

THE BLOODLINE WITH LLS

A PODCAST FOR PATIENTS AND CAREGIVERS

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

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 second 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 treatment 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 treatment 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, Rob, your stepfather had similar treatments as you did for myeloma. Could you go over the treatments that he had?

Robert: Sure. So, my stepfather was diagnosed and after lab analysis and hip bone, bone marrow biopsy, his healthcare team physicians decided that he would be treated with numerous rounds of chemotherapy, immunotherapy, and steroidal medications to be able to help subdue the abnormal proteins that were occurring from the multiple myeloma cancer.

He also had some spine and hip issues, which is where the myeloma originally presented itself in x-rays and MRI tests, and he was having some mobility issues from the pain caused from the lytic lesions in those areas. So, they were also treating him with some pain management and were looking at one point if they needed to do any type of radiation or injections of steroids into that area to relieve some of the pain and allow him to sleep better, rest better, as well as be more mobile.

For my stepfather, I think he understood in generalities what the medications were going to do, but often he would move towards the extreme of how bad will these medications make me feel? And I think for many people who are just getting the diagnosis of cancer, they think of chemotherapy and that means I'm going to lose all my hair, I'm going to be nauseous 24 hours a day, I'm not going to be able to get up and move around and have any energy, that I would be lethargic throughout the day. And so, it was quite an effort of the medical team to kind of walk him back from some of the more extreme side effects of this treatment process to show him where he would still have control in many respects for him being able to exercise or him being able to control his mealtime and what he ate and what he liked to eat and that type of thing.

Jennifer: Rob, how did you support him in making those important treatment decisions? It sounds like he was worried about some of the side effects and so what kind of role did you play in helping him talk through or make some of those decisions about maybe what he would do next?

Robert: So, we worked really well together as a team, my stepfather and I, when we were in front of or in person with the physicians, the physician assistants, the nurses in being able to ask questions to fully understand what their expectations were both on treatment response as well as potential side effects. There were areas where my stepfather didn't understand the disease process, didn't want to understand the cellular level of what was happening in his bone marrow; he wanted general understanding of what was happening with the cancer and then how would the medications effectively

combat the cancer. So, making sure the physicians didn't go too deep into their descriptions but gave enough distinction. He really didn't understand the difference between chemotherapy and immunotherapy, and so the physicians used a whiteboard, and they would draw in just cartoon-like figures what the cancer cell looked like and how would the chemotherapy work against it and then how would the immunotherapy medication also enhance the eradication of that cancer. And I really felt for him seeing the visual and being able to keep it as simple as possible helped him connect the dots and understanding what the treatments are going to do.

The other aspect that I would bring in would be what are the clinical studies that the physicians are aware of that kind of support the benefits of using these types of treatments? And just in generalities being able to describe the number of years these medications have been studied, the outcomes, the benefits and the progress that they've made in diagnosing and treating the disease were of a great benefit and assurance to him.

Jennifer: Yeah. Well, it sounds like he really felt comfortable asking his team questions and they did a good job presenting information in a few different ways to make it more easily digestible. Was he ever relying on you to make these decisions or was there ever a time when maybe you all didn't agree on a decision that he made?

Robert: He would definitely lean on me in terms of what was being recommended to him and did I agree with it based on what I understood the physicians describing. I had to remind him that although I had multiple myeloma cancer, I'm a unique patient with a unique profile and my treatment would be potentially different than what he would go through based on his age and his health history and what they were trying to manage for him.

Nevertheless, he understood that I definitely had an appreciation and a clinical understanding of the disease, the different types of medications that could be used here, and he felt more confident if I gave him a thumbs up or gave him some verbal

reassurance that I believe the doctors were headed in the right path and that this was a reasonable way to manage the disease early on and see, how he would respond to it.

The other aspect that he asked a lot about, he kind of battered the nurses with all the different side effects questions. So, the Internet is good in many respects, but then it arms a newly diagnosis patient with dozens of questions. And so, he asked those numerous questions, and the team was very kind and compassionate and walked through each and every one of those questions and gave him realistic expectations of what they thought he might experience, what their history of treating patients in this disease for many years, and what those patients had experienced.

