traditions that live on.

So, I'll wrap up with these parting thoughts. The end of the year is often a time of reflection. It's an opportunity to look back on all we've been through and where we find ourselves now. I often think about the impact of diagnosis and treatment as a shattering of all we once knew, and thought was solid. It might feel like we're standing in the aftermath with shattered pieces of glass surrounding us all over the floor. Survivorship is a process of going through all those fragments, picking up each one and examining it, and deciding which ones we'd like to take forward with us as we create a new mosaic of stained glass, and which ones will leave behind. That new arrangement, that new stained-glass mosaic will be different than the one before transplant but no less beautiful. Deciding what to pick up and what to let go of during the holidays is a similar process, and I wish you all space and grace, and peace and ease as you move through this period of time. Thank you so much.



**Jennifer Gillette:**

Thank you, Michelle. As always, so much wisdom and we appreciate you sharing it as well as I love the story about what you did after you lost your dad. What a great way to make space for those feelings and to support each other.

And now, I would like to thank Janice for being here with us. She is a blood cancer and stem cell transplant survivor diagnosed with Acute Lymphoblastic Leukemia in December 2017 at just 36 years old. Janice spent six months battling her cancer with treatment, culminating in a stem cell transplant in June 2018. Following her transplant, Janice spent years learning how to navigate her new reality, one which still includes challenges around GVHD, chronic fatigue, brain fog, pain issues, PTSD, and more. Although it's been a rough road full of unforeseen potholes, Janice has discovered how to embrace her new life as a survivor and has chosen to channel her limited energy towards raising awareness of the impacts that blood cancer and stem cell transplant can have on a patient. Through sharing her struggles, Janice strives to provide other patients with hope and understanding, to help them see that they too can find joy and a life that has been turned upside down by illness.

Thanks for being here, Janice.

**Janice Chabros:**

Hi. Thanks, Jennifer and thank you to the National Bone Marrow Transplant LINK for having me and a wonderful hello to everyone on the call today.

Michelle, what a great insight and tips for preparing ourselves for the holiday season. It's so helpful when we can set ourselves up for success and your steps definitely jive with my own experiences. I also absolutely love your analogy with the stained glass. I mean, think about it. We all have an image of ourselves and our lives that is so often shattered by illness. Then, once we begin to rebuild our lives again, those images inevitably looked so vastly different from the ones we started our life journeys with. Picturing your new life as a beautiful and unique mosaic on your own, I think it's such a lovely perspective on just the whole thing.

Now, before I dive into the knotted light strands of this discussion, let me just share a little bit about myself. As mentioned before, I was 36 years old when I was diagnosed with Acute Lymphoblastic Leukemia. And as a young adult facing cancer, my life was instantly put on hold, and the future that I had planned for myself immediately became a giant question mark. At that time, I had an amazing career and my husband, and I had just bought a house and we were trying to conceive our first child. We had envisioned a future for ourselves that went up in smoke the day I was diagnosed. With the uttering of three simple words, "You have cancer", spoken a mere five days before Christmas in 2017, a local ER doctor set my life in motion toward an entirely different direction than I had ever imagined. At the time of my diagnosis, my husband and I were set to host in our new home, our very first big family Christmas gathering. Then,





just five days before Christmas, we were violently stuck through the black hole and spat out with extreme force and cancer levels. As you can imagine, I now have a rather complicated relationship with the holidays. After six months of bone marrow biopsies, chemotherapy, lumbar punctures, and total body radiation, my treatment culminated in a stem cell transplant. Now, regardless of if it was a blood cancer or some other ailment that led you to a stem cell transplant, the aftereffects are the same. Once we allow ourselves to acknowledge the trauma that we have endured and potential latent side effects of our treatments, the next battle begins. It's time to create a new life image, a new mosaic assembled from the shattered pieces of a life now changed. From relationships with others to our relationship with ourselves, from physical appearances to emotional complexities, and from wanting desperately to return to normal only to find oneself in a new sort of existence, our lives become seemingly endless battlegrounds of duality. We weren't nothing more than to step back into our former self as if nothing has happened, but that's just not the outcome for many.

