THE BLOODLINE WITH LLS
A PODCAST FOR PATIENTS AND CAREGIVERS

Episode: 'Cancer & Caregiving: Navigating My Parent's Cancer – Survivorship'

Description:

Join us for our special series where we focus on adult child caregivers of a parent with cancer. In this series we will be listening in on a conversation between a social worker and caregiver as they navigate the various stages of a parent's cancer journey – diagnosis, treatment, the role reversal from child to parent caregiver, and post-treatment survivorship.

In the fourth episode of this series, Jennifer Bires, MSW, LCSW, OSW-C, will talk with caregiver, Rob Coles about the experience of caregiving for his stepfather through the survivorship stage of multiple myeloma.

Transcript:

Elissa: Welcome to the Bloodline with LLS. I'm Elissa from the Patient Education Team at The Leukemia & Lymphoma Society. Today's episode is part of a special series for adult children caregivers of a parent with cancer. In this series, we will be listening in on a conversation between a social worker and caregiver, as they navigate the various stages of the cancer journey – diagnosis, treatment, post-treatment survivorship and the parent-child role reversal. At LLS, we recognize the unique challenges that come with caregiving of a parent with cancer and that these challenges may vary during the different stages of cancer. We invite you to hear about these challenges, learn from the social worker's perspective and find connection as a caregiver.

For today's episode, we will be hearing from Jennifer Bires and Rob Coles about caregiving during the post-treatment survivorship stage of a parent with cancer.

Jennifer Bires is the Executive Director of *Life with Cancer and Patient Experience* for the Inova Schar Cancer Institute. As Executive Director, she works to ensure that patients, survivors, and their family members have access to psychosocial care at no cost to them to help individuals cope with cancer, its treatments, and survivorship in the best possible way. She specializes in working with Young Adults who have been diagnosed with cancer, communication around end-of-life concerns, sexual health and has over a decade of experience running groups for people impacted by cancer. Jennifer also currently serves as the chair for the Board of Oncology Social Work.

Rob Coles is both a multiple myeloma cancer survivor and also caregiver to his stepfather, who also has myeloma. Rob's diagnosis was in 2014 and after enrolling in a clinical trial, he was treated with standard chemotherapy, immunotherapy, and in early 2015, he underwent an autologous stem cell transplant. His stepfather, 81, has also had chemotherapy, immunotherapy, and a stem cell transplant. Rob lives in North Carolina with his wife, stepfather and college-age daughter, who comes home during school breaks. They have a medical family; his wife is a nurse, his oldest daughter, Abigail, is an Emergency Room Nurse and Manager, and his middle daughter, Anna, is a Paramedic.

Welcome Jennifer and Rob!

Jennifer Bires: Thanks so much. It's great to be here.

Robert Coles: Thank you very much. I'm glad to be here as well.

Elissa: So, Jennifer, what is survivorship? Some people consider themselves survivors after diagnosis. Some people consider themselves survivors after they are in remission. What is survivorship?

Jennifer: You know, that is a really great question. I think when we think about survivorship, that word holds a lot of different meanings for a lot of different people. Some people love the word survivor. For some people, it's a really difficult word. Oftentimes, in the literature, we may see it being used from the day someone's diagnosed forward. But for some people who have a chronic illness, like multiple myeloma, it may not be a word that they can relate to, and I think everyone uses the word a little differently.

Rob, could you tell us maybe a little bit about what that word means to you or how you relate to that word?

Robert: So, I would agree with you it has different meanings to different people both, in my family and the community; and then even within the clinical team, they look at it differently. For me personally, it was the surviving part of the process of treatment and of moving to the end of a successful treatment to a complete response from chemotherapy and immunotherapy. It wasn't just getting across the goal line and saying, "Okay, we finished the treatment and your body has responded, the cancer is now being subdued and held at bay." But it was the aspect that you were actively engaged, that you were optimistic and positive, that, you were part of the team and part of the process, and that you had a vision that things would turn out successfully.

There are folks that I was around that would only consider survivorship to be complete remission, to have that declared clinically to them and then they could raise their flag and say, "I made it through the cancer process and I'm on the other side," so to speak.

For my stepfather, he was very worried in terms of how the treatment process would go and whether you could ever say you were completely cured of this type of cancer. And it was hard for him to get his arms around how the body would respond to the treatment, what the clinical laboratory side of that analysis would look like, and then physically once he finished the treatment, which he considered all part of surviving, would he ever be deemed "you're cured of cancer." And if not, how could you live in this space of I've done well, but there's no guarantees.

Jennifer: Sure. Did becoming a caregiver change the way you thought about the word survivor at all or what it meant to you?