So that was a calming effect for him to hear that from them, and then, in private, he would ask me those same questions and just want to know were they talking to him in real world or were they talking to him as we want to comfort you as a patient; and I could say they were doing both. They were definitely being comforting and compassionate, but they were telling him the real-world story of here's the percentages of patients that might experience this but not every patient has to go through this type of side effect or issue.

Jennifer: Yeah. I think we often tell patients how important it is to have a caregiver in the room as they're getting this information so that two people can hear the information, and it sounds like it was really important for you all to be able to talk that out afterwards to be able to relay what you heard but also your own experiences and for him to have a chance to process that.

So, what was it like for you watching him go through some of the same treatments you had maybe having a little bit of foreshadowing given your experience of the toll that it could take on his body or the side effects that he may experience?

Robert: So, yes, I was hopeful that the initial therapy they were recommending that his body would be responsive to and that he would be able to tolerate those

treatments. I was a little bit concerned for him. Again, early on we noticed that, through the early treatment period, his ability to tolerate certain types of meals was reduced. He could not tolerate spicy foods without becoming nauseous. He needed to eat smaller meals at the beginning part of the day and kind of gradually build up into eating more in snacks and then a bigger lunch and then be able to eat a more normal dinner.

And so, I was worried that based on his tolerance there as far as his nutrition and meals go, would that lead to maybe other issues that he was going to have in terms of feeling fatigued, not being able to get outside and garden like he likes to, or not being able to get out and socialize with some of his friends that he likes to do so much. So just being careful. I wanted to be supportive, but, as a caregiver, you also want to be observant of what's happening with your family member to know, are they experiencing something that's isolated and idiosyncratic or are they experiencing something that's directly related to either the disease or the treatment medications they're taking? And being able to kind of keep a diary for him of what he was experiencing, good and bad, was helpful not only so he could see if there was a pattern there, but also to be able to communicate that back to his healthcare team was very important.

Jennifer: It also sounds like you were really paying attention to his emotional health and well-being and even his social well-being. What was it like for you to encourage him to go out gardening or to hang out with his friends? Is that a conversation that came easily or how did that go between the two of you?

Robert: He certainly wanted to maintain as much of a normal lifestyle that he was accustomed to prior to the cancer diagnosis as to after the diagnosis, but he was worried in one sense that conversations that he would have with his friends and just social circles would simply focus on him and focus on the cancer disease. And so, my encouragement to him was he definitely needed that support from people around him who wanted to love and care for him, and they would need to understand a little bit

about what was happening, but then he certainly had the ability to shift the conversation back to areas that would, again, distract him from just the day-in and day-out focus of cancer treatment, of medical appointments, and those types of things. And so, he was able to help his friends understand that he really needed to talk about current events, to talk about sports and sports teams, to talk about he loves to garden both flowers and vegetables, so to be able to relate to those types of activities with his friends and was able to steer the conversation back in that direction and maintain a little more of a balance in his conversation.

Where he was having difficulty, it would be with his grandsons, who were a little bit more cautious and fearful of what to say and how to interact with grandpa now, and so I was able to kind of outside of our conversations coach the grandsons, coach their parents as to here's what he wants to do in terms of interacting with you so don't feel awkward in terms of asking him these questions. And then talking about your school, talking about your baseball team, your basketball team, and being able to move on with talking about normal life because that's what he wants to stay engaged with.

And then the other aspect was making sure that from a faith aspect that he stayed connected with his church pastor and there was a counselor within the church that were tied into regular phone calls and visits with him to help him emotionally, spiritually keep that balance and support in his life.

Jennifer: It sounds like you gave him some really great advice but also other family members to help them connect on a deeper level.

I realize that he went through an initial remission, and I'm wondering kind of as that happened in his course of treatment what that was like for you.

Robert: I was very joyful that throughout the treatment process the physicians were reassuring us that the lab values were showing response to the treatment of chemotherapy and immunotherapy and that once they got through the extended period of time with that, they did another hip bone biopsy and showed that he did

have a complete response to that initial wave of treatment. So that was very comforting to me to know that the time, the effort that he had spent in this journey so far was successful. It wasn't easy at times, but at least it was reassuring that he was coming kind of through the other end of that tunnel, if you will, with very optimistic outlooks for getting back to normal life, to not having to restrict his diet. His back and his hip area seemed to be alleviated from some of the initial pain, so he was back exercising on a treadmill, he was swinging a golf club again, he was out with his friends at social times having dinner together. So that aspect was very exciting to me that he was being able to assimilate back to what he would say his kind of precancer lifestyle was.