Patients experience various reality checks during treatment and beyond. One of the first is how everyone around you changes. Your nearest and dearest remain your nearest and dearest if you're lucky, but most of the relationships you had before illness will undoubtedly change to some degree. Some may improve. Sadly, however, many relationships will fade and dissolve into nothing more than cherished memories of the time gone by. And still others who will remain in your life, but in a sort of altered way. Now, friends and family start treating you differently when you're in the thick of your illness, they see your bald head, options skin, significant weight changes, and more and interpret all of those physical signs as obvious indications of your struggles. They treat you with kid gloves and are deathly afraid of staying or doing the wrong thing. But what most of those well-meaning people fail to recognize is that even after those physical manifestations of illness diminish, we patients are not magically made whole again. We try to return to our former selves but inevitably learn that doing so is virtually impossible. Our lives have been forever changed by illness. The old you ceased to exist the moment you were diagnosed with your illness, and that's reality check number two.

You see, there are three very distinct realities for every stem cell transplant patient. There's life before illness, their life during the cocoon of active treatment, and a new life post-treatment.

Now, the challenge for every survivor is to find some way to merge those three very different realities into one singular life. Despite the inevitable anguish of accepting the considerable changes often forced upon us by illness, we all anticipate healing to mean that we've returned to our former state of existence when in fact dealing doesn't mean that at all. Healing means that we have adapted and found a new minimum level of comfort in our new reality. We have welcomed changes, often begrudgingly, into our lives and woven them into the fabric of our being. We have evolved into a new version



of ourselves. Recognizing and accepting our life evolution is hard enough for the patient, but more infuriating are the expectations of others who are unable to appreciate the changes we patients have undergone.

There are two types of people that contribute to a less-than-ideal holiday experience for us stem transplant patients. The first is the most obvious. I mean, the holidays are a time when you interact with family and friends for whom you care deeply, but which you often only see periodically. Now, those people have absolutely no first-hand knowledge of your struggle to survive, nor your continued challenges in your day-to-day life. And most have no clue what it even means to be immunocompromised. Let alone to realize that your life has changed so drastically. It can be almost forgiven for these types of people to make improper generalizations about your recovery. They rarely see you after all. But it's the second type of person that often causes us patients the most harm things. More often than I'd like to think, those closest to us can often fail to fully comprehend our situation. I could share countless stories of things people have said to me that have cut me to my core, yet they perceived no harm in their seemingly innocent words. This is why only patients have to make important decisions. Do we lash out at our loved ones for their insensitive remarks, which often Prednisone causes us to do? Or do we smile and politely shoulder the burden of their words?

My first holiday season post-transplant, I chose the latter. I was so defeated by fatigue, brain fog, pain, and grief that I didn't have the capacity to reply to the comments of others who, through no fault of their own, were unable to recognize the barbed wire that engulfed the words they spoke. Nor had I yet developed the armor needed to protect my fragile emotions or learned how to adequately advocate for my needs and set my new boundaries. So, after gathering, back in the comfort of my own home, and alone in the dark, I would let the rivers of tears stream from my eyes. I would replay the words said by others and dream up responses that would have stopped those words dead in their tracks. But also, would have likely caused irreparable damage to some of my closest relationships. In time and with much closed-door practice against my own reflection in the mirror, I gradually acquired some better coping mechanisms for when people inadvertently say things I wish they didn't.

Now, it's been nearly seven years since my diagnosis, and for the most part, my outside now looked like anyone else. There are no longer those obvious visible signs of illness to indicate that my life is not just like that of any other person in their 40s. But what people don't see, what is still common in the world of invisible illness is that my insides are far from normal. I've had to navigate numerous negative encounters with family and friends over the years, with some I've actually been forced to sit them down multiple times and thoroughly explain to them how and why their words and expectations of me are hurtful and teach them ways in which they can support me rather



than break me. For others, especially when the relationship is less intimate, such as with extended family for example.

