

Lauren Hixenbaugh (00:00):

Welcome to Living Beyond Cancer. This is a series of podcasts created for cancer patients, survivors, and their caregivers. Hi, I'm Lauren Hixenbaugh, a program manager for Mobile Cancer Screening at the WVU Cancer Institute, and I'm a host for today's episode, and I'd like to introduce my co-host, Andi Hasley.

Andi Hasley (00:17):

Welcome, everyone. I'm Andi. In addition to being the Mountains of Hope Coalition Manager, I am a breast cancer survivor as well. Living Beyond Cancer is sponsored by the West Virginia Cancer Coalition Mountains of Hope and is produced by WVU Cancer Institute's Cancer Prevention and Control. We are thrilled to share today's episode with our listeners. Today, we have with us Julie shooter. Julie and I met through Mountains of Hope. She moved to Morgantown shortly after I became the coalition manager and reached out to become more involved. A series of communications back and forth led to a Zoom meeting, and we have become friends ever since. Julie is an inspiration to me as a cancer survivor every day. We are thrilled that she gets to share her story with all of our listeners.

Lauren Hixenbaugh (01:08):

Julie, I just wanted to say welcome to Living Beyond Cancer. We're really excited to have you today. I have got to hear a little bit of Julie's story, but I'm really excited to dive into it. If you'll just introduce yourself and tell us a little bit about how you ended up here and then we'll get into it.

Julie Schuder (01:26):

Thank you so much for having me on this podcast. I appreciate it. I became a volunteer with the cancer coalition through my former physical therapist. I have been a lifelong volunteer with several organizations and I was looking to join an organization here after I moved. Cancer is obviously very important to me, so she connected me to Andi and here we are.

Lauren Hixenbaugh (02:02):

Thanks, Julie. I really appreciate you being here today with us. I thought we would start, of course, at the beginning of your story. It's so inspirational. I thought maybe you could start with telling us about the type of cancer you had and maybe split some of the symptoms were.

Julie Schuder (02:19):

When I was a teenager I had Ewing sarcoma bone cancer, which is a rare form of cancer that typically happens in children and teenagers. I was 13 when I first started having symptoms and those symptoms were pain in my right femur. It's interesting because I didn't really realize that I would constantly rub my leg every day, my best friend, and I would study together after school. One day she said to me, "Why do you always rub your leg like that?" I said, "I didn't realize I did that, but my leg hurts." Before I had cancer, I was very quiet and shy, which as Andi knows, I am

not that way now. But before I had cancer like I said, I was very quiet and shy and I wouldn't complain or talk about anything like that.

Julie Schuder (03:16):

Once I realized that I was constantly rubbing my leg and was in pain, I got up the courage to tell my parents. Over the course of the first maybe six months, we started off with my pediatrician who at first said that it was most likely growing pains. As time went on and the pain wasn't going away, then I was told I was too athletic. I ran track cross country. I played soccer and basketball, so I stopped doing those things. But what's interesting is over the course of almost a full year, I had this pain in my leg. It went undetected until a tumor presented itself. A few weeks before the tumor was detected, my dad and I were playing Frisbee outside and he fell, tore some ligaments in his leg and the pain was so bad that I could barely walk on my leg.

Julie Schuder (04:20):

He had said to me, "Why don't I take you to my orthopedic surgeon just to see what he thinks." It was in the summer, it was very hot. I was in a pair of shorts. We went to this doctor's office, and you have to remember, I was almost 14 now, very nervous to be at another doctor's appointment. He said to me, "How long has that bump been on your leg?" It was the size of maybe half of an orange. I said, "I have never seen that before." It was on a Friday, and I lived in Massachusetts at the time in Western Mass. He said, "I'm going to send you to Boston." Which was about an hour and 15 minutes away. On Sunday, I went to Boston, on Monday, I had a biopsy, on Wednesday, they said I had cancer and this is what we will do for Julie. It was immediate. I started chemo and the journey began.

Lauren Hixenbaugh (05:27):

Wow, that's unbelievable how fast the turnaround was there for you.

