

The Bloodline with Blood Cancer United Podcast

A podcast for patients and caregivers

Episode: ‘Navigating Challenges as They Come: Resilience for Caregivers’

Description:

What happens when a resilience expert becomes the caregiver? When a loved one is diagnosed with blood cancer, you’re suddenly balancing fear, advocacy, and everyday life all at once.

In this episode, we sit down with Karen Reivich, PhD, a resilience expert, caregiver, and wife of a lymphoma survivor. Karen opens up about the reality of supporting her husband through treatment and a clinical trial, sharing invaluable lessons on managing uncertainty, accepting help, and caring for yourself while caring for someone you love.

Transcript:

Elissa: Welcome to *The Bloodline* with Blood Cancer United. I’m Elissa. Thank you so much for joining us on this episode.

Today, we are speaking to Dr. Karen Reivich, a caregiver, author, and the Director of the Resilience and Positive Psychology Training Programs at the University of Pennsylvania, where she also serves as an instructor for the Master of Applied Positive Psychology Program. In her role, she teaches others how to thrive and create and maintain resilience.

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In August of 2023, her life changed forever when her husband was diagnosed with double-hit diffuse large B-cell lymphoma, a very aggressive form of blood cancer. She became his caregiver and experienced the challenges, fears, joys, pain, love, and growth that are part of dealing with cancer. She saw how it affected their marriage, the ways in which their adult children were changed, and it provided her the unwanted opportunity to use all of the skills that she teaches to others. Welcome Karen.

Karen Reivich, PhD: Thank you so much. I've been really looking forward to doing this.

Elissa: Well, thank you for being here with us today. So, before we discuss challenges and practical tips for caregivers, I'd like to start with your personal story and your husband's diagnosis of double-hit diffuse large B-cell lymphoma. I'm sure many listeners have heard of this type of lymphoma, but would you be able to explain what double hit is and what that means for his prognosis?

Karen: Yeah, so just to back up a little bit, in March of 2023, he had a surprise heart bypass surgery.

Elissa: Okay.

Karen: And we thought at that time, that's the hardest thing we're going to have to deal with as a family. And then five months later, we discovered that he had diffuse large B-cell lymphoma. I had no idea what that meant. I, certainly, the term double hit meant nothing to me.

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Elissa: Yeah.

Karen: I mean, all new. But what we learned pretty early on is that this double hit is just a translocation of some of the genes which just make it so that, as I understand it, the cancer cells die more slowly and double more quickly. So, it just makes this form of cancer harder to treat because it's just much more aggressive.

And so, the prognosis, when we first learned about that is kind of rough. It's not a great prognosis for having specifically this double-hit diffuse large B-cell lymphoma. And he went through three lines of treatment, including a clinical trial.

And I'll jump to the good news part of the story – and there's a lot of rough stuff in between, as I know you and your listeners know – is that the good news is we got connected to this clinical trial; and I hope to talk a little bit about how that happened. And he's been in remission for a year. His next scan is coming up in a few weeks. And so, one of my worries early on, our youngest was just starting her sophomore year in college when we learned all of this. Our sons are out of school. And, based on the data, I was thinking he might not be here to see her graduate. And he was. She graduated in May, and she's starting a new job. So, science saves lives. I know you know that and your listeners know that, so we were very, very fortunate to be in this trial.

Elissa: Oh, that is wonderful that you were able to get connected with a clinical trial.

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Karen: Yeah, I mean one of the things I have taken away from this experience is how so many life circumstances play into treatment outcomes. And we're both in academia, so we both had the ability to travel. We know how to read scientific literature, so we were able to do research into clinical trials. We had people in our lives who knew people that helped facilitate connections; and so, there is so much inequity in the services and the treatment people get, and a lot of good outcomes are partially because of some people have better access than other people, and we were lucky to be in that group with better access.

Elissa: Yeah, absolutely. We cover healthcare disparities quite a bit on this podcast, and for our listeners who don't know, we also have a Clinical Trial Support Center where nurse navigators will look across the country to try to match patients with the trials that they qualify for. And what's great is you can get in a clinical trial at any point after diagnosis; so, you don't have to wait until this is a last resort. Clinical trials are not necessarily a last resort, so I'm so, so happy that you were able to get into that trial and that it worked-

Karen: And it worked.

Elissa: -and he's in remission and that is so wonderful. Do they know what is ahead for him?

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Karen: What's ahead is he's in a follow-up phase, so he'll now have one more year of scans every four months. And for his form of cancer, a cut point is two years without recurrence.