I've learned that there are things we can say in the moment to protect our delicate emotional state without needing to delve into the nitty-gritty of our everyday struggles, much like Michelle discussed earlier. One of my favorites is when somebody tells me how great I look or says something along the lines of, "So you're all good now, right?" Wrong. To those people, my favorite retort is something akin to, "Oh, how I wish my inside looked as good as my outside." Or perhaps, "Well, the cancer is gone, at least for now, but I really just traded in one disease that was trying to kill me quickly for multiple chronic illnesses that I'll have to manage for the rest of my life." These types of comments let other people know that they have accidentally found themselves unfeminine, but at the same time, I've given them a choice to add a reverse course or ask more meaningful questions about how I'm really doing. No harm, no foul.

And if people show curiosity in my struggles, I often use the opportunity to educate them. For example, if they ask about my new chronic illnesses, I teach them about graft-versus-host disease. I share with them how GVHD is something akin to an autoimmune disease, but instead of my natural immune cells doing the damage, it's my donor derived immune cells attacking my healthy cells. Using the term autoimmune can often open people's eyes to the chronic nature of the disease and how its symptoms can even flow over time. Those are just some of the complexities of interacting with others during the holidays or really any time of year for that matter. But what about when we have unrealistic expectations of ourselves?

The old me, the me that was comparable to say the Energizer Bunny, would have been able to handle all of the shenanigans of the holiday season, without so much as breaking a flat. The new me, the me that more closely resembles sloth, not so much. I had to find ways to trim my expectations. I never would have dreamt of enjoying low-key holidays before, so scaling back has been really hard for me. I imagined holidays in my 40s to be filled with children's laughter, elf-on-the-shelf antics, and visits to Santa. Instead, what I would look forward to every year is our now annual get away from my parent's new home in the mountain with just them, my husband and I, and our two little dogs. Days spent roasting marshmallows over an open fire and nights spent around the dining room table, playing games and sharing stories and memories.

Our lives as transplant patients are different than they once were, and inevitably different from most of those around us. Whenever we look at our peers, we often experience a sense of exile in the life we once knew. Their lives are all moving forward as planned, while ours have been set adrift on an entirely unfamiliar path. Depression is common. We feel weighed down by an overwhelming sense of isolation, even while standing in a room filled with our closest family and friends. But with the right support



around you, moments of sorrow or sadness don't have to entrench your life. You have the ability to reframe the narrative in your mind. Instead of getting angry at loved ones who let you down, more strongly embrace the ones who lift you up. Recognize that you can feel both frustration at what people say and do, as well as utter delight in being in their presence. And you can experience great sadness right alongside incredible joy. And remember that without the bad things in life, we would never be able to rejoice in the good. And it took many years, and what seemed like endless tears for me to find peace with my new reality. I still grieve the loss of my former life and the future that I had planned for myself. But I'm also so proud of how far I've come, and I'm excited to see what comes.

I've taken the worst chapter of my life and turned it into an epic tale, a persistent resilience, commitment and regrowth. It has never been easy, but I have to say nothing in life is worth that much ever is. But change is one of the only constants in life. They might as well roll with it. I've actively chosen to embrace my new life with the appreciation that life is meant to be sprinkled with sadness, sorrow, and grief. And I'm committed to writing the rest of my story with joy, laughter, and hope at its core. Things happen all the time for which we have zero control. People and situations will certainly let you down now and then. But you can control how you deal with the roadblocks you will inevitably face. You can choose to write your story as an epic tale or an immense tragedy. It's entirely up to you. You control how you interpret your life and how you choose to respond to the actions and words of others around you. To write the story you are always destined to write, even if it isn't turning out the way you thought it was. And an unexpected plot twist that changes everything can actually make the story more interesting and life more beautiful. At the end of the day, life is what you make it, so make it count.

Now to wrap up. I'd just like to wish you all a happy holiday season however you do celebrate this time of year. So Merry Christmas, Happy Hanukkah, Happy Kwanzaa, Happy Diwali. And since my sample donor is from Poland, I also want to wish everyone a Happy Saint Nicholas Day, which is celebrated in Poland every year just two days from now on December 6. So, thank you and I wish you all joy and peace this holiday season.