Julie Schuder (05:32):

It really wasn't. I remember when I was at Boston Children's Hospital, which is an amazing hospital that first night, I'm 14 years old, and there was a girl in the room with me. Her name is Amanda. We stayed up all night long talking. She was in the hospital because she had a tumor. When she asked me while I was there, I didn't know. I said, "I've had this pain in my leg and I saw my dad's doctor and here I am. I probably tore some ligaments like my dad. I had no idea." She said, "Well, you have a tumor, and that's why you're here to have a biopsy. You want it to be benign." I'll never forget this, "You don't want it to be malignant." I said, "Why?" She said, "If it's malignant, it means you have cancer."

Julie Schuder (06:25):

That Wednesday, when they called us in, it was my parents and the surgeon and a social worker to hear them say, "Julie Schuder was malignant, she does have cancer. This is what we're going to do for her." I just remember thinking that girl Amanda told me I didn't want it to be malignant. To be a teenager, it was really scary to hear that you had cancer and that you're going to start chemotherapy. I didn't have time to really think about it or understand it, but I became well

aware of what was happening pretty quickly. I was the type of teenager that wanted all of the information. The first oncologist that I had, we did not get along at all.

Julie Schuder (07:23):

We had to kindly ask for a different oncologist, which it's interesting to look back now as a teenager back then, I started to become an advocate for myself, which has continued throughout my life. I did get a new oncologist who was amazing. Although, he likes to say that I'm his biggest pain in his ass patient. Lovingly he says that. But yeah, so I started chemo, and what happened with me is, this is 37 years ago, they did not ... What they kept saying to me was, if you're lucky, you will survive. If not, you won't. It's hard to wrap your head around that. I had four full cycles of chemo, and then I quit. I was very, very sick. My parents couldn't cook in the house. I was always constantly in the hospital.

Julie Schuder (08:30):

I would never make it home for longer than a few days. Whether it was by my parents driving me or an ambulance, I was always transported back to Boston. I just kept thinking, "If I'm going to die, I don't want to live like this, being this sick, having to wear hats and coats in the summer." I ended up quitting chemo after four full cycles. Then, I started radiation therapy, and because I didn't go through the full year of chemotherapy, we tacked on two weeks of radiation, which I learned 30 years later was radical radiation, which radical radiation is a high dose of radiation to kill the cells, obviously, to make sure that you can survive cancer. But it did a lot of damage to my leg, and 30 years later back in March of 2014, I was walking downstairs and my leg broke almost all the way across.

Julie Schuder (09:46):

I started off at my local hospital in Western Mass and then a super amazing orthopedic surgeon there said, "For complicated cases, I send them to Boston to this doctor." I said, "That's my orthopedic surgeon." Off I went to Boston and my orthopedic surgeon said to me, "It's either radiation-induced sarcoma or wear and tear on a very fragile leg." I had no idea what radiation-induced sarcoma is, but he told me that that usually occurs 30 years after you've had radiation. He called it radical radiation. I said, "Okay, well, let's figure it out." We did a biopsy and thankfully it was not radiation-induced sarcoma.

Julie Schuder (10:42):

It was just wear and tear on a fragile leg. Looking back, I always feel as though I'm so blessed to have gone 30 years without anything happening to me. But the journey that started almost eight years ago has been a very long journey.

Andi Hasley (11:04):

You have mentioned surgery a few times throughout your description of your journey. Can you take us through what that surgical journey has looked like and maybe share the causes or end results, the before and after of that process?

Julie Schuder (11:29):

Sure. Over the course of those first two years after breaking my leg, I had 20 surgeries, which I know sounds amazing, for lack of a better word. After breaking my leg, I initially had rods and screws put in to heal the break, but again, it was a really bad break. I was in Boston for a week. My orthopedic surgeon of 30 years introduced me to his partner, Dr. Anderson, who is just the kindest, most amazing surgeon. She was very hopeful, as I was, that the break would heal. However, there were many complications that happened. After being in the hospital for a week and having the rods and screws put in, I went home and shortly after developed pressure sores on the heel of my foot.

Julie Schuder (12:34):

We didn't realize that I had a blockage in my leg, so I went to my local hospital, they put me on IV antibiotics. For some reason, vascular did not come to see me. I went home. I went to see a vascular surgeon, who was the rudest person, I think, that I've ever had to deal with. He came into the room and had his back to me because he was talking to his resident and was just asking me why I waited so long to be seen. I explained I had just been in the hospital. I understand I have these pressure sores on my foot, that's why I'm here. The blood flow to the foot was something like 0.5, which is not good. He went on to explain that I need an arterial bypass, but I wasn't a good candidate for that because most likely I wouldn't survive it because my leg is so damaged from the radiation that I had.

