

nbmtLINK
Empowering Panel: Dynamic Advice Regarding Survivorship
Post Bone Marrow/Stem Cell Transplant
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Presenters

Jennifer Gillette, Staff Social Worker

Adam Claxton, Cancer Coach and Survivor of AML

Pat Hodges, Caregiver

Operator

Ladies and gentlemen, thank you for standing by. Please wait while you wait for your colleagues to finalize your Zoom logins. Once again, ladies and gentlemen, please stand by while you wait for your colleagues to finalize your Zoom logins. Welcome, everyone, to today's nbmtLINK, Dynamic Advice Regarding Survivorship Post Bone Marrow Stem Cell Transplant. It's now my pleasure to turn the call over to Jennifer Gillette. Please go ahead, Jen.

Jennifer Gillette

Thank you so much, Kevin, and I want to thank everyone that is here today. We are really excited to bring you this program with two people I think you will just be totally inspired by. And I also, of course, want to thank our sponsors, Insight and Sanofi, for making this program possible.

Just a quick little review of our outline so everyone knows what to expect today. I'm going to do a brief introduction for anyone that's not familiar with the National Bone Marrow Transplant Link. And then we're going to have a survivor's perspective, thriving after transplant from Adam Claxton, who's a cancer coach and an AML survivor. He had his transplant in 2024.

And then we will also hear from our next speaker, Pat Hodges, who is a caregiver's perspective and supporting survivorship. She is caregiver to her husband Steve and has been so for four years. And then we'll open it up for a question-and-answer period.

For those of you who are not familiar with the National Bone Marrow Transplant Link, we are dedicated to helping individuals and their families from diagnosis through survivorship. We work with hospitals, cancer centers, and other organizations to reinforce and complement medical care by providing resources, support, and education. We link you to experts across the country to all topics related to transplant.

And I also need to point out if anyone needs to get in touch with us, I also have emails there that you can reach out to me and Peg. And if you need any support in any way, please feel free to reach out.

Some of the resources we provide, we have our Healing Arts program, which are programs where you can get together with fellow survivors in a creative and fun environment. And this is especially great for those of you who might be experiencing some isolation or just could use a lift in your day. We have our Lunch and Learn programs, which are monthly virtual discussions featuring experts from across the country and other survivors on all transplant related topics.

We have our Marrow Master's program that covers, again, all things related to transplant like chronic graft versus host disease, survivorship issues, new treatments. You can get those on Simplecast, YouTube, anywhere you listen to your podcasts and we've had over 45,000 downloads. Those are really popular and if you haven't checked them out, I encourage you to do so.

We have webinars like the one you are on today and we just did one on exercise and the benefits of graft versus host disease. We have our peer support program where you can talk to other patients, caregivers and survivors that are trained and can assist you and are also thriving today. We have our Celebrating Second Birthdays where you can honor that second birthday you get each year after a transplant and our Survivors Thrive Book Club. We have several books that are in our library, as well, that could assist you on your journey. You can find those on our web page at mvntlink.org. And we also have a Facebook page that provides daily inspiration, support, and tips.

A special thank you to our Link partners that make our programs possible.

And just a little medical disclosure, anything we discuss here today, it can stimulate conversation with your healthcare provider, but your treatment is individualized with you and your care team. And so anything you hear here, just use it as discussion with your team. It is not medical advice.

So, on to what our program is going to include. Our survivor speaker, Adam Claxton, is an AML survivor who, again, had his transplant back in 2024. He is a mindset coach and author of the book, *The Child -- or "Daddy's Magic Blood."* Following his diagnosis and treatment, he became passionate about helping others navigate this journey and helping them with life after cancer.

He draws on his lived experience, personal development studies, and coaching work. Adam shares an honest perspective on resilience, identity, gratitude, and finding purpose amid uncertainty. Through his speaking and coaching, Adam encourages people to recognize that thriving doesn't mean life is always easy or that you always have to be positive. It means finding ways to move forward and reconnecting with what matters, creating a meaningful life even when circumstances remain difficult.

And then we will hear from Pat Hodges, our caregiver speaker. Pat holds a Bachelor of Science and a Master of Arts degree and worked at IBM as a systems engineer and in project management or product management, I apologize. She is a 17-year kidney cancer survivor and

she has been her husband Steve's primary caregiver for the past four and a half years through his AML journey and his transplant and ongoing recovery.

As a caregiver coach, Pat brings her professional skills and personal experience to helping others navigate caregiving with compassion, advocacy, and attention to their own well-being.

So now we will hear from Adam. And Adam, I'll pull up your slides, but you feel free to begin.

Adam Claxton

Hi, everybody, good afternoon, good evening. I am currently based in the UK, so a little bit ahead of time. But it's an absolute honour and privilege to be here today to be able to share not only my story, but to inspire those that are going through this journey and to help them understand that you are not alone. There are many others going through this journey. And I like to see myself as somebody a little bit further down the road because I once started my journey back in 2024, when I was diagnosed with acute myeloid leukemia.

