

Scott: Welcome to the 3P's of Cancer Podcast where we'll discuss prevention, preparedness, and progress in cancer treatments and research. Brought to you by the University of Michigan Rogel Cancer Center. Let's get ready.

We're here with Betsy De Perry to talk about those "what I wish I'd known" questions and concerns when diagnosed with cancer. Betsy is a 15-year survivor of Non-Hodgkin's Lymphoma. She lives in Ann Arbor. I shared her story through a year-long series in the newspaper, helped produce a PBS series on cancer, and written two books, the most recent, "Adventures in Cancer Land." In her daily life, she owns a home-building company with her husband and even built a condo building, naming it after her oncologist.

Now onto the important stuff. When you first heard you had cancer, what went through your mind?

Betsy De Perry: I think my mind just stopped. I was actually on US-23 when an emergency room doctor that I'd seen the weekend before called and said that he suspected cancer. I literally pulled off the side of the road and just sat there. I might as well have been hit by a MACK truck. By the time I actually saw an oncologist at the university about a week later, hearing those words were no longer, "We suspect cancer." It's, "You have cancer." It was even really worse. Your life just stops.

Scott: Wow. It sounds like through that whole process, there's a lot of whirlwind emotions and probably felt a little bit numb. So, is there anything that you maybe wish you had asked the doctor, or questions that maybe you shouldn't ask?

Betsy De Perry: That's a good question. You know, I didn't have any idea what to ask, I think as most people don't when they go in, initially at least. The one question that I really wanted to know was how long I had to live. That was really the overwriting question above and beyond anything. I think that was really the wrong question because there's not a doctor alive who can tell you that. I would say take that question off the table. It's not the right one to ask. Talk about treatment, talk about what your options are. At the end of the day, there's a lot of reason to be very hopeful, even with a cancer diagnosis. Treatments have come so far and there's so many of us out there who are living longer and living healthy lives. I would say take that question off the table initially.

Scott: So you mentioned some of the things to maybe focus on, as kind of what your treatments are, what options there are. Was there anything that you found helpful during your treatment, or was there anything that helped comfort you to help you?

Betsy De Perry: Sleep, lots of sleep. Aside from that, I would say that no matter how many people you have around you, cancer can be very lonely. For me, a wonderful comfort was this support group that was up at the hospital at the time. I found a great deal of comfort in hearing from other people who were going through the

same thing that I was going through or had been through it. It helped me to feel that I wasn't alone with these various side effects, especially my emotions. Face-to-face support groups are fewer and farther between than they were back then when I was in treatment, but online there's so many places that you really can get help and just share your stories, or even if you don't want to share yours, just listen to others. I think it does help to diminish that loneliness.

Scott: So, Non-Hodgkin's Lymphoma, it's more of a blood cancer. We hear more about breast and prostate and-

Betsy De Perry: Right.

Scott: What they call "solid tumor" cancers. What kind of treatment options are there for blood cancers, or what were some of the treatments you had?

Betsy De Perry: Actually, I entered a clinical trial. At the time, again, this is, gosh, 16 years ago, my options were far more limited than they are today. I started out in a vaccine trial whereby I would do chemotherapy and then a vaccine six months later, but I bombed out of the trial because the chemo wasn't working. That sort of leads me into, if I may mention a little plug for clinical trials-

Scott: Sure.

Betsy De Perry: I think that clinical trials will give you an option that you may not otherwise have. Sometimes, these are the very latest and greatest treatments that aren't otherwise available. I would always recommend asking your doctor if any clinical trials might be appropriate because it is a way to get some of these latest medications, latest treatments.

Scott: So you said you bombed out of the one clinical trial-

Betsy De Perry: I did.

Scott: So tell us about, did you do another one or...?