Julie Schuder (13:45):

It's terrifying to hear this when you're sitting in a doctor's office. Obviously, I couldn't drive, so a friend had taken me there, but was in the waiting room. This surgeon said, "Why are you here by yourself? You should have someone with you." I said, "Well, obviously, I can't drive. Someone is with me, but they're in the waiting room."

Lauren Hixenbaugh (14:07):

Julie, how old are you at this point? I'm sorry to interrupt you.

Julie Schuder (14:10):

That's okay. I was 44. This was almost eight years ago. I had a list of questions that I wanted to make sure I got answered. I had said that to him. I said, "I have some questions I would like to ask." He snapped at me and he said, "You don't ask me questions. You listen to what I'm going to tell you. Then, if you have questions, you can ask after." I looked at him and I said, "Can you speak to me as though I am slightly intelligent because I am slightly intelligent and I don't appreciate your condescending manner." Which surprised this arrogant surgeon. He went on to just say I had a blockage. It was severe. I needed surgery right away. He didn't know if he would be able to save my leg. I started crying, of course, because what else would you do? He just kept berating me for waiting so long, which I tried to explain.

Julie Schuder (15:20):

I was seen as soon as I could. He was talking to the resident mostly just saying, "Her leg is a mess. She probably won't keep this leg for long." I left that appointment and he wanted me to make an appointment for surgery, and I went to the front desk and I said, "I am not making an appointment with the surgeon. I would never let him operate on me. I went out to the car with my friend, got in the backseat." My daughter had been trying to call me because she lived here, I lived in Massachusetts, several times and I just picked up the phone and I was bawling and I could not stop crying. I felt terrible for her because here she is so far away and it's hard to watch your mother go through something like this. I immediately called Dr. Anderson in Boston.

Julie Schuder (16:17):

When I called my doctors in Boston, they immediately get back to you, which I am so thankful for. The nurse called me back and I explained what just happened. She said, "I'm going to talk with Dr. Anderson. I will call you back." Probably within 30 minutes, she called me back and she said, "We have this vascular surgeon that's joined Beth Israel." Because my surgeries were all at Beth Israel Deaconess Medical Center in Boston at this point. She said, "He came from Vanderbilt. He's amazing. He will see you tomorrow. Can you make it?" I said, "I will make it happen." Now, keep in mind, I couldn't drive. I had to constantly ask people to get me back and forth to Boston. I said, "I will make it happen."

Julie Schuder (17:02):

Because I have the most amazing friends, I was able to make that appointment the next day, and what a difference. I sat down in Dr. Guzman's office and I call him my hero, which he hates because he's a very humble, kind human being. But immediately upon meeting him, he just had such a nice demeanor and they did repeat vascular studies. I explained what had happened and he said, "I do agree that you probably do need an arterial bypass, but I don't think you would survive it. Here's what we will do. We're going to take care of you and you do need surgery and we need to have that done immediately." He said, "But it will be okay. We will come up with a plan." I was crying, of course, after almost a full year, the brake failed to heal. What happened is the femur collapsed. The femoral had crumbled and my hip fractured.

Julie Schuder (18:06):

But because I had this hole in my foot, they couldn't do much about it. They put a cement spacer in and it was interesting and very painful, but we had to just go through several surgeries to try to heal the foot. One of them was a free flap surgery, and it was more than I anticipated. It was a procedure where we took a muscle and a vessel from my left leg. I still get upset talking about this. We took a muscle and a vessel from my left leg and attached it to my foot. It was, I don't know, an eight-hour procedure. Several hours after that procedure, I needed an emergency surgery and I ended up losing a lot of blood and I needed a massive transfusion, so I had 12 blood transfusions in a row.

Julie Schuder (19:22):

I didn't realize at that time how traumatic that experience was, because, during those first two years and all of these surgeries, I just kept plowing through it. I was like, "It's okay. I can get through this. It's a four-hour surgery. It's a six-hour surgery." That surgery really took a toll on

me. I had moved to West Virginia a few years after this happened to be closer to my family, because my poor daughter, through these 20 surgeries, she would fly back home for every surgery. She had a one-year-old daughter at the time. Well, she has a daughter. She was one years old at the time. She worked full time and her in-laws would come in from Illinois to help, and it was very overwhelming, as you know, being a caretaker. I eventually moved here to be closer to my family once all of my major surgeries were over.