**Jennifer Gillette:**

Oh, Janice, thank you so much for that. Thank you for your authenticity and bringing your true experience to this call. I know I am truly just blown away by what you said, and I thank you for sharing that. I'm sure there's others that feel the same. Now, we are going to get the part of the call where you get to ask questions to these wise souls. Jericho, can you please tell everyone again how they can ask their questions?

**Operator:**

Yes, of course. 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 your question, simply press star one again.

**Jennifer Gillette:** Okay. While we wait for the queue to get a lineup, I'm going to ask one of the pre-submitted questions and I think we'll start with Michelle. But then Janice, I also would love your thoughts on it too.

Is it only fair for my caregiver to start to return to holiday parties but I'm not comfortable with the risk of group settings or them being exposed to others and bringing home illness? How do you advise I handle this?

**Dr. Michelle Bishop:** It's a great question and I think there isn't a single answer, but I think this is where that open communication that I talked about is just so important in trying to find a balance between the needs of each and the needs of the couple. Actually, I was just working with a couple recently and talking about how there's with transplants and of course, other illnesses as well. I always think about it, there's three paths. There's the path of the patient, the path of the care partner, and then the path of the couple. And they're all moving in the same direction, but they have actually three separate experiences and different roles. And so, try to navigate that and balance the very real needs and reality of health and safety, particularly this time of year when there's lots of different flu and viruses and so forth going around. And then social needs to not be isolated, to go out and to see folks and so forth. And so, I think in an ideal world, a couple or a family could have conversations about that and could talk about what each person feels comfortable with and then what do they feel comfortable with as a family. Really understanding and respecting that there's the physical aspect, and then there's also the psychological aspect in both directions. So, there can be a lot of anxiety for the patient and actually for the caregiver, quite frankly. And caregivers often feel a lot of pressure and fear to not bring in or bring back illness into the home if their loved one is immunocompromised and is not able to go out, and yet they have their own needs to socialize. So, maybe together figuring out what do they feel comfortable with. You know, socializing with the mask, socializing outside, thinking about events where there might be less crowded. And so, I really just think about it as a process of navigation, but hopefully doing it together with open communication, with respect and care, and hopefully from a place of love. So, I'll leave it at that to Janice if she has anything to add.

**Janice Chabros:** Yeah, Michelle, I think you really hit the nail on the head there. A lot of times we patients get into a bit of a panic bubble and what I mean by that is that everything is a threat to us, absolutely everything. But we have to remember that our caregivers are human, and they need social interaction. They need to get out, they need to not develop that cabin fever that we patients almost kind of find comfort in sometimes because of our fears. For myself, I mean when it came to gathering, especially in those early days



when I was heavily immunocompromised battling pretty significant graft-versus-host disease, I just got out and I sent my husband in place of our family, and we made sure to check with the host prior to the event and reiterated that we were...he was caring for someone who was severely immunocompromised and if anyone was feeling ill, we would like a head-up beforehand so we can make the decision to either attend or not attend that specific event, family gatherings and gatherings of close friends, that's pretty easy to do. There were some other larger-scale gatherings where that kind of thing wasn't possible, and so at that point, my husband would just wear a mask. He had no problem. I mean, this was before COVID. And most of his work colleagues and people who were connected to his life in one way or another knew that his wife had leukemia. So, it was a little bit easier to deal with that. There wasn't the stigma of wearing a mask. But yeah, I think it really has to boil down to having those conversations, like Michelle said, making sure that you're not just focusing on the patient alone, but you're focusing on the caregiver as a human, as an individual, and then as a couple, if you're a partnership in any which way whether you're a spousal partner or a parent and child partnership navigating this incredible path or you're just friends who are helping other friends. Regardless of what it is, there is a relationship between the patient and the caregiver that definitely needs to be fostered and needs to be helped through these kinds of difficult navigational challenges.