Elissa: Okay.

Karen: And if he's at two years without recurrence, and we've just passed the one-year mark, they talk about cure. So, he feels healthy; and he's back to all his normal activities. And I am too, and so we're in a good place.

Elissa: I love to hear that.

Now, I want to go backwards a little bit. How did he end up getting diagnosed? You said he'd had the bypass a few months before, and then what happened in those next five months?

Karen: Yeah. I mean, he was tired; but was also recovering from bypass surgery. So, he had a little, what initially everybody thought was a cyst in his groin; and he was getting that looked at, through dermatology. And I think because of the nature of the double hit, it went from a tiny little, what we thought was a cyst, to this very big tumor very, very, very quickly.

And, got a biopsy and the PET scans, and pretty quickly it was determined that this was cancer. His first appointment, he was hospitalized and started receiving R-

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EPOCH, a form of chemotherapy that was seven days of treatment in-patient, then two weeks home, and then another seven days in-patient. But it was just that little cyst; and it was definitely a reminder that you have to pay attention to these things in your body. It would have been so easy for him to ignore it; and we're fortunate he didn't.

Elissa: Yeah, yeah. So, after all of that and then he was diagnosed with the lymphoma, what was that emotional impact for you and your family?

Karen: I think initially, given that we had just gone through this surprise bypass surgery, it almost felt surreal. Like, wait, how is this possible? We just did our stint in the scary health world. Luck isn't a big concept in my life. But I think it was the first time I heard myself saying and certainly thinking how can we be this unlucky? It just felt hard to fathom. In retrospect, it made the heart surgery seem like just a common cold in terms of the complications and the life change that it led to.

And I think telling our children, as I'm sure so many of the people listening to this have had that experience. It was just realizing that I had to find the words. I guess we are lucky because we won the lottery with our kids. They are the most delightful human beings, and to find the words to tell them after what we just went through that dad has this serious cancer was, just so difficult to do. And they jumped in their car. The boys all three live in different places in Brooklyn, and they drove down. And they became a

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critical part of the care. And I feel one of the things sometimes I think about is how different it would be if we had four young children-

Elissa: Yeah.

Karen: -as opposed to four adult children and their lives were turned upside down, as you can imagine. But for me, they became, a part of, not the central part of my support system because, I wanted to protect them from taking on that role with me; but they really were here with us throughout all of it. And the decision-making, which was really tough, and to have adult children who could help me think through choices and ramifications and all, questions to ask the oncologists and the teams was really helpful.

Elissa: Yeah. I feel like we see that with adult children quite a bit is that they also become a support system for the primary caregiver, emotional support and, helping with decision-making, not being the decision-maker but providing insight, providing that objective opinion from what they're seeing from the outside a little bit. And that can be very helpful to them as well.

Now, all your kids were in their 20s when that happened?

Karen: Yeah, so, the boys were in their mid-to-late 20s; and our daughter just turned 20, you know, just starting her sophomore year. And for her it was different because

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she needed to be at school. She was in New Orleans, and I wanted to keep her updated, but I also wanted to make sure that she had the space to be a college student.

Elissa: Yeah.

Karen: And so, for each of the kids, it was a little different. Like that was one of the things I kind of learned is that each of the four wanted to be involved in slightly different ways and wanted updates at slightly different times and paces. And I had to kind of learn that as this was all unfolding.

Elissa: Yeah, because as a parent, I'm sure you still want to protect your children on some level from the full bit that you were getting.

Karen: Yeah. We rely on like a lot of people humor in our family to cope with things. And one of the things that I remember, as the dust was settling and we were all, like, realizing the enormity of what we were just walking into together. My husband is from California. I'm from Philly; and so all of the stereotypes you have of those two-

Elissa: Yes.

Karen: -personalities, they're right. I'm a action-oriented, problem-solving, get-it-done kind of person; and he's a little more laid back, a little more chill, and a little more absent-minded in delightful ways. But one of the jokes in the family became, if one of the parents had to have the cancer and one of the parents had to be the caregiver, it

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broke the right way because he had this unbelievable ability to just roll with the next thing. But if he had to schedule an appointment or remember to sort the pills, it wouldn't have happened. And I had this capacity to approach it like a problem that needed to be solved, but I was not chill.

Elissa: Yeah.

Karen: So, that became the joke in the family.

Elissa: Yes. So, you mentioned how this all had an effect on your children. How did this affect your marriage?