And one of the things that drives me most is when I went looking for the information, I couldn't find the words, the posts, or the people that I needed to get that inspiration from. And they say the best thing to do in that situation is to become the person that you were looking for. And as my journey has progressed, I've essentially stepped in to be the person not only that can help others in find the dark, find the light during the dark, but help yourselves become the person that you were born to be.

And then as I've gone through treatment, I've learned so much about cancer after treatment, where it's not learning to live or to exist, it's not about surviving. It's about thriving. And I've put together a couple of things today just to help you kind of get a grasp for who you are, what you're capable of and giving you a couple of footsteps to follow along the way.

So next slide, please. So survival is not the finish line, and we've all experienced that ourselves. It starts with diagnosis. Where my diagnosis happened in September 2024, I had been ill for quite a long period of time through that year with various infections. And I just couldn't shake anything off. It was a trip to the doctor, back and forth. I had some antibiotics for this, treated for this. I had a 100-day cough.

And it got to a point where on a weekend I woke up and I felt really, really bad with my chest. So I went to the local A&E department just to get some sort of antibiotic to help me get through the weekend. And as I was leaving, the doctor said, let me do a blood test quick and I'll send you on your way. So we did a blood test and off I went. I was about two minutes away from home and I had a call from hematology to say, pack a bag, you're coming back in. So we were very uncertain as to what was happening. I didn't actually find anything out on that day. It was the following day, so many blood tests, questions about how I feel.

And then a hematology consultant came and delivered the diagnosis that you never think or imagine that you are going to have; Mr. Claxton, we're really sorry to tell you, but you have acute myeloid leukemia. And in that moment, your life changes, straight away. Everything that used to matter no longer matters. Your business, your finances, your house, it all just stops. And straight away, only thing that you kind of think of is, what have I got to do to get through this because you can have many problems, but when one is your health, you only have one problem.

So we quickly kind of started making the calls to the family. And then it was about, what do I need to do, because you get told what treatment is going to happen and what that path looks like with chemotherapy, when's it going to start, biopsies depending on genetics, etc., etc. So you're very well informed, but straight away for me and very fortunate being a mindset coach, I was thinking, what have I got to do? What is my responsibility here? Because lying and taking all the medication is one thing, but then creating and having an attitude to go through the situation is another.

And you've got so many questions and family trying to reach out and find out and Google, which is a problem in its own right where people look at prognosis and the question of how long have I got? I did none of that. My consultant told me not to Google anything, so I did, I didn't because you don't want to have those thoughts coming into your mind. And I've seen, unfortunately, what happens when people get diagnosed and I know the importance of being able to manage and control your thoughts.

So then started treatment. I had my first five weeks I was in hospital for and one thing that stood out for the staff in the hospital and the consultants was the stuff that I was doing in my room. I was exercising on an exercise bike. I was practicing gratitude, every day. I was journaling. I was sharing my story. I was meditating. I was praying. I was doing so many holistic practices because I thought if I'm using like the science and the medicine and linking that with the holistic practices, the mindset work that I'm aware of and surely with having like goals set, I'm going to be in better, instead of receiving this treatment.

So I was in hospital for five weeks. I had a couple of weeks back out, back into hospital for round two of chemotherapy, which by then I was in remission and I had a match for a stem cell transplant. And luckily for me, I know him very well because he is my brother of just under two years younger than me. So they were lining my brother up very quickly. And again, very lucky to have a match. He was a 12 out of 12. And my consultant said that he couldn't be any more like me, without being me.

So again, just truly blessed and grateful that that was able to happen. And then when I saw my transplant consultant, he was like, we're going to get the ball rolling straight away. We have a match. We have you, we have him. Let's get it done.

So and I went December 2024. And two weeks before Christmas, I was admitted, went through the transplant process. So it was really tough because that transplant chemo is pretty brutal. It's tough going. But again, one thing that I went in there with was the mindset of I am getting through this.

Bad days will happen, but good days will happen, too. I stuck to my regime of getting around the ward when I could to do my walk, talks with the children at home. That was the hardest thing, especially being in hospital over Christmas, not being able to see your kids. That was one of the biggest things that hurt me the most.

But then my mindset was about, one Christmas versus the rest of my life. And I was like, if we can get through this, next Christmas and all the Christmases after are going to be simply incredible. And you very soon realize that it's not about the presents under the tree, it's about the presence of people that you have around it. That's what makes Christmas even more special going forward.

So transplant came Christmas Eve. I received the best Christmas present from my brother as his cells went into my body, and the next day was Christmas Day. I had the worst Christmas dinner ever, courtesy of our hospital service. Grateful for the service, but the food is terrible. And then after that, it went into the transplant recovery, mucositis is the worst pain I've ever felt in my life. I've never had a baby, and I'm sure that that is worse, but for me, that mucositis was something where I didn't eat solid foods for two weeks, just trying to get by on popsicles and protein shakes and water. Water became my best friend because it's so important to help with everything going on.