Robert: I don't know that I was as aware of this as a cancer patient, but as a caregiver, I really tried to help my stepfather frame every day as a unique gift, a unique experience no matter whether it was a free day for him to do what he likes to do – gardening, getting outside for a good walk, having friends over to have a good social time with – or whether it was a day where he was having to go through treatments and an infusion and he knew that by the end of that day he would be wiped out, but that each day had its own special moments and to really live in that moment and to enjoy that moment. And in this idea of survivorship, it was accomplishing what you could in that day and not worrying about tomorrow.

And so, helping frame that for him so that he wouldn't get too far ahead of himself, which he was accustomed to doing. If he had a bad day on a Monday, early on, he would paint the whole week as going downhill and yet you could try to encourage him that, okay, Monday was tough, but Tuesday is a completely new event. Let's take Tuesday when it comes and not worry about Friday, Saturday, and Sunday that are so far out that we don't even know what those days we will encounter. And helping frame that for him and even for myself as a caregiver was very beneficial. It broke the big battle of cancer into more bite-sized chunks, and it helped us enjoy and keep that conversation light and positive and optimistic. And it helped us keep each other in check from not getting too far out on the horizon.

Jennifer: I love this idea of each moment, each day having its own special moments and also, this idea of living in the moment, because, like you said, it's really easy to get so far ahead and think about what's going to happen three months from now or six months from now or a year from now. And that anxiety can really make it very difficult to live in the moment and to, to enjoy the benefits of all of the treatment you have and getting to the space that you were in.

Now that you and your stepfather are both, for lack of a better word, in this survivorship phase or in an area of survivorship, how has it changed your caregiving relationship?

Robert: I think it's interesting for both of us that now that we're in this part of the journey that we encourage each other to live life as normal as we possibly can, meaning that we don't look upon ourselves as a cancer patient who's still on maintenance therapy, even though our bodies have responded well to treatment, but that we look at ourselves as we're a patient just like many people are with their doctors. Some people are dealing with high blood pressure, some people are dealing with high cholesterol, other people are dealing with cancer but that doesn't make us a person who is actively sick, actively needing around-the-clock care. That we can maintain some, what I would consider, normal activities working around some of the issues.

Both he and I have neuropathy as a side effect of our treatment and yet we're encouraging each other to get up and walk, to get up and exercise, even to go play Par 3 golf and use a golfcart to help us in that mobility. But to have fun, to do normal things that everyday people are doing at this age and time of their life. To do things with the grandkids. Go out to a baseball game, go to one of their sporting events and be able to participate and enjoy that.

And I think we remind each other of not letting the idea of being a cancer patient overshadow what we can enjoy at this time of our life and not let those concerns, or those fears come back and overwhelm us. We're much more apt to share from our hearts intimately, "Hey, I'm having a bad day. I'm feeling lethargic and I'm fearing that this is the beginning of the potential of cancer coming back." We need some reassurance to walk us back from the ledge, and to each other, we're good in that in reminding each other that if there's no clinical reason for us to go to that extreme, then emotionally we can walk back away from that and reassure each other in those times and get back on kind of an even keel for enjoying the day. So those are some of the aspects that have changed during survivorship.

Jennifer: You're really right in that cancer does have a heaviness to it that oftentimes other chronic illnesses don't, like diabetes or other chronic illnesses. And so, this reminder that even though you have a chronic illness that there's still a lot of life to live and a lot of quality of life I think is so important.

And there is a lot of anxiety around reoccurrence. The fact that you all are able to talk about it and really look at what is the evidence for or against that can be an important piece in combating that anxiety or even recognizing it.

As a caregiver, what's it like for you? Your stepfather did relapse at one point and now is doing quite well, but is there anxiety that comes along with that, that you have to manage as a caregiver?

Robert: I think particularly when he did relapse, there was concern throughout the family that the relapse would be worse than the initial diagnosis, that the treatment would be worse or more difficult to tolerate, and would the outcome be as positive or successful.

The healthcare team was wonderful in reassuring us of the alternative treatments that are now available today that weren't even available five years ago, that the ability to manage this chronic cancer disease that they had learned so much over these past years and were in a much better place to be able to deal with relapse situations, and then helping my family be open to expressing their concerns not only to me but to my stepfather was important just so that there was a level of realness, of intimacy there, and that everybody could kind of put that out on the table and yet say, "We believe in faith that you are going to do well. We believe in the goodness of the physicians that are guiding us, the nurses that are taking care of us in this process, that are going to do well here." And that was comforting to the family to be able to express that and to come through that with strength from other people around them.

Jennifer: You have such an incredibly positive attitude, and it sounds like some really good coping skills. Other than talking about it with family, and that may be where you go, is there anything that you do when doubt creeps in or when you do get concerned?

