THE BLOODLINE WITH LLS

A PODCAST FOR PATIENTS AND CAREGIVERS

Episode: 'Cancer & Caregiving: Navigating My Parent's Cancer – Role Reversal'

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 third 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 role reversal 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 role reversal stage of 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, when older parents get a cancer diagnosis, it often falls to their adult children to become the caregivers. This presents a type of role reversal where the older adult has been living independently and now needs to move in with their child to be taken care of throughout their treatment. Can you speak to the challenges this presents to the patient but also to the adult child caregiver?

Jennifer: It presents a lot of different challenges. Ultimately, we have a relationship oftentimes with our parents and a way that we do things. And when the roles get reversed in this way, it can take a lot of getting used to. And so, it's really important to have a lot of communication and patience and space because it's hard for kids of any age. We're talking about adults but kids to see their parents' sick. And it's also really hard for parents who are used to taking care of their kids even when they're adults and being really the person who's in charge and the adult in the relationship to have to accept help from their kids. And so, figuring out that balance can sometimes be hard.

Rob, what was it like for you and your stepfather as he moved in with you and maybe the roles that you all had together shifted a little bit?

Robert: Yes, there was definitely a shift in the way we communicated, interacted with each other. I think there was a desire on both my part, my family's part, and my stepfather to try to make this transition as natural as possible to make each other feel as comfortable as possible. My stepfather didn't want me or my family to change the way we were doing things in terms of family activities or meals or that type of thing just to be special for him. And then on the other side, we wanted him to feel as comfortable as he could making our home his home and being able to use our kitchen just like he would his own kitchen, to read books, to watch TV, to do the things he wants to do on his own schedule and use our home just like he would his own.

So that took some time to get used to, and as best as we tried, we certainly still had to make accommodations. Because of his treatment and the medications, he was going through, we had to adjust meals, both types of meals and times for meals. And we adjusted, obviously, to helping him get to and from appointments, so that sometimes interrupted some of the other activities that we were doing, or we worked around those activities with his appointment schedule.

The other aspect was the emotional side of this. I was used to going to him for advice in different areas of life and now he was coming to me for advice. And while I was more than willing to help him and communicate with him, I wanted to do that respectfully and I wanted to make sure that I was doing that with love, with grace and not trying to be condescending, I guess, in the way I was communicating and interacting with him.

And then there was the adjustment to when he was going through the treatment process that you were helping him when he was undergoing chemotherapy infusion, helping him to the bathroom and back from the bathroom, that you were helping make sure that the port that he had was remaining clean on days that he wasn't in the clinic, those types of things. And that was an adjustment for him to allow us to help him even though it was getting into his personal space to a degree, but he accommodated that and understood that we were there to love him and that it shouldn't be embarrassing and that this was going to occur for a time and then, as his body responded, he was going to be able to kind of take control over these areas of his life again.

Jennifer: Rob, how did that initial conversation go where you all decided that he was going to move in with you, because for some people it's hard to know when the right time is to move in with family and caregivers because we all want to be independent as long as we can and not a burden on other people. But how did that conversation go with you and your stepfather and how was the decision made that he would come and live with you all?

Robert: So, we had a family gathering outside of our doctor appointments and healthcare team discussions. And it was with his daughter and with other key members of the family, and we were kind of discussing and trying to encourage him and be optimistic. Make sure that humor was still a part of the mix. But then we got into the more sincere discussion of the physicians being worried for him as he was independent that, one, his mobility in the early stages was poor, that he was having to climb stairs to get to a bedroom and that was posing a risk for fall or injury, other complications, and that the alternative was to have someone stay with him in his home and help in that way, or my family was more than supportive to have him move in with us, even if it was just for a season of time, to be able to make his life easier during this treatment process and journey.

And once you put on the table the benefits and risks of those options, it became pretty clear to him that, while it wasn't going to be easy, it would be better for him in the long run to move, even if it was just for this season, and that it would help him both from a supportive standpoint but, hopefully, also from a treatment and outcome standpoint. And the rest of the family was supportive of that as well, and they knew that they could come and go in our home just like they could come and go in his home to interact with him independent of us.

The discussion certainly had some emotional aspects to it. Some tears happened, and that's okay. It's good to acknowledge that this isn't an easy time for anyone, but that's what we're here for. We're family, we love each other, we want to carry each other through even the difficult times and enjoy the good and fun times together.

Jennifer: I'm glad you mentioned that there were some tears because I was thinking, wow, your family sounds so rational. I don't know that we should tell everyone listening that this conversation will be that easy, but you're right these-

Robert: No, definitely not.

Jennifer: -are such hard but really important conversations to have. And setting up some of those expectations of he could still have people over and making things as easy as you could for him but also talking about that as a group sounds like it was really helpful for you all.

One thing you mentioned was that you used to go to him for advice and now he was coming to you for advice. And I imagine in that kind of role reversal, perhaps you couldn't go to him as often with some of the things you were scared about with your own diagnosis. And so, I'm wondering what that was like for you to shift into that caregiving, advice-giver role and maybe not be able to go to him like you would have in the past.

Robert: Yes. I was acutely aware of his mood, his emotional well-being. You could pretty easily tell with my stepfather whether he was having a good day and was upbeat and energetic or whether it was a more difficult day, either emotionally or physically. And being aware of that, I wanted to be able to feed into helping him manage the tough days where he was physically not feeling well or emotionally not feeling well and reassuring him that that was normal, that was just part of the journey here and something that he was going to grow from and learn from. But I also didn't want to add or burden him with aspects of my own cancer journey or concerns or fears.