And then came January. So saw the new year in my hospital bed, and into January, back home. And this is where the challenges and uncertainties start. So I went out for my first walk a couple of days after being home. I got halfway around my block, and I thought, how the hell am I going to get home from here, because it felt like miles away. And it wasn't. But a few days later, I went back out and I walked a little bit further. And I got home.

In those steps, every day, you take a little bit more forward and eventually, you're walking miles. A mile became two miles, became five miles. And after about six weeks, I was on top of a hillside nearby celebrating the achievement. My lungs were burning. I could see the view. And it's that reminder of when you climb and look back, that is when you truly see how far you've come.

So going forward, you move into the 100-day period. And in the UK, the 100 days, you have a bone marrow biopsy just to see how things have gone. post-transplant. And I was in remission, complete remission. It was great, no sign of disease and then have this sort of who am I? What am I? What do I do now? Am I still a patient? Am I living my life fully? Am I a little bit of both? The uncertainty kicks in.

And for me, this is where another journey began and I kind of want to call it the mental battle. It's the journey that you don't really get told about during your treatment because when you're in hospital, great, they have a plan, here's for medicine, here's for support, here's you sort of getting your blood levels back. And the mental load, the emotion, the grief, the feelings of sadness because of the things that you used to do, you now can't do.

And this is where my passion in helping people had changed from what I was previously doing to going, well, if I'm struggling at 100 days, then so many more people are having this sort of identity crisis. And I realized that survivorship is a different kind of journey. And recovery is never linear.

So I was doing fantastic. And in July 2025, I went for a routine blood check and I was again delivered a blow that the AML had returned and it was aggressive, more aggressive than when I was first diagnosed. I started treatment straight away and was told that if it doesn't work, then two weeks, that's it, I'm done. It was devastating because I never had conversations before with funeral directors to put plans in place for a funeral to tell the children that if this doesn't work, Daddy might not be coming out of hospital.

So I went into hospital because my original treatment wasn't working. And it was kind of like I'm in the last chance saloon now. I went in, and this time the mission felt different. It felt like personal, whereas me against me. And I went in ready to go and give everything that I've got. And after having neutropenic sepsis, followed by double pneumonia, I was back in remission and then it was about recovery again. So yeah, moving forward from that, it was back into recovery, living life again.

And then after DLI, donor lymphocyte infusion, I developed chronic GVHD. And first of all, it started as markings over my face. Then it was on my body. Then we had a little bit of back and forth with my mouth, like temperatures, my skin flares up and then down. And I then started noticing things weren't quite right. I had some like lumps appearing over my body. I was diagnosed with leukemia cutis. I then received radiotherapy for leukemia cutis. The sites were getting blasted and destroyed. But there was some underlying issue going on. And I've recently found out that it's a molecular relapse that I am now going through. So I'm back on treatment.

And just an update, fast forward to today, where I've been to clinic today, my blood counts are all very low, doing what they should be and I'm going to be receiving DLI again in December time. So yeah, back into it. So it kind of reinforces that it is a different kind of journey and it was also the beginning of who I'm going to be next.

Next slide please. When I was diagnosed, the first night when I went to sleep, I had three words come to my head: allow, acknowledge, and accept. This became my mantra and for everything that I was going through in that situation was to help me. I knew that I couldn't resist or fight or battle against not having cancer. So I had to allow, I had to allow the treatment to come to me

and through me because if I'm allowing it in and allowing it out, I felt that it was going to give me a greater power to be able to move forward.

So I was giving myself permission to feel. I felt my emotions. So if I felt sad, I allowed them. If I felt happy, I allowed them. I didn't hold back. I let them go. I made peace with myself and understood that it is okay to have difficult days because you will have good days and you do have bad days. I had to acknowledge, recognize what I was going through, what was difficult, and even now it's about acknowledging how far that we have come. So I had to acknowledge the fact that I had cancer. I couldn't pretend that I didn't have it. So I was acknowledging the situation.

And when I acknowledged the situation, I was bringing myself to the present moment because, ultimately, that is all we have. Anything that happened in the past has gone. Anything that's happening in the future is a gift that's coming. So the real gift that we have is what we do, right now.

And I want to just highlight that we have two lives. And we start the second life when we realize we actually only have one. So when you ought to kind of acknowledge that today and take that on board that as we move forward, we appreciate life even more so now. And we have to accept. Now acceptance doesn't mean giving up. It means recognizing where you are today so you can decide, you can decide how you move forward because everything in life is based on a decision and we are the pen holders to our stories. And you can change the way that you think. And when you change the way that you think, the things that you think about will change.

So we have to start accepting where we are currently. But that doesn't define how we move forward and it doesn't define who we are or who we were. The beauty in survivorship and being given another chance to live means that we can be the person that we were born to be. It's not about who we once were, it's about who we're going to become. And from these situations, cancer can take a whole load of things away from us.