Jennifer: Yeah. That sounds really important. We know oftentimes cancer is such a rollercoaster and that he did end up relapsing after some time in remission. What was that experience like for you all?

Robert: For my stepfather, I think that diagnosis that the cancer had come back was even more difficult to understand and to accept with that second kind of conversation with the oncologist than it was with the original diagnosis. I think he felt like that meant his form of myeloma was even more aggressive and that it was going to be even more difficult to treat, that it was going to be a, a more onerous treatment path that would potentially have him experience a greater degree of side effects. He was very dejected, even depressed in the days after that initial discussion of remission.

For me it was also a time of all right, let's take a step back, be able to kind of digest what was being discussed with us, and while the news wasn't pleasant, the physicians were very confident that they could continue to treat my stepfather, and treat him with even alternative medications. And since he had been responsive previously, they felt that his body would be responsive in a second treatment path. And they also brought up the idea of doing a stem cell transplant as part of the second treatment regimen.

So, I understood from the clinical side the optimism that they had, and it just took some time between my stepfather and I to have just some conversations of reality that, hey, that there's no doubt about it cancer sucks, getting news like this isn't fun, isn't pleasant, but our world and our life and our experiences don't stop at this point. There's a lot of life to live and even through the treatment process we could experience fun, humor, joy, and let's focus on the optimistic side of that. And then being able to walk him back through a lot of what he missed in that conversation, which was the doctors' confidence that even with a second treatment, they felt like they could get him back to a complete response.

Having some time to really process, having some other people to talk to and encourage him, my stepfather kind of came back around to having a better outlook for this second treatment and for kind of recapturing his energy and his drive to work through this with the same spirit and enthusiasm that he did the first time.

Jennifer: Rob, you just have all of these gifts of wisdom, this importance of having more than one person in the meeting because we can all hear different things and then really being able there for someone to kind of process and go through the emotions.

I'm wondering if you can talk to us just a little bit about how you take care of yourself during all of this because certainly being a caregiver oftentimes, we're always thinking of the patient and what they need, but, you know, you were going through this too and so how did you make sure that you could keep showing up for him in what sounds like a really incredible way?

Robert: So, I think that's a really good question, and I think it's something that I had to adjust to myself along the way. I wanted to really support him as much as I could. I was also working at the time, so it was almost like balancing two very full-time jobs, if you will – balancing my personal work as well as balancing the work that I was doing with him and his healthcare team.

I think things that I realized that was important was keeping up a balance for myself in terms of having others even outside of my family to talk to about the situation, to support me emotionally, to help give me balance when I was fearful or concerned and didn't want to express that directly to my stepfather and increase his worries. But I could do that to some very close friends, and they were there to support me and kind of hold my hand through those days.

The other aspect was making sure that I was eating and sleeping correctly, that I wasn't burning the candle at both ends, which I had a tendency for, and that when I was working, that I would still eat healthy, that I wouldn't just do what was quick and easy such as fast food that wouldn't support me nutritionally in what I needed to do in having stamina and energy for this process.

And then the other aspect I learned in this journey was being able to ask others to come in and support him. Even though I could do it, it gave me a break to invite others into this circle to help him either go to a chemotherapy infusion appointment and bring him home or stay with him during the afternoon when he wanted to garden and do that type of thing. So, letting other people take a role in this gave me a break, gave him some different energy and enthusiasm from those people, and kind of livened up his day and his experience. And so, I thought that was a learning experience for me.

Jennifer: Yeah. It certainly sounds like you learned a lot. And allowing other people to help is such a gift for them as well to be involved in that process. So-

Robert: True.

Jennifer: -really wonderful self-care, Rob. Thank you for sharing that with us today. And I really appreciate the information that you've given us. Thank you.

Robert: Thank you.



Elissa: Hello and thank you for listening to the 2nd episode of Cancer & Caregiving:
Navigating my Parent's Cancer.