Julie Schuder (20:36):

After I had this free flap surgery, the flap ended up dying, which means the surgery was not a success, through no fault of the surgeon. It was just the damage that I have in my leg. But eventually, we did get the foot healed. In August of 2016, once the foot was healed, they had to put in a hip joint and femur prosthesis, which was a really big surgery. I hadn't walked at that point in two years on this leg without crutches. I was homebound for a year with my foot needing to be elevated, attached to the wound VAC. I had to learn how to walk again after this surgery. I was constantly worried about this hardware that I have in my leg, and always waiting for it to fail, which is a terrible way to live. Because as my surgeon said, the hardware could last three years, five years, 10 years, you never know.

Julie Schuder (22:00):

Well, I had moved here in December of 2018, and that following summer, I had a vascular emergency. It's really hard moving to a new state not having your medical team that you're used to with you. The first surgeon that I met here, the first vascular surgeon that I met her, to her credit, was very honest with me and said, "You do have an occlusion, which is a blockage, but I don't feel comfortable operating on you because you have a very complicated case. You need another surgeon to do it." Which is scary, but thankfully the vascular surgeon here spoke to Dr. Guzman in Boston to get a picture, a clear picture of what has transpired and he was able to clear the blockage.

Andi Hasley (23:08):

I wrote down something that you said while you were telling this overwhelming story. I've heard this story, for our listeners, this is maybe the fourth time I've heard Julie's story. Every time, if you could see my face right now, I just keep shaking my head from side to side, because it just blows me away. But you said, very casually, you said this ended up being more than anticipated. That makes me chuckle a little bit just because you say it so calm and it's definitely not calm, but I feel like more than anticipated is a good summary for anyone that has dealt with a cancer diagnosis, because I think that we handle things.

Andi Hasley (23:58):

You have X, then you do Y, then you do Z, and to the people outside of your inner circle, they think, "Oh, they must be good. Everything's good." Then, there's all these other things that happen, in your case for decades, that in John Q Public's idea, it's, "Oh, well, she's cured. She doesn't have cancer."

Lauren Hixenbaugh (24:26):

Her treatment is done, we hear that treatment is over with.

Andi Hasley (24:31):

Yeah, treatments are done, "Oh, they must be great." Granted, as a cancer survivor, we're thankful to be here, but all of this what's next is what, more than anticipated, is the phrase that I'm going to use from you because it's true. You and I have talked about this a little bit because we both moved post-cancer diagnosis and initial treatment. Can you talk about what the overall transition from your established care in the Boston area to how that becoming reestablished for care has been in your move?

Lauren Hixenbaugh (25:19):

I would also tack on Julie, what would your advice be to people that are experiencing this? What would have helped you along the way as you were transitioning? If there's anything that you can speak to that would help folks as they're transitioning.

Julie Schuder (25:35):

These are excellent questions. Let me just start by saying, Andi, as you know from our meetings, these last eight years have been very challenging. I have always been the type of person that tries to stay calm and show grace through adversity, but it's hard. Making the transition to having your doctors who know you, who are invested in you probably more than they need to be, I would say is a blessing, but then also very difficult when you get a new team, and you're just, I hate to say it, not a number, but surgeons are here for a reason. They're here to fix the problem and move on. My orthopedic surgeon in Boston got me in touch with a surgeon in Pittsburgh, who I went to see first.

Julie Schuder (26:48):

Just so I could have someone a little bit closer to Morgantown should I need him. Then, I on my own, with the help of my physical therapist and people I know here got me in touch with an orthopedic surgeon who became my doctor, but it was not an easy transition. That vascular emergency led me to my vascular surgeon here, who is also a great surgeon, but it hasn't been easy. As a patient, to find a new team is anxiety-ridden because I knew in Boston the care that I received was exceptional. You hope for that same care, but you don't know.

Andi Hasley (27:50):

Not to interrupt you, and I think the other aspect of this, and this has been on my receiving end too, is that you have this initial diagnosis and treatment. In your case, the challenges that came post that, and those specific physicians are guiding you through that initial care. Then, when you move after that, you almost feel like you have to start over with the aspects of your care that these specific doctors are not going to ever have any part of. Do you feel that way?