**Jennifer Gillette:** Thank you both. Jericho, is there anyone in the queue yet?

**Operator:** Our first question comes from Rachel. Please go ahead. Your line is now open.

**Jennifer Gillette:** Hello Rachel. You might be on mute. Jericho, is it possible to maybe put her in another spot in the line and bring the next caller? And if there's any way we can give her support, that would be great.

**Operator:** Okay. Our next question comes from Ann Marie.

**Ann Marie:** Hi.

**Jennifer Gillette:** Hey, welcome.

**Ann Marie:** I loved your talk. And it's really helpful. You mentioned expressing to others what you need. My question to you is what if you don't know what you need and you get overloaded at the number of decisions that you have to say? You know, people ask you, what do you want? What are you comfortable with? And you just don't know.

**Dr. Michelle Bishop:** I think that's a wonderful, wonderful question. Thank you so much for bringing that up. And it is overwhelming sometimes, first, like you said, to be in the position where everybody's looking to you to say what you are feeling or needing and then to even know what that is. And you know my very first thought is you can say that. You can

say, “I don't know. I don't know what I want. I don't know what I need. I feel overwhelmed.” But I think if you feel overwhelmed, that actually is really important information. And so, it's saying at some level you need less of something you need, whether that's to step back, I mean, again, maybe creating some space. Maybe it's you feel like you need to not have to decide something. So, you might say to someone, “It would actually help me if you decided.” I don't know if it's something that you feel comfortable letting go of. Sometimes it might be, “I just need a little space or time to figure that out, thank you for asking. I'll get back to you.” And it reminds me too of... and this really is more for support folks than for survive patients and survivors, and it's just part of our society, it's sort of unfortunate but we have this tendency to say to the person who's going through it, “Let me know how I can help you, right?” Well, that actually is not very helpful, it puts a lot of pressure on that person and then it the onus is on them to then reach out, which is often really hard to do. And I think as support people, we can do a better job, and I think as organizations, we can do a better job of educating, support people to say it's more helpful sometimes to offer specifics and also to keep checking in with folks. So, to say, “Hey, you know, I'm going to the grocery store later this week, can I pick something up for you?” Or “I'd be happy to pick up prescriptions or pick up your child.” Or I don't know, “Take your dog for a walk”, or like, actually offer some concrete things and kind of give a menu of options. And I think sometimes then that actually addresses the question. One of the questions that you just asked, which is, “Oh gosh, I never thought of that, I never thought they might be helpful to have someone walk my dog for me or pick something up. Yeah, that would be great.” So, I think it can be kind of a dialogue, but unfortunately, I think sometimes the support people are not quite attuned or not quite aware of what actually might be more helpful, a more helpful way to approach things. So, I don't know how well that answered your question. And again, I bet Janice has some wonderful wisdom from direct experience if she could share.

**Janice Chabros:**

Oh, I do. What a great question, Ann Marie. As soon as you spoke the words, I was just instantly transported back to those early days post-transplant when I was just so overwhelmed with everything, I couldn't make a single decision about anything. And what helped me through that was to actually sit down by myself and write things down. Write down things that when people said, “Oh, you know, like I really want to help you. I just don't know how.” Or “I'm afraid to say something like, I don't know what you need. I'm so confused.” I actually wrote down different things that I could tell people that they could help me with. So, I had a grocery list pun intended of things that people could assist my husband and I with when I was going through the hardest parts of everything. So, things like picking up food for us, if they could deliver some kind of frozen meal for us, if they could walk the dog for us, if they could babysit the dog. For instance, if I needed to go to the hospital for me, it was a 150-kilometer round trip to go into the hospital every time I had an appointment. So, sometimes it was full days



I was gone, and I would be sitting in the hospital for four to six hours waiting for tests to come back or getting fluids or other nutritional things that are needed post-transplant. So, for me, a lot of it was carrying...making sure there was someone there that could care for my dog when we were gone for an entire day much longer than my dogs used to being left alone. So, having those kinds of pre-prepared modes to tackle things, to take some of the pressure off of you are huge. Even just things, "Can you just make me something for lunch? Or "Can you just pick something up for me from the store, just I need some food?" Or "I'm out of milk" or whatever it might be. Like Michelle alluded to, there's a lot of parents that go through this and dealing with young children, that's a big challenge. I mean, kids are a huge stress on a person, and you add an illness to that, and it just goes exponentially through the roof. So, having some key people in your life could help reduce some of those stresses, pick your kids up or drop them off at school, take them to your extracurricular events, arrange sleep over so that you have a night off. Those are the kind of things that can really help when you're feeling that overwhelmed, especially around the holidays, because there's so much going on. You don't want to have to worry about it.