Karen: Yeah. I was thinking about that a lot and like what were the key things I noticed. So, one is I did become the primary caregiver; and that included not just the logistics. I did feel like it was Central Command; and I was-

Elissa: Yeah.

Karen: -making charts and all of that. But it also meant like being really aware of what his needs were and his appetite for information. And so, I took on the role of, trying to stay very attuned to what he wanted to know and didn't want to know and being really supportive in the ways he wanted, which were not always what I wanted, right? Like, there were times where I wanted him to know everything because he was my partner; and I wanted to be able to use him as a partner in some of these things.

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But he didn't want to know everything, I think I got much more skilled at tracking what he needed.

But the other thing I wanted to say, because sometimes I think there is a tendency, like we romanticize trauma and challenge like you're going to come out stronger, and I think we have. But there were also things that, while we got a lot closer and he relied on me in ways that I don't think he did before and I was open to having him rely on me in those ways.

There were also things that were really, really hard. I remember the first time I allowed myself to get mad at him while he was in cancer treatment. A part of me was thinking, you can't have fights. You can't, fight because he's in cancer treatment; and he's the patient. And, then there was this one moment that; I think people will understand this. Some of the side effects would, he would be very tired, and he would sigh a lot.

Elissa: Oh!

Karen: And, you know, it was just a sigh. But he would sigh a lot, and at one point realized, can he just sigh on the inside? His sighing became a little bit like nails on a blackboard for me. And initially, I was like, if he has to sigh, he has to sigh. Anyway, the first time I allowed myself to be a little frustrated with him and to say things, like, "You know if you're going to sigh that much, let's just go in different rooms for just like

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the next 20 minutes; and you get all your sighs out, and then we'll come back and we'll finish dinner," or whatever it was.

And that was an important moment. It was important for me to realize that our marriage is still bigger than patient/caregiver.

Elissa: Yeah.

Karen: And I'm allowed to have the full range of emotion-

Elissa: Yes.

Karen: -just like we did before he was dealing with cancer. And so, I wanted to say that because I think sometimes it's easy to feel like the caregiver, there's not enough space for us to have all of the emotions, particularly towards the person we're caring for. And I think that's a burden that is realistic to carry.

Elissa: Yeah, yeah, I fully agree. And, coming from a patient perspective, myself, I think the patients can also sense this; and they don't want to be treated as somebody that is fragile, that you can't talk to anymore, that you can't share your troubles, that you can't share the bad things going on outside of this particular situation. And so, I think the patients can sense that.

Karen: Yeah.

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Elissa: And they want to feel normal. They want to feel included and feel like, they can be there for you too. Even though it's good to not lay everything on them, it is good to know that you can still have those wide range of emotions, even if you, mostly share them with friends or other family and people outside but still keeping your loved one included on some level.

Karen: Yeah. I think identity for both the person dealing with the illness and then the caregiver and our children, it's, I think, one of the challenges I've thought about as this was unfolding for us is like how to maintain your identity bigger than the primary piece.

So, for my husband, he was a champ. He continued to work. He's a therapist, and he continued to see patients virtually throughout his entire treatment, including when we moved to Houston. So, he did a really, really great job of making sure that Guy – his name is Guy – that Guy was always bigger than patient Guy or Guy who has cancer.

Elissa: Yeah.

Karen: And I think I learned not quite as easily to maintain things outside the role of caregiving so that Karen was also bigger than Karen, the caregiver. But I think that's hard, and it takes time to sort out how do you do that. He was great at it. It took me longer.

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Elissa: Yeah, yeah. So, you've mentioned a couple challenges, the sighing and, of course, this recent one in keeping your identity. Are there any other challenges that stick out to you as a caregiver that you went through; and how did you get through them?

Karen: Yeah. I think a very common one for me, is taking care of yourself and even knowing what does that mean-

Elissa: Yes.

Karen: -in the context of in and out of hospitals and, dealing with the stuff at home and medications and clearing PICC lines and all of that stuff. Like, what does it mean to take care of yourself, and how do you do that? And so, there were many things that I did prior to Guy's cancer that weren't viable. I'm a big walker; and I would take long, long walks and do a lot of my meetings, like ten miles a day of walking where I would be on the phone with my colleagues and so forth; and that wasn't realistic anymore. So, I had to think about what is taking care of myself look like within the realm of what's possible, given what our life is going to be like in some period of time.