Julie Schuder (28:34):

That is such a true statement. Not only that, Andi, but my doctors in Boston knew who I was. They knew, "Listen, I'm a straight shooter. I want to know what is going on. I want to know what the treatment is. I want to know what the expectations are." But more than that, I know my body. I had had so many times where I had to, on an emergency basis, head to Boston because something was wrong because I knew something was wrong. If I called my surgeon and said, "I need to come in to be seen. Something is not right." They said, "Absolutely, come in." Every single time, something was wrong. I needed an emergency surgery, and an emergency hospital stay, so finding doctors here was the easy part.

Julie Schuder (29:36):

I ended up, a year after moving here, my hardware failed and I got up one morning and I had a fever, which is never a good sign for me. I initially went to my primary care doctor here who is amazing. The blood work showed that my white blood cells were fine and not to worry and I was sent home. Then, the next day or the day after, I couldn't lift my leg. It was dragging. I called my daughter and I said, "I need to go back to the doctor. I think my hardware failed." She said, "You're kidding." I said, "My leg is bright red." It's very different here. I went back to my primary care, who shifted me to the ED, which is the emergency department.

Julie Schuder (30:41):

Here, when you start off in the emergency department, you're followed by a very generic team. Just to backtrack, DVT is a deep vein thrombosis, maybe is how you say it. I had a clot in my leg, which DVTs can travel and kill you. Before we could even do this surgery to replace the failed hardware, my vascular surgeon had to go in and put what's called an IVC filter in first, so the clot, the DVT wouldn't travel. But it's a very different experience when you are used to being in a place where everyone, from the nurses assistants, which are called PCTs, the nurses, the nurse practitioners, the surgical residents, they're just so kind and caring and took me under their wings. It was terrifying.

Julie Schuder (31:49):

I was too sick to travel back home to my orthopedic surgeon there. Andi, as you had mentioned, there's a lot that happens after you've had cancer. For me, yes, I had Ewing sarcoma bone cancer 37 years ago, but these last eight years I now have peripheral vascular disease. I've had what started off as just clearing the blockage. I now have two stents in my leg, which I generally don't go longer than 12 to 14 months without needing maintenance. I just had vascular surgery January 18th, and one of the stents had compressed, but thankfully we were able to get it open. It's always a constant worry. I have lymphedema, which lymphedema is when you have swelling from radiation and cancer.

Julie Schuder (32:56):

My lymphatic system has been damaged, so I have constant swelling in my leg and I see an amazing lymphedema therapist here weekly. I have to keep my leg wrapped, but lymphedema in and of itself is another, I don't even know the right word, it's another set of just frustration. Because a lot of times most insurance companies do not recognize lymphedema nor do they often pay for necessary garments that are needed. There's a huge out-of-pocket expense. When

you're going through all of these surgeries and hospital stays and the hospital bills are adding up, it's overwhelming. It really is. It's overwhelming.

Julie Schuder (33:54):

I may sound calm, but to backtrack, when I first moved here, because a big piece of my journey is, when I first moved here three years ago I had two weeks off from school because I was getting my master's degree in nonprofit management and philanthropy. During those two weeks, it was the first time my mind was quiet and I just started crying. I would be watching TV and I would just start bawling. I started to get nervous thinking, "Okay, am I finally cracking here? Am I going crazy?" I saw my doctor and I found a therapist and I was diagnosed with PTSD. What's so interesting is I didn't realize that that free flap surgery was such a traumatic event, because I just tried to plow through everything.

Julie Schuder (34:56):

But I didn't process what was happening. It was a free flap surgery. Then, in August of 2016, like I mentioned, they put this hip joint and femur prosthesis in. Then, in January I saw my surgeon in Boston and we did X-rays and I said to her, "It's really weird, but something's not right with my leg. I can't explain it, but something is not right." She said, "The x-rays do look fine." But she did say, she's like, "You make me a little nervous because you are usually spot on with your feelings." I said, "Yeah, I don't know how to explain it." Well, the next day I went to PT, and during doing my first leg raise my hip dislocated. I was back to Boston the next day. Thankfully, under anesthesia, they were able to pop it back into place.