Betsy De Perry: No, there were no other clinical trials that were appropriate for me, so I went into standard chemotherapy and was supposed to have eight rounds of the chemotherapy. My cancer just continued to grow and the chemotherapy wasn't working. It had to be stopped halfway through. I always laugh and say, "Chemotherapy did a lot of things it was supposed to do: it made me a couch potato, it sent me to the hospital for numerous vacations, it popped out my hair," but it just didn't kill the cancer. At the end of the day, a new treatment became available literally in the nick of time. It's called radioimmunotherapy. It behaves differently; it detects the cancer differently than chemotherapy. That's what ultimately saved me, and so here I am, 15 years later. I would say to everybody don't give up. I can tell you that there was a time during that year through everything that I went through that I really didn't know that I was going

to make it. I remember one day, literally collapsing on the floor of my closet just sobbing. Not necessarily completely giving up hope, but wondering if I should really get my will updated. All the things that you need to do before you die.

That was probably the worst day. My doctors, the nurses, they literally never, ever, not once ever gave up on me. That was hugely helpful. There was always something to keep me going. Again, I would say don't give up hope. Believe. Keep going. Show up, take those treatments, as miserable as they are. That's our job.

Scott: So it sounds like you were originally diagnosed through U of M and you continued your care at U of M.

Betsy De Perry: Right.

Scott: Was there any thought of looking somewhere else? Going online and looking at stuff, what you'd maybe find on Google or searching? What ultimately made you stick with U of M?

Betsy De Perry: You know, it's interesting that you ask that because prior to my diagnosis, my husband has lived in Ann Arbor since he went to school here. I came here when I married him, so I'm not the old Ann Arborite, but that said, even though we lived here and drove past the hospital and the cancer center, we truly knew nothing about it. Fortunately, we had never needed to know anything about it. When I was diagnosed, my husband literally took the bull by the horns and he was going to find the best place for me to be treated if it meant going to who-knows-where. He started doing all of this research, and it kept coming back to Michigan. One day, he actually called one of the very large cancer organizations and I happened to be with them. He asked that question, "Where's the best place?" The woman on the other end of the line said, "Where are you located?" He said, "I'm in Ann Arbor, Michigan." She paused for a moment and she said, "You have one of the finest oncology programs in the country. Why would you go anywhere else?" We were sitting in the office, and we looked at each other and went, "Oh, well okay."

So, that's why we stayed in Michigan. There were certainly a lot of people who gave us the confidence that this really was the best place to be. As it turned out, it really was. I am truly convinced because of the timing of my treatment and the timing of the availability of the treatment, and the fact that my doctor happened to develop the treatment, I am truly convinced that given my illness and knowing what I know, I probably would not be alive had I not been here. Everything just converged to make it happen.

Scott: So it sounds like your husband did some research online-

Betsy De Perry: He did.

Scott: And he kept coming back to this. But, there is so much information out online about different things. I mean, I've looked up certain things and said, "Oh, maybe I've got this, this, or this." It's just like, "Oh no, I just have a sore back."

Betsy De Perry: Right.

Scott: Are there things from people who might be searching online that maybe might be good to look for that maybe aren't in Ann Arbor and don't necessarily have the access to some of the care?

Betsy De Perry: Right. Well, I think that Dr. Google is not necessarily the best doctor. Clearly we're all going to search online, but watch where you search. Where does that information come from? One of the things that I would say to people, there are two very good sources that I found helpful and that have even gotten better these days. The first is the National Comprehensive Cancer Network. It's nccn.org, and that's a coalition of, gosh I'm not sure how many hospitals now-

Scott: I think it's up to 20-

Betsy De Perry: 20-something.

Scott: 23 maybe?

Betsy De Perry: Maybe. I think it was about 21 when I was diagnosed, but yeah. These are the very top experts in the field, and they get together and they come up with what's the best recommendations. Patients, caregivers, family can get on that site, go through it. It's a wealth of really good, accurate, up-to-date information. I would say if anybody is listening to this and happens to be out even in a community hospital, that's information you can take to your doctor and talk to him or her about. The second thing I think that's really important is understanding what I call "medical-ese." Those 36-syllable words that unless you went to medical school or have a science background, all these big words come at us and we have no idea what they mean-

Scott: Along with all the acronyms, too that they probably spew out-

Betsy De Perry: Oh my gosh. It's like, "What?" You can have much more meaningful discussions with your doctor if you can, at least, speak the language. Two things: I would say never be afraid to ask what something means. Some people are better at conveying or simplifying that than others, but there's also a really good source; it's called medlineplus.gov. It's basically a medical dictionary online. It takes the most complex words and it really puts it into very easy-to-understand lay language. I went there and looked up one word at a time, and was able to really understand. Those are two sources, I think, could be really helpful.