But with the new perspective that we have, and if you're working on perspective, I want you to think about today is What does cancer give you? Because there's many things that cancer will give you, and I'm talking opportunity. It gives you chances to do things that you never did before because now we're not afraid of anything, right? Fear is just an imaginary thing.

And when we step forward now, we step forward with faith, with hope, with belief, with strength, with resilience, with gratitude, kindness. And one of the biggest things is love because when you've got a heart full of love, that belief makes you believe that you can do anything and anything is possible. And I can be grateful to be alive and still find life difficult. Those two things can coexist, just like good days and bad days.

Next slide, please. So my question for you today would be, what would thriving look like for you? I want you to have a think and set some goals. What do you want to achieve in this life

that you've been now given? I know we struggle and we have conditions and things like GVHD that we have to kind of navigate and learn to live with. But when we focus on what we can control, when we reconnect with what truly matters, how we find purpose in this next chapter, and when we take small steps consistently and open to a new version of you, you find a version of you that was already inside of you waiting to exist.

Cancer didn't destroy me. I actually found beauty because I found the person that I was longing to be and it was already inside of me. So I want you to remember that today and just take some time later to reflect on what does thriving look like for you. Thank you very much for listening today.

Jennifer Gillette

Thank you so much, Adam. We appreciate you so much. Pat, thank you for coming today.

Pat Hodges

Well, thank you for having me. Let me get my chart up. Okay, becoming a caregiver. Well, Adam and I had a lot of things in common, but he is speaking from the patient perspective, and now I will speak from the caregiver perspective. But we had so many of the same things, different person, different people. So anyway, thank you for having me.

I want to talk about the person who sits behind the patient, the caregiver. My husband, Steve, was diagnosed with AM, four and a half years ago. I never planned to become a caregiver, and I certainly never expected caregiving to such a large part of my life. Nothing could have prepared us for what lay ahead. Suddenly, our lives revolved around blood counts, chemotherapy, bone marrow biopsies, hospital stays and eventually, a stem cell transplant.

What I am sharing today is not a medical lecture. It is what I learned the hard way and what I wish someone had told me at the beginning. Every family's journey is different, but I hope that some of the lessons I learned about advocating, preserving a relationship, accepting support, and looking after yourself will help someone who is just starting down this road.

My caregiving journey. Steve's AML was discovered after routine lab work showed dangerously low platelets. He had also not been feeling well, too, and that led to his diagnosis. We also learned that he had several adverse mutations, which made his leukemia particularly challenging to treat. Thus, it took eight to nine months of intensive chemo to get rid of it.

His allogeneic transplant was February 23rd, and there were no donors anywhere. So our son donated his haplo, it was a haplo donor. And I often think of our journey as it's a marathon, not a sprint. It continues this way.

My responsibilities change, constantly. At first, I was learning medical terminology and trying to understand treatment decisions. Later, I was learning new medicines, watching for complications, and trying to recognize when something wasn't right.

One of the first things I did find was Steve had skin GVHD several weeks or quite soon after his transplant. That became chronic, and then he developed another GVHD, which is under control now, fortunately. Another thing I learned about, fever of unknown origins; got to see that a lot. And like Adam, sepsis and double pneumonia and many other things were in our vocabulary. One of my biggest lessons was learning that caregiving isn't a fixed role. You must learn to adapt as time goes on.

Learning to advocate. I'm sorry, I'm not really good at this. Learning to advocate. Advocacy is a learned skill. When he first became ill, I remember sitting in medical appointments, hearing unfamiliar terms, trying to understand what was happening, and worrying that I might miss something important. I did have a research background, so I did a lot of research, and it wasn't on Google.

So I quickly learned that being a caregiver meant more than being by a side. I needed to ask questions, understand the treatment plan, keep track of information, and speak up when something wasn't clear. At first, I felt overwhelmed, but I learned that advocacy is a skill you develop, over time. You don't have to know everything from the beginning.

Here are a few things that helped me. Before appointments, I wrote down questions, noted any new symptoms or concerns and kept an updated medication list. Although the hospitals do a great job of doing that now. it's really good to check. During appointments, I took notes, asked doctors to explain unfamiliar terms and repeated important instructions to make sure I understood. After appointments, we recorded changes, next steps, follow-up dates, and anything that needed clarification.

Staying organized, for me, was very essential. I kept a loose-leaf binder with test results, treatment summaries, contact information and questions. It became an invaluable resource for me. And a digital or a notebook would work just as well, but I'm a paper person, so that's why I did that.

Most important, you don't have to be perfect and you don't have to understand everything, immediately. Becoming an advocate doesn't mean challenging the medical team, it means becoming an informed, involved partner in your loved one's care, and that is something every caregiver can learn to do.

Caring for your relationship. Cancer can take over every conversation you have with your spouse. I had to remind myself that Steve was my husband first, before he was a patient chart. We needed to laugh. We needed ordinary conversation. We still needed to be a couple. Sometimes a familiar routine or a conversation about something other than cancer can make a day feel more normal.