For me, that meant taking things that used to be the mainstay of my well-being and figuring out how to tweak them to work in the current context. And so, an example of that is part of the reason walking is such an important part of my wellness is that it helps me. I like to move. It clears my head. It centers my emotion. And one of the

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things that never fails for me when I'm walking is I see something beautiful. And it doesn't matter where I'm walking. It could be on a city block, but no matter where I'm walking, I see something beautiful; and I have that pang of awe, of just like, "Wow, how lucky am I to be in a world that has moss!" Like where does moss come from?

And so, I wasn't taking 10-mile walks, but I decided that I needed to still have that emotion of awe and beauty. And so, I would start each day, as close to the start of the day as possible, with my cup of coffee; and I would just go stand outside in our yard. And I started this habit. It's going to sound a little hokey, maybe, but it worked for me, by asking myself the question almost every day, "What's beautiful here?" or "What's beautiful now?" And I couldn't take 10-mile walks, but I could still stand in my yard and look at the tree or watch our dog or see a neighbor playing with their little child and there's never been a time where I asked that question, "What's beautiful here? What's beautiful now?" that I couldn't answer it.

And that dose of beauty, I mean it didn't solve the problems of the day, but it enabled me to, start the day in a much different emotional space; and it was taking care of me. Like, even if he had to wait a few extra minutes before I brought him breakfast, let's say, that was okay. He could wait a few extra minutes so that I could launch myself into the day in a very, very different headspace. So, that was really, really an important part.

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There's one other thing. I think early on, I felt angry a lot and, I know people often say, throughout this, the person never asked why me or why us. That was not me. I asked why us. Like how could this be happening to us? I asked why me, why us a lot; and I was angry that we were confronting this again. And I did think early on that his life was going to be fairly short from the time of the diagnosis.

And so, I started this list on my phone in the Notes app that I titled, "People Are Good." And I just wrote down, typed in anything that I noticed in the day that struck me as showing that people in the world are good. And that was so helpful to me because I was still angry at times. I still ask why me at times, why us. But a part of my attention was always going to scanning not for the bad things that were happening to our family and the fears and the worries, all of which were happening and true. But I was also actively scanning for who's helping us and what little good thing happened in the day. And it made a big difference.

Elissa: Yeah.

Karen: Eventually, I stopped doing it because I think I needed it less; but in the early weeks and months, that Notes list was really important for my wellness. And that was just something sort of like a gratitude journal, which people know a lot about. I adapted it though. It wasn't only gratitude. I mean I was grateful for those things, but it was more just the act of noticing kindness and goodness and, like, kind of showing to myself, "Look, even though bad things are happening to our family, to many families in

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the world, there still is goodness in this world as well.” And that was a wonderfully anchoring habit.

Elissa: That’s beautiful. So, are these part of skills that you teach to others?

Karen: Yeah. And one of the things in our work around resilience and well-being, you mentioned, I’m at the Positive Psychology Center at the University of Pennsylvania, and that’s the mainstay of my job is to take the science of resilience and well-being, look at what are the, empirically supported strategies that people can use to enhance resilience, enhance well-being, and then develop programs where we go into all sorts of different organizations and teach these skills to other people.

And one of the things I always say when I’m running these workshops is, “Look, these are tools, and it’s going to be really important that you experiment and figure out how to make this tool work for you,” because nothing is one size fits all.

Elissa: Right.

Karen: And so that was my experience, that things that I taught others, I realize, okay, that doesn’t work exactly right for me in this challenge. And so, how do I take it and adapt it a little bit to make it more, so instead of a gratitude journal, which felt a little fabricated. I don’t know, just something about the word gratitude. I’m not sure why, but the word gratitude wasn’t resonating with me at that time.

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But people are good and the world is good. Okay, I can get behind that. I feel that in my body, and so I just tweaked it. And so, I think that's an important thing. I guess one thing I wanted to say is I'm a big, big believer in taking what works and adapting it; and I'm also a really big believer in noticing when something that you have been doing stops working. Then stop doing it. Like-

Elissa: Yeah.

Karen: -at some point I stopped the good, notice the good journal because it wasn't working anymore, and I found something else. I think that's important, to give ourselves permission to quit the things that are no longer working.

Elissa: Yeah, absolutely agree. So, let's get into some more practical tips for caregivers. One thing that you have written about is the seven skills for resilience. Could you share what those are and how they relate to cancer caregiving? And also, if you use them yourself.