So, one of the things that Michelle spoke about early on was ways of giving yourself grace and things like buying something instead of making it from scratch. Things like not hosting. You don't have to host anything. Just attend if you want to attend, and if you're not feeling up to it, it's okay to bow out. People will understand, they're not going to take it personally, and if they do, they're not the right people to have in your life at this time anyway. And maybe you can pick that relationship up in a year or two when you're feeling better. But definitely, have some strategies in place, give yourself some time to sit down and think about your life and ways in which other people could help reduce some of that feeling of overwhelm that you're experiencing by just removing some of those day-to-day things that you just don't have the capacity for right now, and that will help go a long way in allowing you to feel a little bit more relax.

**Jennifer Gillette:** Great advice. Thank you so much. Jericho, do we have any other callers in the queue?

**Operator:** Yes. The next question comes from the line of Steve. The line is now open. Please go ahead.

**Steve:** Thank you. I've done some informal research on language use in the cancer community and there was a lot of support for your last point that just saying, "How can I help you" is really not very helpful. People appreciate specifics. Another thing I'm wondering about is I think people often say well-intended things that don't land that way because it makes them feel more comfortable if it's true. So, when they say, "You look great!" and you say "thanks" or something like that, they don't have to deal with someone who's sicker than they are comfortable dealing with. If you follow that. And it just





seems to me there's something in it for them if you answer in the right way. So, if you don't answer in the right way, do you have to take that into account in your response?

**Janice Chabros:** Oh, I would love to tackle this question.

**Dr. Michelle Bishop:** You go for it.

**Janice Chabros:** Steve, you are preaching to the choir. These are things that we patients deal with on a really regular basis. I would even say depending on how much you are out and about in the world. These things happen on an almost daily basis, and it is so stressful to have to carry the burdens of others. But as I mentioned before, you have to be in control of how you are responding now. A lot of the medications that we patients have to be on mess with our moods. They mess with our nerves, and they leave us with very short fuses. So, it's very common for us to bite back. And that is not a constructive way of dealing with any situation. So, we have to understand that our emotional state is incomplete patterns after transplants, especially early on after the transplant or maybe we have some latent issues that we're dealing with, like graft-versus-host disease, or fatigue, or pain issues, whatever it might be. Our fuse is very short, so we have to find ways to better manage the situations that we cannot control. So, what people say and do, even though they are well-intentioned and as you say, see they are saying things because they don't have the capacity themselves to deal with your illness. They're perplexed by it. They're scared for you. I mean, maybe they've lost someone to cancer, and they don't know how to deal with someone who has had to fight for their life like that. Or maybe they grew up in a situation where a parent was ill all the time, and they just don't have the capacity to be the caregiver. They've run dry, they have no more to give. Their cup is empty. And we have to not only navigate our own struggles, but we have to anticipate that others will have their own struggles that we have to navigate with them. And just like any other relationship or communication between two people, there's two sides to every coin, and just because you're feeling one way about the way that they're speaking, you have to understand that they're feeling a different way about what they're saying. They firmly believe that what they're saying is not hurtful. They firmly believe or they just aren't even aware that what they're saying could be taken a different way than what they're intending. I mean, it's a human condition. Our societies have become so sensitive to what they say. It's really challenging to be able to stay in contraindication to what someone has said to you that "Hey, this is hurtful to me." But you are in your full rights to say that. Now, the caveat to that is I would always suggest that if you're going to snap back at someone for something that they've said, let's just say, you have to do it with kindness. You can't do it with anger, you can't do it as a response. And again, I think a lot of it boils down to preparing yourself, having those maybe might happen conversations with yourself in the mirror and practicing different ways of responding and seeing how you feel about each one of those ways.