Sometimes, the best thing you can do is not solve anything. You just want to sit there and you can ask, do you want me to listen today, help solve this or just be here. That's what you could ask your patient.

There's a lot we cannot control during illness, but we can try to protect the connection that existed before the diagnose. You are still a team. Right now, something we do at night is we watch a funny show at night and we did this, gosh, four and a half years. We're looking for new shows but some of the ones we watched was Everyone Loves Raymond and America's Funniest Videos, so we go to bed laughing most of the time in a great mood.

Okay, your circle of support is very important, and it needs to be done before you get involved in the treatment. So I could have not done this thing without my family and friends, especially during the first weeks of induction, which were 47 days and around transplant. They were there for me. I learned that saying I need help is not a weakness, it is a caregiving skill. Support may come from your family, the medical team, online or in-person caregiving groups, neighbors, coworkers, or your faith community.

Many people are going to say to you, how can I help you? And so many people said that to me because they don't know what else to say. But over time, and especially when bone marrow transplant came into place, I would say, can you bring dinner on Tuesday? Could you go grocery shopping for me? Can you drive Steve to the clinic next Wednesday on his post-100 days? And I think that was very helpful. The people, they want to help, but they don't know what to do. And if you're succinct, very specific, they can help you, and it's so much better.

Starting an e-mail thread or a private group update can help you from getting a lot of phone calls or a lot of texts, a lot of emails and that way, people are updated with the illness. You cannot do this alone, and you shouldn't have to.

Caring for yourself without guilt. Well, this is very personal for me. During the most intense part of Steve's treatment, especially in the beginning, I exercised every morning before I went to the hospital. I'd get on my Peloton or do strength training, Pilates, bar, whatever. And it was not about fitness; it was about survival for me. This is how I survived. It gave me one hour where I could breathe, move, and feel like myself.

It was my lifeline, hence, the picture in the background. Exercise gave me a sense of control, but so much else was beyond my control. I continue to do this every day, even now, and it just helped center me.

In addition, when I went to the hospital, Steve and I would walk laps in the hospital so he could get his exercise for the day, too. So exercise was my sense of control. Your sense of control may be something else. It might be a short walk, meditation, which I love to do, a quiet few minutes, or a phone call with a friend. What matters is finding something that helps you restore a little and get your energy back. Eat well when you can, make time for rest, and keep your medical

appointments. I do know one caregiver who did not do that during the process, and it didn't turn out to be a good situation.

Accept an offer of help. Take a break without feeling guilty. Taking care of yourself is not taking something away from the patient, it helps you stay beside them. Your needs matter, too.

Grief, fear, and hope. This was, without question, the hardest journey of my life. When Steve was diagnosed with AML, I experienced a kind of grief I had never known before. I wasn't grieving the loss of a person, I was grieving the life we had expected to live together, our plans, our freedom and the future we had taken for granted. We both experienced this, and there was fear, so much fear.

During those first weeks of treatment, which wasn't going right, so they had to add on more intense chemo, I felt like I had to be strong for Steve. I didn't want him to see how frightened I was. Sometimes, I would leave his room and go down the hall and just cry. But I learned something important. You do not have to be strong every minute to be a good caregiver.

I was fortunate to have family and friends with whom I could completely be honest with. I could tell them I was terrified, that I was exhausted, or I simply didn't know what tomorrow would bring. Every caregiver needs at least one or two people who can listen without judgment.

I also learned that hope and fear can exist at the same time. I could be frightened about what might happen and still believe that better days were possible; and they were. And I want caregivers who are just beginning this journey to know that life can get better. It has for us. Not without setbacks and certainly not overnight, but with time, we have found moments of happiness, gratitude, and normalcy again. Hope doesn't mean the absence of fear, it means allowing yourself to believe in tomorrow, even when today is difficult.

This is one of Steve's favorite pictures. We had just had dinner at our house with people, probably out in the backyard, or it could have been a birthday celebration. But when treatment ends, your life does not go back to normal, and you don't stop being a caregiver. You may stay in crisis mode for a long time because after years of being alert to every fever, lab result, appointment, and setback, it takes time to relax. You can stay in crisis mode a long time, and recovery can be uneven.

A difficult day does not erase the progress made on a better one. We tried to celebrate milestones, even the small ones. And I'll tell you about some of the milestones. One of the first ones, I kept watching for those neutrophils to come back and that was a big party in the room the day the neutrophils came back, and I could see them again. We could see them again. It was a small milestone, but an important milestone, as you know.

And then, six months, we had a celebration, and then every year, we have a birthday cake for his new birthday. Steve has now passed -- I think I did say -- recovery can be uneven. Okay.

Steve has now passed three and a half years since his transplant. We celebrate that. We appreciate every day, but life after AML is not simply going back to the way it was before. Life has changed for us, and Steve has endured some other diseases since he had the transplant, too, but he's doing great.