Julie Schuder (35:50):

But it puts a lot of stress and worry and anxiety on you. But I didn't realize that at the time, because I wasn't processing what was actually happening, so I found the kindest therapist and I work really hard with her. I'm actually doing EMDR therapy, which is a very intense therapy. EMDR stands for eye movement desensitization and reprocessing. Basically, the easiest way to explain for me what was happening is when something happens in our lives and you don't process it goes into a filing cabinet and it just stays there. Then, eventually, it will come out. For me, when I moved here and I had that quiet time, everything came to the surface.

Julie Schuder (36:47):

EMDR therapy, it's a safe way to, I guess, let your brain reprocess the traumatic events that have happened and the traumatic memories, so you can process it and heal from it. It's been a huge help because what happens, what started happening to me after I moved here, my body goes into fight or flight mode when I need surgeries because I'm so fearful. For instance, with my vascular surgeries, they use twilight meds and the twilight meds do not work as well as they should. I am more awake and alert during these procedures, which is terrifying. Anytime I have these procedures, it takes me weeks to recover because I go into that fight or flight, and it's a lot.

Julie Schuder (37:48):

Yes, I seem calm and positive, but I do work really hard to manage the anxiety that I have now. One of the most important things that I didn't do in the beginning, which I had to learn to do, was mourn the things that I can no longer do. For instance, I'm no longer working. I have two stents in my leg, which I can't sit at a 90-degree angle for longer than 60 to 90 minutes, because I can have an occlusion, which is a blockage. I am still on crutches. I'm in an orthopedic boot, and these are not complaints. Every year I'm having surgery of some kind.

Julie Schuder (38:43):

I'm on a lot of different medications, which when you're going from being a healthy person, taking no medications, to now being on a blood thinner, aspirin, cholesterol med, not that I have high cholesterol, but it helps with the blood flow. I now have high blood pressures.

Andi Hasley (39:06):

Julie, you and I speak candidly every time we're together about our challenges and our life changes as cancer survivors. Just so the listeners understand, Julie and I do laugh a lot when we are together because we recognize the benefit of laughing and sharing our frustrations and it's greater than our negative thoughts. But Julie, could you share, what is the number one biggest challenge in your day-to-day life through this whole journey?

Julie Schuder (39:45):

It's hard to pinpoint it to one, but I would say I live with chronic pain. This leg has been radiated. I've had 28 surgeries now on it. I live with chronic pain and I know a lot of people think that's like, woo-woo, and chronic pain isn't real. Every day my leg hurts. It's just the reality of how it is. You have to learn to live with that. But with the chronic pain, oftentimes, I don't sleep well. When I don't sleep well, I have to be really careful in my just day to day because I don't want to fall and God forbid something happen again. But that is a big, big thing, is living with the chronic pain.

Julie Schuder (40:44):

I know you asked for one thing, but I would say the anxiety that comes with this medical journey, always worrying about any little new symptom or pain. Again, I work really hard with my therapist to try to manage it.

Andi Hasley (41:08):

Do you think that those things are often connected into one thing though? The chronic pain plus the anxiety? Because for me, it's like a chicken and egg thing. The more pain I have, the more nervous, stressed out I get and then I'm not sleeping, and then, and then. I think that that really is one thing. I think those things are all linked together in the challenge of the day-to-day. Though it's like you said, you are calm and you're positive, that doesn't mean that those challenges don't exist.

Julie Schuder (41:50):

Yes, I am a very positive person, but you know what? Life is not always rainbows and butterflies. I don't like to complain about things because I feel so blessed to be a cancer survivor. I feel blessed just to wake up every day, but there are days that just suck and there's no other way to say it, but for me, what has helped is having the most amazing support system, and I think that is really important. For two years my friends would come over and do my laundry every week. They would go grocery shopping. More than two, I couldn't drive for four years. They would take me back and forth to doctor's appointments. They would be there to listen to me cry.

Julie Schuder (42:43):

I remember having a conversation with a group of girlfriends that came over and we were joking because I used to be the no-maintenance friend. Now, I was the high-maintenance friend. I remember saying to them, "Listen, if I'm still like this in six months, we have big problems." Here it is almost eight years later. But to have such kindness in my life, people that I had worked with 10 or 20 years prior were coming over, were calling, the joys of social media, connecting with people, my mother and I still joke about this. My neighbors that lived across the street from me at the time who I knew to wave and say, hi, knocked on my door one day. My mom's like, "Hi." They said, "Is everything okay with Julie?"