Karen: Yeah, absolutely. So, it's interesting, that number seven has grown because as the science continues to grow about how we enhance our resilience and well-being, the tools and options people have continued to grow. So, one of the most, I think, foundational ways that we can enhance our resilience and strengthen our well-being, even during very, very, very difficult times is cultivating the mindset of optimism. And whenever I use the word optimism, I know that there are people who will hear that word

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and think, oh, gosh, here she goes. Eyeroll. Like optimism is toxic positivity or it's about pretending things are good when they're not. And certainly, as a caregiver, pretending things are good when they're not is dangerous, right?

Elissa: Yeah.

Karen: I mean there's things that we have to be doing. And so, I want to just say that that isn't the style of optimism that is really helpful to resilience and well-being. The style that is what I would describe as a "yes and" mindset. What I mean by yes and is, like, it's seeing the world as it is, seeing the situation as it is, and then being able to focus on one thing that you can control or notice something positive or reach out to somebody who has a resource that you need in that moment.

So, this mindset of optimism is about seeing the world, seeing a situation accurately, and then also believing and anchoring to that belief that there is some positive change possible. And we can practice that mindset. That's a mindset that all of us can enhance by engaging in some simple strategies like noticing the good or reaching out for support or when you're noticing that you're starting to catastrophize, which how can you not catastrophize-

Elissa: Yeah.

Karen: -when you're in the world that we're in?

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But when you notice that that's starting to happen, to be able to see it, hear it, but then say, "Okay, well what's one thing I can do right now, one action I can take right now that feels purposeful, that will help me to feel more calm?" Maybe it's deliberate breathing, maybe it's taking a walk, maybe it's calling a friend. But by hearing the catastrophizing and then moving to one purposeful action, our anxiety can slow down or can lessen; and then we can feel more empowered again. So, that mindset is, I think, a critical mindset for caregivers for all of us. So, that's one strategy I always encourage people to practice.

Elissa: Yeah, I like what you said about the toxic positivity because I think that is very common to talk about in the cancer community, that as a patient, it can be frustrating that, you're told to just be positive. Why aren't you just positive? And, you're not always going to have positive days. It's a really difficult experience. It's a really traumatic experience.

Karen: Yeah.

Elissa: And it is the same for caregivers, that it's a very traumatic experience to go through. And so just saying to stay positive is not realistic. But having that realism but also being able to have hope for the future, I think, is something that is a wonderful way to look at it as well, that you can still be hopeful.

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Karen: Yeah, thinking of optimism not as positivity but as a mindset that keeps our energy going. So, I mean one of the things that, whether you're the patient or the caregiver or family member or part of the support system is this is, a marathon, right, and the treatments are, arduous, and so anything that we can do to help our energy being maintained is going to pay dividends in all sorts of different ways.

And that's one of the things I've come to really appreciate about optimism. It's not about being happy all the time. It's not about positivity all the time. It's not about pretending things are good when they're not. But it is about saying, "Okay, what if I believe positive change is possible, that there's something I can do to create some goodness or a slightly better chance of a good outcome, what is that thing?" And then this mindset gives me the energy to kind of go after it.

And I think a really important part of that sometimes people don't maybe associate with optimism is that when I'm sort of lost in my own pessimism, which happens, I isolate. And that's a common experience of when we're more pessimistic, when we're worn down by the things that we're confronting, is that we start to isolate. And when you isolate, your energy gets lower, your anxiety gets higher, the sadness increases.

And so, one of the things that I always like to underscore about optimism is that reaching out is such a mainstay of resilience. I think sometimes we have this belief that resilience is about, shouldering the burden alone and trudging up the mount. It feels

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very like Herculean; and resilience is about muddling through and having people who you can rely on while you're muddling-

Elissa: Yeah.

Karen: -is critical. And this is something we teach in our programs, it became so helpful to me in our situation, was realizing that different people in our lives are capable and willing to provide different types of support. And the more I was able to realize in a moment, in an hour where Guy was, what type of support do I need right now? Do I want someone just to listen and let me vent? Do I want somebody who's going to help me problem-solve? Do I want somebody who's just going to distract me? Do I want somebody who's going to laugh, the person who I can say all the most honest, horrible, scary thoughts too. Like those weren't the same people.

Elissa: Yeah.

Karen: And so, one of the things that I think, whether you're dealing with cancer or another illness or a job loss or whatever your challenge is, becoming a connoisseur of your own needs and then answering the question who is the person who can best give me that? I call that, in our work we would describe it as like a reach-out roster because my ability to support Guy became so much easier when I was getting the support I needed; and I knew my sister for this, this friend for that, my coworker for this other

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thing, and my needs got met much more effectively by not thinking of it as there's one person who can give me all the different kinds of support I need.