So, life after AML is simply not going back to the way it was before. And just as our loved one needs time to recover, give yourself time to recover, too.

What I want you to remember. If there's one thing I hope you remember from today, it's that you don't have to be an infallible caregiver. You will make mistakes. You will become tired. There will be days when you feel overwhelmed, cranky, or sad. That doesn't mean you are failing.

So find moments to enjoy. Take one day at a time. Hold on to hope. You will not always know the right thing to say or do; I certainly did not. But showing up, listening, asking questions and caring for each other makes a difference. Try to remain positive, even when circumstances are difficult. Appreciate the good days.

I want to leave you with the words on this slide, "A good caregiver is not a perfect caregiver, they are a present caregiver."

Finally, thank you for allowing me to share our journey. I wish each one of you, strength, courage, and moments of joy along the way. Thank you.

Jennifer Gillette

Thank you so much, Pat. We really appreciate you being here today. Kevin, can you tell our callers how they can ask a question in case they're not familiar with the Zoom format?

Operator

Certainly. We'll now be conducting a question-and-answer session. There are a few ways you can ask a question today. On the bottom of your screen, you're going to see some buttons. One of them is going to say Q&A. Please use that to type in any questions. If you do not see the Q&A button, it may be necessary to click the more button to get to the Q&A function. You may also use the raise your hand function to verbally ask a question. If so, you may need to also use the more function to get to raise your hand. So if you'd like to verbally ask a question, use the raise your hand function, or you could type your question into the Q&A pod.

Over to you, Jen.

Jennifer Gillette

Thank you so much, Kevin. And we're going to start with our first question here, which I'll ask Adam if you could answer first and then Pat, I'll have you do the same. A lot of people, I think, struggle with other people not fully understanding what is happening. And one of those things

might be like people maybe want to visit and they don't understand about blood counts or they have the best of intentions. Adam, how did you handle that when people struggle to really understand why you needed boundaries.

Adam Claxton

I think the first thing that happens as a patient is that we start to understand the language, neutropenic, what that actually means, risk of infection. And once we understand that we understand the importance of why I'm being safe, why I don't want you to come to my house, why I want to speak through the window.

And I think one of the biggest experiences that we have all had is the coronavirus pandemic because it was the most recent thing that we could actually go, do you remember when we were in lockdown and we had to be really careful with who we were mixing with? This is very similar to that situation. So it was like a very good reminder because in 2024, lockdown was in the UK, 2020, 2021. So it was very recent on everybody's minds, and that way of living for a part of all of our lives was normal.

So, when people wanted to come around, it was more of a check in on the day, one, to see if I was up to having visitors because there's days where our energy is more important for ourselves than to have somebody come around and kind of sometimes, you felt like a bit like an animal in a zoo where people just come and look at you and see how you're really doing. And there's days where you go actually, yeah, I'm willing to see you or to come outside and sit in the garden at distance with no hugging and stuff like that.

And I think connection is really important. We are humans, we need connection, we thrive on connection. So you don't want to isolate yourself too much because obviously, then you, the anxiety and depression kick in, separation anxiety from being around people.

And it's about choices, as well, so doing things when life is quieter. So if you want to go out to a public place and have a coffee, do so, but don't do it the weekend when it's going to be really busy. Go to those places in the daytime when children are at school, instead of going supermarket shopping in the evening.

So your whole lifestyle changes around that situation where you can actually get out and do things and see people, but you just have to be mindful. And I'm back in that space now where it's about the choices that I'm making. It's about masking up when people want to come around to the house. We're going into that autumn full time now where colds, viruses are circulating. So yeah, we just have to be really careful.

And one thing that I always say is that I honor my immune system more than giving somebody a hug because of how it can compromise my recovery and my illness. And yeah, you have those boundaries where you respect yourself more. Old versions of us may have gone, when people go, I've got a bit of a cold, you go, I'll come around anyway, it'll be all right. Now it's like,

absolutely not. Don't even come and knock on the door, like we'll speak through the camera. And it's a season, it's not this isn't how it's going to be, but it's how it's going to be right now.

Jennifer Gillette

Thank you. Pat, how about you? How'd you and your husband handle that?

Pat Hodges

Well, we did a lot of Zooms with out-of-town relatives because it was right after COVID. I mean, immediately after COVID, our daughter had just gotten married, and it was immediately after that. So as Adam said, masks were the norm. You know, people understood. And if we got together with people, we'd be out on the patio. We have a sunset or two that comes out, so Steve wouldn't be in the sun.

So I think Adam covered everything that was important. People respected what we had to say, and they did not try to overstep their bounds. But one of the things that really got us, a lot of times they go, oh, Steve and I would be walking the neighborhood all the time, and we were careful. I mean, if anyone came up, he would have a mask on. But one of the things that they would look at him and think, oh, he looks great, because he did look great. He recovered well. He was strong. We were walking and exercising. but he was not the same person, anymore.