Robert: So, a very good question. I'm not naturally wanting to share emotions that are of concern or worry or fear, and so I've had to grow in that area of my life not only with my wife and daughters but even with my stepfather. When I do become troubled like that, I have found that journaling for me is a good way of thinking and expressing myself, thinking through what I'm dealing with in my head and in my heart. I am a person of faith, and so I spend time praying and meditating to be able to express that as well. And then I also have developed some other friends of mine socially who I can go to and talk with when I'm having struggles or difficulties like that, whether it's about my own cancer journey or what I'm experiencing as a caregiver for my stepfather.

I think I've grown in the area of being transparent with my stepfather. He can see it on my face when I'm concerned now. He can read me much better than he used to, so I can't really hide that from him at times. And I've gotten more confident to express that to him without feeling like I'm going to unravel his world as I discuss this.

Jennifer: Yeah, it sounds like you all have really grown in your relationship in a number of different areas getting you to this point that you're at today.

Do you have any other advice for other caregivers? You've really taken us through this journey on this four-part series but any other advice for people, as they are assuming a caregiver role as a child of a parent who has cancer?

Robert: One of the areas that I wanted to mention was an area that we missed or didn't think through well in the beginning. With my stepfather, we thought we knew different areas of his life for hobbies and for enjoyment, and we thought we could kind of splice that into our role as a caregiver to make sure that he had these outlets for gardening, for exercise, for sports. But we didn't stop and really ask him what aspects of his every-day lifestyle did he want to maintain. If he wanted to have a fun and happy excursion, what would that look like, where would that be? And when we did that one day, and this was months into his treatment, he told us things that we had not even thought of, like going to a particular favorite restaurant that we didn't know about or having a particular type of breakfast that we had never fixed or prepared for him.

So, taking the time to just sit back and say, "Paint a picture for me, dad, of what you would want to happen if you could have a fun outing this weekend, where would you want to go?" One time he said, "Hey, it would be great if we could take a drive and go to the beach for the day. Just sit in the sand, enjoy the warm sunshine, see the ocean, eat some seafood, and then come back home." So being able to elicit and be able to meet your family member on a different level of helping them to enjoy this experience and to maintain balance that was one thing we learned.

Another aspect would be being careful that the caregiving role doesn't overtake your full identity. And I mean that by I'm a husband, I'm a father, I'm a friend to others, I'm a church member, I'm a worker, and I have to give in these other roles as well. And sometimes being a caregiver, you feel like that's so important in this season of life that you're devoting all your energy into that. And my wife and my friends were really good at helping me maintain balance in these other areas of my life and make sure that it wasn't becoming too overwhelming for me and that, again, I was allowing others to step into these caregiving roles to use their gifts in loving my stepfather, to benefiting from growing that relationship and allowing me to continue to grow in the other roles that I maintained.

Jennifer: Yeah. You bring up such an important point that we all are really multidimensional people and that remembering everything that makes us who we are not just the one that is most prominent at the time, is really important.

I want to go back a little bit to this idea that you said about you asked your stepfather what he wanted to do for the day or what would bring him joy, and he gave you some suggestions that surprised you a little bit or things that you didn't think of. And it made me think of this idea that we all change as we go through an experience like this too. And so just because your roles or the way you interacted look one way when you first started this journey together, when you get into survivorship, it may look really different. You may be relying on each other in a different way or his needs or your caregiving may look very different.

So how did you create space to allow the relationship to change as the needs changed based on where he was at health wise and what was going on in his diagnosis and treatment into survivorship?

Robert: I think one aspect that changed in this area of survivorship was giving him more autonomy over his schedule, his day-to-day, week-in and week-out schedule. Rather than him having to go to multiple medical appointments or treatment appointments, most of that was behind him. He had to go in for checkups and for routine lab visits, but he wasn't a slave to the treatment and the clinic schedule. So, giving him that freedom back and instead of us organizing his day or his week, kind of putting that responsibility and that freedom back in his lap, which I think he fully appreciated.

At the same time, our communication had matured that he was more than willing to tell us what he wanted to do, what he was planning on doing, and would that fit into our schedules? Did he need to work around something? So, there was a more candid dialog back and forth. And we weren't tiptoeing around each other's feelings here. We were able to freely express what was going on in our lives, what was going on in his lives and trying to blend that together.

The other aspect was we weren't physically caring for him as much in this stage of survivorship, so it was more an emotional support and then also helping him connect back with more of his friends from his home, more getting him to visit his church from his home and letting him accommodate to his life more than become part of another family member in our activities.

And, again, I think that helps with the family member, the patient's autonomy. It helps with their feeling of reconnecting with people in their age group, in their social sector that they want to interact with and enjoy those aspects of their life.

Jennifer: Great. Rob, thank you so much. I think you shared the caregiving journey really beautifully with us today and so I'm grateful for your wisdom and appreciate everything that you shared with us. Thank you.

Robert: Thank you for this time and especially for The Leukemia & Lymphoma Society for giving us this chance to dialog.

Elissa: Hello and thank you for listening to the 4th episode of Cancer & Caregiving: Navigating my Parent’s Cancer.