So, I would encourage people to do that. What are the different kinds of support you need and like list it all. Like if you need to just say the horrible, scary things, you need it. Who's the person that can be your partner in that? That's very helpful.

Elissa: Yeah. Now, are there other skills for resilience that you'd be able to share?

Karen: Yeah. So, we talked some about optimism. We talked some about reaching out.

Another skill, and I've already mentioned it, is tending to positive emotion. And that can sound a little weird in the context of you're dealing with a significant, traumatic health issue. But positive emotion, so I don't just mean happy. I mean gratitude, awe, contentment, joy, amusement, love. Curiosity. There are so many different positive emotions that human beings experience.

And what we've learned in their research is that positive emotions play an incredibly important role in stress. So, thinking about which positive emotions are most important to my sense of self, like laughter and amusement, and it's just like that's core Karen. And when that's not there, I don't feel myself. That's one way to think about it.

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Another way to think about it is, which positive emotions most sustain you. Like when you have a little bit of that – gratitude, serenity, humor, love – it has an outsized effect on your overall wellness. And so, it's really important for people to understand that it's not selfish to experience positive emotion while you're caring for somebody who's suffering. It's, in fact, one of the best things you can do for the other people in your life is to be able to carve out experiences that bring on the positive emotion that's most sustaining to you or the biggest part of your identity.

And so that's a question, again, that people listening could answer. And one way to think about it is, when this emotion is not present, I don't feel fully me or, sometimes I'll say it's the opposite of the *Wizard of Oz*. Like when that emotion is present, things are technicolor. And when that emotion is not present, things feel monochromatic, right? It doesn't mean feeling that emotion all day long.

That's not real in any circumstance. It's certainly not real world in the circumstance of having cancer or being a caregiver. But we can all do simple things, and I talk about it, one way to help with this is habits, that you can bookend your day around that emotion that is most important to you. So, if it's gratitude, maybe while you're brushing your teeth in the morning, you take those two minutes to not only brush your teeth but also to think about somebody who helped you in the last 24 hours. And so, you're pairing the emotion to something you're doing already so it doesn't feel like a burden. Like, oh, another thing I have to do?

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Elissa: Right.

Karen: And so, bookending the day around the positive emotion that's most important to you, again, doesn't matter which it is, will increase your energy. It helps you to feel you. It helps you to manage stress, so we are able to manage stress more effectively if we have a healthy diet of these microbursts of positive emotion. It helps all the anxiety and anger, whatever those other emotions are of, your physiology to return to baseline faster. And it's doable. So, I would encourage people even just scribble on a piece of paper all the different positive emotions you could think of.

People are really good at that. You might come up with 20. And then look at the list and say, "Of all of these words, which one or two are most important to me," and then design a little habit around it, something that takes two minutes or less and experiment. For me, it's I stand outside and say, "What's beautiful here?" I get a dose of all. That launches me into the day in a different space than if I don't do it. And so, you could experiment with habits that give you, again, micro. It's not about feeling it all day long but a little hit of that emotion, and maybe you can try for three of those a day. People will probably notice that it has a really powerful effect on their wellness and their endurance, which is a really important part of being a caregiver is having the endurance to keep going.

That's another, positive emotion is another resilience, well-being strategy.

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So, another one. I mentioned the word catastrophizing. So, I would guess it's near impossible to be either dealing with cancer or being a caregiver or family member and to not have times when your anxiety is just through the roof and your brain is creating the imagery of all of the horrible things you're fearing.

Elissa: Yeah.

Karen: And I think it would be silly and glib to suggest that we can eradicate that.

Elissa: Yeah.

Karen: I mean part of it is just learning to know that that voice and those images are going to be part of the experiences of the world that you have now dropped into. That said, there are some things that I've learned and that we talk about in the work that can be really helpful. And one of those is when that catastrophizing is getting really strong, I mean one is to move around, to take some deliberate breathing, go outside. I mean changing your environment can start to change what's going on in your mind; and that's really helpful. But sometimes, it just comes back again.

Elissa: Yeah.

Karen: So, learning to think of yourself as the future version of you. So, for myself, when I would have the really scary thoughts about Guy not being here, not being here for Shaina's graduation or, you know, all the things he would miss, and then my mind

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would go to all of the things I would have to handle alone – managing the house, anyway, just all of it – my anxiety would just, you know, just through the roof.

And I learned to use the technique of first of all, acknowledging it. Those are really, really scary thoughts, Karen. I use my own name because by using my own name, I was talking to myself the way a friend would talk to me. So, acknowledging it. Those are so scary. Those thoughts are so scary if those things happen. Those things happen; it will be horrible. You don't want those things.

