

THE BLOODLINE WITH LLS

A PODCAST FOR PATIENTS AND CAREGIVERS

Episode: 'Cancer & Caregiving: Navigating My Parent's Cancer - Diagnosis'

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 first 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 diagnosis 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 diagnosis 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 the primary 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: Rob, in our introduction, we mentioned that both you and your stepfather were diagnosed with multiple myeloma. What was going through your head after your stepfather was diagnosed with the same blood cancer just a few years later?

Robert: Well first I thought it was a strange coincidence in terms of having the exact same type of cancer, but then the other part of my thought process was since I had been diagnosed previously and treated previously, that maybe I could be of further assistance to my stepfather as he was going through these same steps along this pathway. And for him, he was much more anxious and concerned about what this

would look like, how he would experience this, what would his survivability be, those types of questions. And I think he was looking for reassurance from everybody around him. So, I could help in a unique way in that regard.

Jennifer: Rob, what did it feel like for you, having gone through this yourself and now knowing that you are entering into this caregiving space? I hear a lot of the logistical pieces about really being able to be a guide for him, but what was going inside your heart or your head as this was happening?

Robert: Well obviously, my first concern for one of my key family members was wanting him to be assuaged in his concerns and fears but also to have successful treatment that he would continue to be with us and our family for many years to come. So, I did have, in terms of my concerns, they were wrapped up in I'm hoping that his diagnosis was caught early, I'm hoping that treatment would be effective, that he would be responsive, and that he would appreciate the same successful outcome that I had received.

My other concern was for other family members who were worried that, and not understanding much about blood cancers or multiple myeloma, they hear the term cancer, and they think that's a death sentence. And they were very concerned that their father, their stepfather wouldn't be around much longer. And so, it was a unique position to be able to help mediate some of those concerns.

Jennifer: Rob, what was it like to have to tell the rest of the family that your stepfather was diagnosed with multiple myeloma as well?

Robert: Scary to be able to try to explain that it is a serious diagnosis and yet we're fortunate to live in an area where we have quite a bit of healthcare resources and that my stepfather would be able to avail himself of all those different types of resources. And at least from the front end of the diagnosis, the physicians, healthcare workers, the team that he was working with was giving him a very positive outlook that they believed treatment would be well received and would be successful.

Now this is my stepfather, so my stepsister was probably the most difficult person to interact with because this is her dad, and she was very concerned. Her mother, unfortunately, had died of breast cancer many, many years ago and she was concerned that she was going to lose her father in quick order. So, it was good to be able to walk her back and explain what I had experienced, the different parts of my diagnosis and treatments. And not that his would be identical but at least, from the teams of healthcare professionals that have a great amount of expertise in this area, the amount of new medications that are now available, that treatment and treatment alternatives would be plentiful to help him respond. So that seemed to assist her and kind of giving her a more optimistic outlook.

Jennifer: It sounds like you were a great resource for the family. I find with a lot of times the initial diagnosis can be the scariest time because there's so many unknowns about what's going to happen next. And I imagine that you had some of that information having gone through it yourself, but given that this was a different circumstance for your stepfather a little bit, what was the period like for the family as they were just waiting to get all the information and knowing about what treatment would come next? How did you all manage that time period?

Robert: So, there were some family members that really wanted to understand the details of how his cancer would be fully diagnosed and staged, and they wanted to understand the language of monoclonal proteins, and they wanted to understand M spike and those types of terminology. Others just wanted to know how confident would they be in the diagnosis and then would the treatment be tailored to my father based on his age, his health history, his particular stage of myeloma. So, it was good to be able to understand the needs of the family member and then kind of build a dialog around how deep did they want to understand the clinical side of this diagnosis and how much did they just need reassurance that the health team was very strong, very competent, and would guide us step by step through that process.

For my stepfather in particular, he was overwhelmed by the diagnosis and then by the resulting conversations about what are the next steps. He knew of my myeloma cancer, he knew of the generalities of how I was treated, but now he was in the driver's seat and having to go through this. And I think the shock of the diagnosis kind of hit him very hard. He's been very active even into his 80s, and to get a cancer diagnosis made him feel like, okay, my world's going to change radically now.