Scott: Betsy, how has being a cancer survivor changed you from the person you were before your diagnosis to where you are now?

Betsy De Perry: That's a good question, Scott. I don't know that necessarily I'm any different. I think that we're the sum of our experiences, all of them: the good, the bad, and the ugly throughout our lives. The one thing that cancer did for both me and my husband is that it truly gave context to compassion. Prior to cancer, to be perfectly honest with you, we'd been so healthy. We'd never really seen that much human suffering. Seeing it up close and personal, going up to the cancer center, sitting in the chemo room, talking to the other patients and their families, seeing the kids. Oh my gosh, those kids and their parents. I saw so much resilience, so much true caring from perfect strangers. I think that's, again, given context to the meaning of "compassion," and hopefully we've been able to pay that forward a little bit, hopefully.

Scott: Before we kind of get to the end, I want to go back to something I mentioned at the very beginning. I alluded to you and your husband building a condo building and naming it after your oncologist.

Betsy De Perry: Yes.

Scott: Why name it after him?

Betsy De Perry: Well, there were a number of reasons actually. It started out as a little bit silly, to be perfectly honest with you. It's on Liberty, and there were just too many buildings with the name "Liberty." My husband jokingly said to me, "Well, you could name it 'The Mark.' It sounds like a very elegant name, and you could name it after your favorite oncologist." I said, "Oh, that's a great idea." So, as we really thought about it, we actually realized that in many cases, buildings are named after people for their achievements. While my own oncologist clearly saved my life and developed a drug that has saved thousands of others, I think that sometimes the researchers don't get the recognition that they truly deserve. Here in Ann Arbor, there are people every day working to prolong and save lives and make our lives healthier. This is what they do. That is so impressive to me, and so we just wanted to give a little shout-out, to give a little recognition to that achievement and to all of that hard work. That's the real story.

Scott: That's a nice story, and I'm sure that he along with many of the researchers appreciate that extra recognition.

Betsy De Perry: Well, I hope so. They certainly deserve it.

Scott: Well, as we're wrapping things up, let's maybe recap and get some final advice. One thing I think I would like to ask you about as well through this is, your husband seemed to be pretty much involved from day one.

Betsy De Perry: Yes.

Scott: What do you feel as far as the importance of caregivers or a very much close support group as well as any other additional advice for newly diagnosed patients?

Betsy De Perry: It is crucial to have a good, strong support system. I don't know what I would've done without my husband. The one thing that I would say is to this day, we still debate on who had the harder time: him or me. I think he did, and he thinks I did. The reason that I think he did is because all of the focus was on me and he had the burden of running the business every day, dropping everything when I needed to get to a hospital, dealing with my emotions, trying to deal with his own emotions and keep me hopeful at the same time. All I had to do was sleep on the couch a whole lot and show up and take a whole bunch of terrible drugs. We still debate on that, and I think for caregivers, I would say that your role is so important and so appreciated, but be also careful to take care of yourselves. That's one piece of advice I would certainly have for caregivers.

For newly diagnosed patients, I would say what I said before, is I know that it's awfully hard, especially in the beginning, to just believe that there's hope. There are millions of us, literally, who have heard those words, "You have cancer." We've gone through some things that we never thought that we could go through. You're stronger than you believe or may think you are, but you can get through this. Don't ever give up hope. There's always something to be hopeful for.

Scott: Great. Well I appreciate the time, Betsy, and I'm glad that you've been, obviously, a very long-time survivor-

Betsy De Perry: Yes.

Scott: And that you continue to thrive. I appreciate it. Thank you.

Betsy De Perry: Thank you so much, Scott.

Scott: Thank you for listening, and tell us what you think of this podcast by rating and reviewing us. If you have suggestions for additional topics, you can send them to cancercenter@med.umich.edu, or message us on Twitter @UMRogelCancer. You can continue to explore the 3P's of Cancer by visiting rogelcancercenter.org.