But then I would say, and you know what, Karen of six months ago never would have thought that she would be able to cope the way Karen of today is coping. And so, you can trust that future Karen is going through all of the life experiences she's going to have between now and if that horrible thing happens, future Karen is learning all of the things that she'll need to be able to handle it if that happens.

And that, there was something very both emotional for me in thinking of myself as past Karen, current Karen, and future Karen. But knowing that I didn't have to today, Karen today doesn't need how to handle all of the finances and all of the things and how to plan a funeral. Karen today doesn't even have to do that.

Elissa: Yeah.

Karen: And if future Karen does, and I hope she doesn't, she's going to have the skills and the people in her life to help her then. But I think for people who are listening to

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this, reminding ourselves that who we are today is constantly changing, and we're acquiring new skills. Many of them we wished we would never have to acquire. But that is going to enable the future version of ourselves, to be able to confront what needs to be confronting. And Karen today can be anxious. That's okay. I can give that part of Karen a hug. Like, yeah, this is really scary. And the future version of you is developing every day, and she'll be in a different spot than you are.

And that's a strategy that all of us can use; and just last piece I wanted to say about that is, that means tracking what new skills am I developing? How am I growing through this really, really horrible thing that we're confronting? And, of course, I'd rather not have the skills. I would trade the skills. I'd rather be less skilled and not be in the world of cancer because I don't have a choice if I track the skills I'm developing. And if the people listening are like, "Oh, wow, I learned how to do that. I learned how to speak to physicians. I learned how to be assertive in ways that I never had to be in the past. That's setting me up for the future with whatever I'm going to confront down the road."

Elissa: Yeah. I'm thinking of probably all the planners listening to this and thinking, how do I not plan for this? But it is wonderful advice to stay here right in the present that you don't have to deal with those things right now, that may or may not come.

Karen: Yeah.

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Elissa: At any time in the near future. And so, while preparation is good, I think it's nice to kind of draw back a little bit and remind yourself that I don't actually have to deal with any of that right now. None of that. I can work on what's happening right now in front of me and know that, in the future if I have to deal with that, then I will be better prepared-

Karen: Yeah.

Elissa: -in six months, a year, a few years down the line. I will have people surrounding me to help me through this. My children will be there and help me through this. And so, I think that's really important advice.

Karen: Yeah. I use the word identity in the beginning as we were speaking. Our world's shrink when somebody we love has cancer or if you're the person with cancer. Your world just becomes like so, so small. What you're focused on is the next appointment, the next treatment, the tracking the side of it, whatever it is. And that's okay. I mean I think that's protective.

I mean, we have to be focused on just the next thing. And so, I think part of that is also giving ourselves the grace to know that there are things that we might be experiencing that seem- lots of anxiety, right? Maybe prior to a person's family experience dealing with cancer is like, "I didn't see myself as a very anxious person, so like what's wrong with me? Like now when it really matters, I'm experiencing so much anxiety as a

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caregiver.” I think helping all of us understand that all the things that are evolving as part of dropping into this new world are okay. And that we have to sort of be gentle with ourselves in knowing that our identity’s going to grow again as the situation unfolds.

Elissa: Yeah. I think there’s something to be said, whether you’re a caregiver or a patient that a lot of these things that you’re experiencing are normal. And other people experience those things as well, and that can be a great part of peer support that other people are experiencing this. And so, it is always nice to know that you’re not only not alone, but you’re also not that unique in those experiences either.

Karen: Yeah. Yeah, I mean I think that sense of community and were talking about this a few minutes ago, but the tendency to isolate, I think, is common. And that, too, and I think one of the things that was most helpful for me as a caregiver was to fight the urge to isolate and to challenge myself to know who were the people in my life that can give me the things I need and not to worry about burdening them. I had to sort of give up that guilt. Like, they’ll take care of themselves; and if I’m calling too much, they’ll stop picking up the phone. But it’s not my responsibility to monitor if I am asking too much of the other people in my life.

One other thing, you just reminded me of it, I don’t how this will resonate with other people; but, I think, part of the task of caregiving, I know we’re like tracking so many things and I think choosing wisely what to take on. Part of resilience is the word I tend

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to use it navigating. Like it's navigating the challenges as they come, and part of that is choosing what is not yours to take on. And I mean that by saying no to things that normally you would say yes to, but you don't have the energy. And that was a hard thing for me as a professional. Like, I'm not going to take on that project; and that took me a while to get used to it, but I did.