Julie Schuder (43:33):

For three weeks we've noticed every day flower deliveries, is something happening with her?" My mom's like, "Oh, it's a big story, but she will be okay." To me, it was remarkable that these people in my life, some whom I hadn't seen in so long, would think of me and just care so much. That really got me through that. Again, another silver lining in this whole situation are these kind healthcare heroes. Now, this has all been pre-pandemic. I have been blessed to become friends with so many of my nurses in Boston, my nurse practitioner and OR tech who anytime I would end up in the hospital, one time, I forgot a phone charger. I had five people come in with phone chargers, just coming to visit and just being so kind. I cannot say enough about the nursing staff that I had in Boston and how much I care and appreciate them.

Andi Hasley (44:51):

I always say, if you want to know how much people love you, tell them you have cancer. That sounds terrible, but it's true. What a blessing those people are whenever you're going through what you're going through.

Julie Schuder (45:06):

For me, it's been, March 22nd will be eight years that I've been going through this journey. To this day, I just have such kindness in my life. I'm just so appreciative for that.

Lauren Hixenbaugh (45:21):

Julie, your story, obviously, as people are listening, they're going to notice that I think the constant theme throughout your story is advocacy and resiliency. One of the things that always resonates with me when you talk is, and you touched on it, mourning the things you could no longer do, mourning your loss of independence, that old life. I just wanted you to touch on, we're

going to start to wrap up, so I thought one of the things that I'd like for people to hear is what would your advice be to people to keep that resilient spirit and how do they move on and continue on past, I know Andi hates this word, but the new normal, but how do you find that new normal and get past that loss?

Julie Schuder (46:21):

Well, as I touched on, I think you definitely have to have a strong support system because listen, things are going to happen. Things you never expect. One of the hardest things for me to do at the beginning of this medical journey was to accept and ask for help because that was not my MO. I am very independent. I like to be the giver. I don't like to be the receiver. I've always been that way, but I had to learn really early on that I needed a lot of help and I needed to accept that help. I'm just always thankful that I can say I'm a cancer survivor, because a lot of people, unfortunately, can't say that. I have hope in science and in medicine, and life is a journey and I enjoy all aspects of it.

Lauren Hixenbaugh (47:28):

Thank you. Thank you. I appreciate the inspiration here at the end. I hope that your journey is easier than it has been for you. I'll pick up a couple points as we start to wrap up for our listeners. Julie talked a good bit about her financial strains and insurance. We did do a pretty extensive podcast with some really great resources with some financial experts. You can find that on our website. If you go to Living Beyond Cancer podcast, you'll see the financial episode there with two experts in the field that really walk us through finding insurance coverage. As Julie talked about, there are some different tips and tricks to finding ways to pay for things. There's also some foundations and things like that that are also often able to help. If listeners remembered one tip out of today's podcast, what would you hope that it would be?

Julie Schuder (48:32):

Oh, geez. One, just one? Geez. I go back to being an advocate because nobody knows your body like you do. If you have a doctor that just doesn't feel like a good match for you, find another one. If you know something is wrong, fight for that. You can't just think that things will go away. You have to make things happen for yourself. I would say, just be an advocate and find inspiration, like I said, where you can.

Andi Hasley (49:25):

Thank you so much, Julie. I am so grateful for our friendship and that I have someone like you that reminds me that there will be a next day. I know that our listeners are going to love every minute of your podcast. I just feel really grateful to have you in the coalition. To find out more information about Living Beyond Cancer, visit MOH.wv.gov or WVUcancer.org. To join our Facebook support group, visit Facebook and search for Living Beyond Cancer. We have more than 200 members on our Facebook page now, so come and join in with people like us that want to help.

Julie Schuder (50:17):

Thank you so much for having me and I am also grateful for our friendship.

Andi Hasley (50:23):

Thank you.

Lauren Hixenbaugh (50:23):

Julie, thanks so much for being here and sharing your story with us, and trusting us and our listeners with the details of your life. We really appreciate it. I know you said this before, but I'm going to reiterate it because I thought it was really powerful. You said to us when we were talking about recording this, that you hoped that by sharing your story you could help at least one person. That's always mine and Andi's goal as well, is to be able, if we helped just one person today by recording this, then it was worth our time.

Julie Schuder (50:54):

Absolutely.

Lauren Hixenbaugh (50:56):

Listeners, thanks for being with us today. We hope that you'll continue to join us.