So, to be able to kind of slow that process down, to be able to work with the nurse navigator and the physician, to be able to make the language simplified for him, and then just to be a support with him to his appointments, to the lab appointments, to his first bone marrow biopsy, to be able to walk with him in that I think was very reassuring to him.

Jennifer: Wow, you mentioned so many important pieces. I just want to kind of summarize a few of the things I heard. One, this idea that everyone really likes to receive information differently or differing levels. And so, I heard you talk about how some family members really wanted to get into the nitty gritty, the science of it and that for other people, they just wanted to know he was going to be okay, really those basics. And so, I think that can be true for patients and caregivers and family members. And so, it's really important to check in with people so that you know what kind of information they need because, like you mentioned, that word overwhelm it's not uncommon for people to get overwhelmed. And I love how you said "the shock of the diagnosis" because it's so important to realize that period of diagnosis can be such a stressful time for caregivers and for patients.

How did you support him as a caregiver as he was just adjusting to that news and what it may mean for him going through treatment?

Robert: So, I think my initial interactions with my stepfather were based around the reassurance that, with his permission, I would be with him every step of the way in this process to be able to just be a support, be a friend, be someone that he could talk

to whether it was asking questions or whether it was just, "I need to talk to you to be able to relieve some of my fears and stress and I can't talk to others about this." So, making myself available on a number of different avenues for him I think was important. We have a pretty close relationship as a stepson to a stepfather, but this definitely grew our relationship to a much deeper level.

The other aspect was making sure that he was aware of other resources around him that, with his permission or invitation, they would also jump in to support him. So, he is a man of faith and his church wanted to be there as a support and as a prayer team for him. The medical team not only from the nurses and the physicians but they also had a social worker that was more than willing to supplement and help as she could for his care. And then being able to open up to the family as much as he could at different intervals and express how he was doing was important.

I think the other level about the diagnosis was not only overwhelming but a little bit confusing for him because he came in with symptoms that he thought were related to a muscular skeletal injury, and when they did an x-ray and then subsequent blood labs, they discovered the issue with myeloma cancer. And it took him a while to adjust to what is myeloma, and why is it causing these types of symptoms, and now what do I do that I'm diagnosed.

Jennifer: So, given the symptoms that he was having, was there any type of logistical support or did you change his living arrangement? It sounds like you were taking him to his appointments, but as a caregiver, were you stepping in in any other way to help take care of him as all of this was happening?

Robert: So fairly soon after his diagnosis, he actually came to live with me in my home because we had a first-floor bedroom for him and that would help in terms of his limited mobility. He had back spinal involvement and hip involvement with the lytic lesions in his case of myeloma and that was causing pain and some difficulty in walking. So, we did have to get some supportive aides in terms of a walker and a

cane to help him be able to get up out of bed or out of a chair and then to be able to ease some of the mobility issues.

Outside of that, we helped him, not only with nutrition and daily meals and that type of thing but helped get him to and from appointments and then help keep his calendar, his schedule organized so that he understood what was happening each week and each day of the week in terms of his schedule for treatment and that type of thing.

Jennifer: Sounds like you all had a lot going on right there at the beginning of his diagnosis.

Robert: It was a busy time and a busy time of adjustments not only for him but for us. We were more than glad to support him in this way, but we knew that, we were taking him out of his home environment, so we tried to bring items along with him that would make him more comfortable. You know, even within our home in this bedroom, make sure that we made him as comfortable as we could and then helped to continue to reinforce that, our home was his home now and whatever he needed we would help to accommodate.

It was good to have him close by because that helped us in our communication. And when he was tired and either taking a nap or going to bed earlier and a family member called, then we could help describe how things were going and be able to keep the family in kind of a continuity of his care and his progress. So that was good.

And then I don't recall from my personal experience that I had the difficulty in nutrition and daily meals, but he definitely became intolerant to some types of foods and needed supplements to help him nutritionally, so we had to work through that through the advice and help of the healthcare team.

Jennifer: You really are bringing up such important aspects of being a caregiver. One, this idea of things shifting so quickly, that he got the diagnosis, that he was a little limited in his mobility and needing to move in with you all, and you really finding

a way to support him and make him feel at home bringing in things that made him comfortable. And I love how you said that you wanted him to feel like it was his home too, really going out of your way when it was such a difficult time to really make him comfortable.