But it's also within the world of cancer choosing what you're going to take on. I want to just give you an example is this is a very individual, some people listening might have a completely different take on this. But I found some of the language around cancer to be off-putting. So, when people would say to me or to Guy, you're so strong. You're so brave. You're battling. That, language was not working for me. And initially, I kind of found myself being irritated by it.

Elissa: Yeah.

Karen: And then at some point I had this like moment of I could think about that language the same way I could think about Merry Christmas. So, I'm Jewish, and when people say Merry Christmas, I don't feel irritated. I think how wonderful. They're wishing me merriment. Doesn't matter what their attributing the merriment to, what holiday, but they're wishing me merriment. I love that. I receive it. But with the brave and strong and battle and all of that language, I was getting irritated.

Elissa: Yeah.

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Karen: So, I chose to let that go and to say, people are just using the language that makes sense to them; and the intent is they're trying to connect to me and cheer me on. And I can receive the intent and not worry about the word choice. So, I let that go.

But not always. And so, an example of something I didn't let go, and again, to me this is about well-being and resilience. It's like, I'm not going to sweat the language part, strength and battling. But when people in the healthcare world would, look at my husband's chart and say, "Okay, so Guy failed the first two lines of treatment," and the first time I heard that, I'm sure there was a reaction the other person could see. But I didn't say anything, and at one point when I heard that, I said to the doctor, "Hey, you know, my husband didn't fail the treatments. And the doctors didn't fail him. The treatment didn't work."

Elissa: Yeah, and the treatment failed.

Karen: Right, the treatment failed. And that's part of cancer or any illness.

Treatments don't always work. My point in this is that for me letting go of certain language; but knowing that this other language was really important to me because it had meaning that I was going to take that on. And I think that's a lesson that I learned over and over and over again as a caregiver is where's my energy going to be best spent? And sometimes it's letting go of battles that are just not the right battle to fight.

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Elissa: Yeah.

Karen: But that doesn't mean not standing up for the things that do matter and have an impact personally in ways that really matter to me. And so that lesson of letting go, not of everything, but letting go of some of the things was something I had to learn over and over and over again. But when I learned it, my ability to be present and to have the energy and all of the things that we've been talking about was much greater. Maybe the question for people listening is like, "What do I need to let go of?" You know, whatever languages. What's not mine to battle or fight, but what is? Because as caregivers, we do have to fight for certain things. And that's important.

Elissa: Yeah, you're advocating for your loved one; and it is so, so important. Yeah.

Karen: Yeah.

Elissa: So, our final question today, on our patient podcast home page, we have a quote that says, "After diagnosis comes hope." What would you say to other caregivers to give them hope after a loved one is diagnosed with cancer?

Karen: That's a great way to end this. I would say that as scary and hard and painful it is, there are always people that are willing to support and help. So, that's one part that always gives me hope, that I'm never alone. And then the other part, I would say, is as somebody who has had a husband in a clinical trial, the access to new treatments that didn't exist only a few years ago gives, for our family, incredible grounds for hope,

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that the brightest minds are working on finding cures and treatments that, I think, are real world and tangible. And in our family's case, my husband is alive because of that. And that, I think, is something we can all be hopeful about, the continuing science around cancer treatments.

Elissa: Absolutely. It has been truly amazing to see where cancer research has come; and you're seeing new breakthroughs all the time and clinical trials that are working, as we can see with your husband. And so, that is so wonderful.

So, thank you so much, Karen. You gave so many incredible tips for caregivers; and I'm sure they resonated a lot with your story as well. We really appreciate you joining us today and sharing all these tips and advice for caregivers who are going through just such a difficult time right now.

Karen: It was a pleasure. Thank you so much for letting me share some of our experiences with you.

Elissa: And thank you to everyone listening today. *The Bloodline with Blood Cancer United* is one part of our mission to improve the quality of lives of patients and their families.

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In addition to the Lounge, we could use your feedback to help us continue to provide engaging content for all people affected by cancer. We would like to ask you to complete a brief survey that can be found in the show notes or at TheBloodline.org. This is your opportunity to provide feedback and suggested topics that will help so many people.

We would also like to know about you and how we can serve you better. The survey is completely anonymous, and no identifying information will be taken. However, if you would like to contact Blood Cancer United staff, please email, TheBloodline@BloodCancerUnited.org. We hope this podcast helped you today. Stay tuned for more information on the resources that Blood Cancer United has for you or your loved ones who have been affected by cancer.

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