So that was the hardest thing. Like, I don't understand why you can't go out and come to this party. You guys look great. You look great, Steve. But he wasn't. But on a side note, it's been four and a half years, and Steve just got permission to get vaccinated. His immune system has been knocked down for four and a half years because of other things he has had, particularly in January of last year, so he's just starting his vaccination process now. So that will open up a lot for us. It's a big deal.

Jennifer Gillette

That's exciting. I'm so happy for you guys. Thank you. I'm going to start with you on the next question, Peg. One person asked, what if my person starts to give up? How do you handle that? And I'll start with you on that.

Peggy Burkhard

Okay. Well, I can understand that. I would probably try and get each hospital, I mean, in here America has MSWs or has like therapy people. I probably would go to the therapists, the MSW at the hospital support group, because they are really helpful. First, talk to them and then try. I understand completely, you know, you have to do everything you can to fight it. It's a daily fight every day because, sometimes, you do get bad news one day after another. So I would probably go to a therapist and see how I could help the person. Exercise, too. I'm a big advocate of exercise. It releases endorphins.

Jennifer Gillette

I definitely got that from your presentation.

Peggy Burkhard

I know, I'm really overdoing it.

Jennifer Gillette

Sounds like it was a wonderful tool for you. Oh, that's wonderful. I think it's so important to have a release from all that energy, as well as releasing the endorphins.

Peggy Burkhard

It helps up here. It's happy hormones, you know, you're releasing, so.

Jennifer Gillette

Absolutely.

Peggy Burkhard

I'll try that. And if that didn't work, I'd try a private therapist. I would engage a private therapist to help.

Jennifer Gillette

Absolutely. How about you, Adam? Anything to share in that regard? Because you certainly know, of all people, too, there's days that are really rough to get through.

Adam Claxton

Yeah, absolutely. And I think the biggest thing as well is when, I mean, the person that answered the question, it's not them that's going for it, it's somebody else. And I think it would be coming from the angle of, but these are the reasons and these are the whys of why we need to keep on going.

Sometimes you need that reminder or that wake up, because we need to hear mentally, like, this is what I'm doing, this is why I'm doing it, this is why I am going to get through this. And having that belief and family members, for me, it was no brainer straight away. I'm like, I've got a three-and-a-half-year-old boy. I've got stepchildren. He needs his daddy and I need him. It's about connecting with that why, and I think, essentially, who you are.

And again, definitely seek help. It sounds like the help can navigate you back onto a road that you should be going down. Because I've seen what happens when people get to that give up stage, and it's not always the right kind of result. When I relapsed last year, I had two options and I didn't like one of them and it wasn't going to end very well. So I had a choice, but I've also got age of why.

I've got stuff that I've not done in life yet that I want to set out and achieve. I've got things that I want to do, memories to make. I've got so much to look forward to. And those are the things that, regardless of how hard my day was, I was going to get through it because tomorrow I was

going to get closer to making those memories and making things happen. But yeah, definitely seek advice because if you're in that place, you can spiral very fast and if you reach out it just takes a conversation to get back onto a path where you can move forward again.

Jennifer Gillette

Thank you. I also have to say I really love, because I know you put a lot online to try to support people and I love the mantras I see that you have, too. I feel like in moments I've heard from other survivors, like one of them used to sing that song from Rudolph the Red Nosed Reindeer, put one foot in front of the other when they had days that like, oh, bad test results or things like that. And I think of your mantra, "We can, we must, or we will, we must" And just really holding on to your mantra. I see so much in what you share. Thank you for that. I see other questions coming up, so I'm going to get to those.

One is I was just diagnosed with MDS Q5 syndrome. My doctor does not advise me to pursue bone marrow transplant. He is monitoring my Revlimid treatment that works for now. However, I feel that MDS Q5 can become a different type of cancer and I'll be pushed to have a bone marrow transplant, without being prepared. They do not offer bone marrow transplant in Hawaii where I live.

Well, for this person, do either of you have anything to say? I am happy to answer it but if either of you have thoughts, I would love to have you share.

Pat Hodges

Well, I'm not a doctor, but I always -- because I am a coach, a caregiver coach, as my husband is, much more involved patient coach. I always look at MD Anderson for help. You can send your records there and get a second opinion if they're able and can afford to go to Texas, Houston, Texas.

Jennifer Gillette

Absolutely. Any thoughts, Adam? Thank you so much, Pat.

Adam Claxton

Yeah, again, some of that is a hard question to answer, obviously. I'm not a doctor. The logistics of where you live, we can't answer that. But there are always, and I've learned that there's no point worrying about what might happen with different types of cancer down the road because I've got to get down that road first by getting through what I've got currently in front of me. So I think sometimes to help ease that pressure, don't worry about what might happen because it also might not happen. But why are we worrying about events when we need to be focused on. So yeah, definitely.