And then this idea of communication. I find that when someone's diagnosed, figuring out how you're going to communicate, you know, from caregiver to patient but also to extended family and friends can be one of things you have to figure out pretty quickly after a diagnosis. And so, it sounds like having him nearby really aided in the communication between the two of you but also between the medical team and maybe even the extended family by sharing a space and being able to do that together so closely.

How did you in that beginning period start to figure out that you were going to need some nutritional assistance? Was there anyone that you talked to or anything you did to kind of figure out the next steps for that?

Robert: Sure. As I mentioned, my stepfather is very active. He has a normal exercise routine early in the morning, he's an active volunteer in the community, and he's fairly tall and slender, and so in the early part of the diagnosis, one of the nurses reviewed with him just the aspect of maintaining good health in what you're eating in your daily meals and that as you go through this process, you may find yourself lacking appetite but yet you still need to persuade yourself to eat even if it's small meals incrementally throughout the day to be able to keep up good nutrition, a good immune system, and to keep up your weight.

So, in those early appointments, we were finding that he was losing weight. They asked him more questions about how he was tolerating foods, whether he was having nausea issues. And through those conversations, we discovered even though he has a penchant for wanting to eat spicier foods like Mexican type meals, his body was just becoming intolerant to that and so avoiding those and moving to something that was,

if you will, a more bland diet that wouldn't spike his body response to nausea was important to get him to eat fruits or snacks intermittently throughout the day, which wasn't his normal habit. He was more of a, I eat three meals a day and that's what I do. So, getting him to adjust his own habit and his own understanding of that.

And then we moved to him drinking protein supplemental milkshakes like Ensure® or Boost® to be able to supplement his nutrition and his vitamin intake that was important. And then finding which one of those drinks he liked that he would actually drink the whole product versus he would taste it and say, "No, I'm not going to drink this." So, it was kind of funny to work with him on which flavor he would prefer and would like or could we mix it with something else that he liked. And my daughter when she was around from college, she would make smoothies for him, which he really enjoyed, and I think that was just to connect with his granddaughter, but it was also, I think, something different for him to use for nutrition.

Jennifer: That sounds really great. It sounds like he was really lucky to have you on his caregiving team as an advocate. You mentioned this idea of him wanting to connect with your daughter, his granddaughter. Do you feel like the rest of your family felt that they were in a caregiving role as well as he was getting diagnosed and started to go through this process?

Robert: Yes. I think for, the majority of our family felt like they were going to support him in their own unique or special way. Some were more gifted on the healthcare and clinical side and could reassure him from having worked in healthcare. My wife, my eldest daughter are nurses, so they could talk the talk and help reassure him from that level. His stepdaughter, my youngest daughter, don't have much to do with healthcare, but they were there to support him emotionally, to keep his humor up and about even going through this disease and treatment process. He has a number of grandsons, and I think it took them some time to get comfortable with interacting with their grandpa again. I think they were very nervous being around him, which wasn't the usual case. I think they weren't sure what to say, how to say it, what

questions could they ask that were safe around the cancer diagnosis and treatment. So, it took a little while for them to get to that level of comfort in this new relationship. But then they brought in the aspect of being able to talk about cars and sports with my stepfather, which gave an alternative to his perspective on what was happening around. Gave him some distraction away from the actual treatment process.

Jennifer: Yeah. It's so important to have that distraction because I think oftentimes everything becomes about cancer when you're first diagnosed. It's what you're reading about, it's what you're hearing about, it's what everyone's talking about to you. So, to bring in some folks who can add some humor or even just talk about something that maybe is outside of cancer or outside of that person that's been diagnosed is so important. So, it sounds like you really helped pull together an incredible care team to help you in that caregiving role.

Rob, thank you so much for joining us and sharing all about the diagnosis. You gave us a lot of really helpful hints to think about as other people may be entering into the caregiver role, so thank you.

Robert: Thank you. I've enjoyed it.

Elissa: Hello and thank you for listening to the 1st episode of Cancer & Caregiving: Navigating my Parent's Cancer.