When people say things...and I'll share a really, really hard story for myself. But I was trying to conceive my first child when I was diagnosed, and my fertility was taken away from me. There was no time to do any sort of harvesting or protection or anything. So, my fertility was gone, and I was left with a section of my family that was very eager for my husband and I to have children. And would make comments to that effect constantly, even after my transplant, even after I told them that I was now postmenopausal and that I would not be able to conceive or carry a child and that I was dealing with so many challenges around my recovery that even adopting even an older child was just not going to happen. And I had to sit these people down and I had to explain this to them. But before I did that, I had these imaginary conversations with myself for weeks ahead of time. And I planned it out how I thought that they would react, what I thought that they would say, and things that I could say and retort that maintain the respect that I think we always need to have with one another. Maintains the level of integrity for them so that they didn't feel like I was attacking them because if you start attacking someone, they're just going to go on the defensive, they're not going to hear you. They're not going to understand what you're trying to say. So, I think the most important thing for me in that kind of situation and what you're saying, Steve, is to have some cues that you can dial into when you need to, have some phrases just tucked away in the memory banks and pull them out as needed. But remember to do so in a way that is not triggering for someone else. So, try to be as kind-hearted about it as possible. And it's okay to pull the cancer card, go right ahead just say, "You know what? This is really hard for me. I can't have this conversation right now. Can we just like change the topic?" Or saying something like, "I don't think you are understanding where I'm coming from, can we just discuss this later?" and then regroup later and have the conversation later. But just understand that you are taking it in a certain way that is maybe not the way that you would normally take it, and it might be your heightened emotional state that's causing you to feel like the comments people are making are more inappropriate than they are and the other person is not going to recognize that. What do you think, Michelle, anything else to add?

**Dr. Michelle Bishop:** I think that's great. And the only thing I would I would add is just very quickly that I think finding support with others who have been down the road can be really be invaluable, whether that's someone you've met along the road, whether it's peer-to-peer support like National BMT links, peer-to-peer support program or support group. Because to be with others who get it where you don't have to explain, it's just...It's amazing. It's palpable in groups when you feel that just that ability to let down because as you're describing that, I mean it's amazing, but it takes it into more enormous amount of work, and it can be kind of exhausting. So, I think in terms of thinking of different types of support sometimes it can be really helpful to have someone in your life who gets it without you having to explain, so you just can be yourself and I'll leave it at that.



**Janice Chabros:** I also just want to add like none of these things are going to happen overnight. So, if there's anyone out there on the call today who is kind of fresh into this, maybe your stem cell transplant is pending or you've just undergone your stem cell transplant, nothing is going to resolve overnight. It all takes time. So, give yourself, as Michelle said earlier, give yourself that grace and be patient with yourself. It takes time to develop the confidence to deal with your new body. You have no confidence in yourself right now, your body has turned on you. So, don't worry, it will come back in time and with practice. So, there's nothing wrong with talking to yourself in the mirror. There's nothing wrong with having conversations with loved ones, even if they're challenging. Your loved ones will appreciate that you're reaching out because they want to help you, they just don't know how. But give yourself time.

**Jennifer Gillette:** And on that note, I think it is time for us to wrap up. But wow! What a bunch of great nuggets for anyone that is trying to deal with post-transplant and people's reactions and how to handle the holidays and frankly beyond. If anyone is interested in listening to this again, it's going to be on our website within a few days at [nbmtlink.org](http://nbmtlink.org), and as well as I want to make everyone aware we will be sending out a survey. This helps us to just continue to keep quality programming for you. We are always open up to ideas and I just want to thank both Michelle and Janice. Amazing presentations. Thank you for all the wisdom, tips, and for sharing your authentic experience, that it truly is a gift. We wish you all a healthy, happy, peaceful holiday season. And for those of you that are struggling with GVHD, sign up, next week is our webinar. Everyone, take care of themselves and have a great day.

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