The bone marrow transplant, I mean, technology, medicine, it's improving, year on year. And I'm very lucky over here that one of my consultants is world renowned in stem cell transplant transplantation and the things that charities are doing are incredible. And without them,

they're putting together plans and treatments that were, like 20 years ago, they would have been trials, but now they are first methods of treatment.

So, as we progress, trials that are happening are going to be getting better and medicines are going to be coming in and they're talking about things that are less evasive with chemotherapy. So let's just get through the challenge that you've got now. Trust in your team. And if you have to, like Pat said, if you have to find somebody else, do so because the more knowledge you have, the more understanding you're going to have of the situation.

Jennifer Gillette

Absolutely. I'm just going to tie on to that as well, that you are the captain of your healthcare team and if something is not sitting right with you about your care, I want to remind you that you are able to get second opinions. If you live in Hawaii and there is not anyone in Hawaii that offers transplant, one, I will tell you, you can look on the BMT InfoNet provider guide and look for specialists in your area. Just kind of off the top of my head, if there's not a good place in Hawaii, I know City of Hope in California, as well as Fred Hutch, which is on the west side.

Pat Hodges

City of Hope is excellent.

Jennifer Gillette

Amazing facilities for second opinions and you could reach out to Blood Cancer United or NMDP or even DKMS and see if there's any funds to help if you are lacking in that. And if you need any help with If you wanted a second opinion, please reach out to me and I could try to see if I could come up with resources to help you get there for a second opinion.

But sometimes, there might be places that you can start, digitally. And so, I would look into that further if you're not feeling comfortable with your plan.

There's another question here. First of all, it says, thanks, Adam, well done. I was diagnosed with AML in August of 2023. a stem cell transplant in March of 2024, and I am currently living without restrictions. I deal with survivor's guilt, really. I call it grief now because I'm not guilty of anything, but I grief those who have not had the same outcome that I have, and forgive me, it just moved. Do you feel this way? And if you do, what strategies do you use to work through those feelings? And then it says, Cheers, Adam.

Adam Claxton

Yeah, I think that a lot of us, at some point, will feel survivor's guilt. And I've had it in the last 24 hours where somebody that I had transplant at the same time has sadly passed away, yesterday. We go to the same clinic together. And when you go to the clinics, you often see that some people aren't there anymore. You wonder and find out what happens.

And I think the thing that I kind of got into my head early, I mean, four days into my diagnosis, I saw a man pass away the other side of a room. We actually called the emergency, called when we saw it happening. And it was their story, not mine. And I sat there, covered my ears, put headphones on, and I just kept on saying, his story, not mine, his story, not mine. And it helped. It really did help.

And I mean, we know what it can do. We've all probably witnessed what it can do. But that guilt is, it's a feeling, allow it, accept it, acknowledge it, move forward and know that it's not you and you are and do have the right to live and to move forward. It is hard, but I think we've been through our own situations and it's the pathway and almost the life that we had put before us.

So don't let that guilt, guilt is a horrible emotion to have. It's one of the nastiest ones that all humans have, that feeling of guilt, sometimes, but it's also one of the heaviest that we deal with. And I think after transplant and the experiences that we've had, it's something we need to kind of not carry through forward with life. So step into your greatness. Acknowledge your feelings, but don't let someone else's story take over yours.

Jennifer Gillette

Good advice. I also wanted to validate another person typed in here. I'm a caregiver of a spouse who is two years post-transplant, this month, for MDS to AML. He's doing well physically, aside from some chronic graft versus host, but I was not prepared for the emotional struggles he and I both still face. Would love advice and/or assurance we are not alone in the emotional impact. I feel the transplant care team does not do enough to address this before or after transplant.

Anything you want to add to that, Pat?

Pat Hodges

Actually, we've been working on some research here in the United States about just that, that the physicians see that they need to be more open and helpful to the patients and their caregivers.

It depends. We loved our hospital in Durham, and they have a great transplant team where there's MSWs to talk to you. The doctors are very open. I perhaps maybe would get involved on some caregiving online groups. That helped me in the beginning because I didn't know anyone with AML, and I would get on AML support groups. And it was helpful to talk to somebody who was going through what I was going through. But in getting back to the doctors, I mean, try and open up a conversation with a PA or a physician or a nurse that you feel most comfortable with.

Jennifer Gillette

I think that's a great idea. I also will just say too, again, with that BMT InfoNet directory, getting a counselor who understands oncology, joining support groups, joining online groups, these are all places where you can talk to other people, like Blood Cancer United has some great groups

and things, too. And so, just talking with other people, you're not alone. And that's a very common issue, so please feel validated today.

But unfortunately, we are already at that time. And I just, again, I want to thank both Adam and Pat for being here today and sharing your experiences and the wisdom you have for walking through this. And I thank everyone for being here for this presentation today and of course, our sponsors. We just appreciate you all. We wish you the best and please reach out if there's anything we can do to support you on your journey. Thank you.

Operator

Thank you, everyone. That does conclude today's webcast. You may disconnect your lines at this time and have a wonderful day. We appreciate your participation today.