And I quickly found that it was, as you were mentioning, not going to him I needed an outlet to talk to others and be able to share my personal emotions, good and bad, about what was happening to be able to at times rant about difficulties within appointments being changed or delays happening, and a two-hour infusion became a five-hour infusion. Those types of difficulties needed an outlet for me, and so I went to a group of friends and expressed to them, "Hey, can you support me in this way? If I need to make an impromptu call just to get something off my chest or to unburden myself, would you be there for me in that way?" And they were more than willing to help care, not only for me but to support our family and my stepfather in this way.

The other aspect would be that my stepfather along the treatment pathway still wanted to be the patriarch of the family. He still wanted his grandkids to come to him for advice or to hear of his experiences and that people didn't need to tiptoe around conversations because grandpa was focused on cancer treatment. So that was another aspect to making sure that we kept our family open to that and that there was that dialog going back and forth, particularly amongst the grandchildren and him. And I think that helped the well-being, the wholeness and feeling for my stepfather.

Jennifer: Yeah, I bet. That sounds like an important role for him; and him being able to maintain that I'm sure had a lot of meaning for him. How did dynamics in the house change? So, it sounds like it was you and your wife living in the home and you bring in your stepfather. How did it shift? You talked a little bit about how mealtimes may have changed and certainly some of the nutritional components, but how did things change for you as a family unit during this time?

Robert: I guess one way to describe one of the major changes was we felt like our house quickly became Grand Central Station for people coming and going to visit my stepfather. Once they were given the okay that he would receive visitors, it was almost like the floodgates opened, which was fine for us, but that was something that we had to adjust to because we just weren't used to walking in from the end of the workday and there would be three people seated around the kitchen table with my stepfather sharing a glass of iced tea and swapping stories. We were encouraging of that, but it was an adjustment of, okay, we had people coming and going in our space; how do we accommodate that for my stepfather and how do we make some concessions in the way we were used to living?

The other aspect was just our schedules. My wife works as a nurse. I'm full-time employed. My stepfather had treatments and medical appointments. And so, it was being able to coordinate not just two people's schedules and on the outer rim of that interacting with our daughters and their schedules, but now it was definitely including a third schedule into the mix in terms of transportation and then the daily routine of going to the grocery store or to the drugstore to pick up a prescription for him or being able to make phone calls for questions that he had in between medical appointments, that type of thing.

And we quickly, for my stepfather, put together a calendar that was on the refrigerator so that he could see clearly what his schedule was going to be throughout the month and then how that fit with my wife's work schedule, which changed week to week, and then if I had to be out of town, where would that fit into the calendar. So that was reassuring to everybody that we kind of knew what we were planning for and who was, kind of maintaining the day-to-day life in our home.

And then the other aspect was the need to adjust to, as he was going through treatment, when he had side effects, when he had issues with diet and nutrition that we were there for him in the middle of the night, in the wee hours of the morning when he needed us to be helpful and supportive to nausea and issues with that, to not being able to sleep, that we could come alongside him and help him through those spells, get him cleaned up, get him back to sleep, get him comfortable in a chair, that type of thing. And my wife being a nurse was so compassionate and so giving in that way, and that was really a special role that she could fill that was beyond my skills and gifts and was very helpful to him during this time.

Jennifer: Wow, yeah, I can really hear that. You mentioned earlier, and it may have been in an earlier session, just this idea of your relationship changed with your stepfather and almost that you all became closer throughout this experience. I wonder if you could talk a little bit about that.

Robert: I'll speak to it on two different levels. There was a relationship that I had with him as a stepfather. He wasn't my biological father, but he had been married to my mom for many years. He was definitely a good friend, a confidant, and was wise in his advice for me having gone through similar experiences at work or in life, and he was more than willing to share and to give that aid and counsel.

But there was a certain respect in our relationship that we didn't go too deep into our emotions. Now we were very fond of sports and we're sports fans and we would go crazy watching sports football/basketball games together, but when it came to sharing our feelings, our fears, our concerns, our worries, I'm sure it's a guy thing, but it's definitely a level of I'm not sure I want to burden my stepfather with some of that. I can share that intimately with my wife, maybe with my other closer guy friends, but it wasn't a level that we did at least for many years.

Through the cancer diagnosis, we had a bond because we both were experiencing something similar. I had been diagnosed and had gone through treatment, he was actively going through treatment, and it formed a more intimate conversation, not just about the medical or clinical side of this, but on our ability to open up and share more candidly about what we were concerned with, what our fears were not just about the disease but what would happen if we passed away? Who would take care of my mother? Who would take care of my wife? What would the grandchildren do without their grandfather being part of their lives? And we were able to have some really deep discussions in these areas and reassure each other of the support circles that we had around us to take care of us even during the more dark times of our treatments and for him for his remission. And it really brought us to a different level of trust, it brought us to a different level of even humor in our relationship, and it helped us even open up to other members of the family that we hadn't before.

Jennifer: You bring up such important pieces about this idea of being vulnerable and that through vulnerability we can really connect on such a different level. And it sounds like you and your stepfather were really able to both do that with each other, which is really powerful when you're supporting one another.

So as a father, obviously, you were already a caregiver for your children. But as we're talking about role reversal, I'm wondering if there are any other pieces you want to tell us about what the difference is about when you're caring for a parent with cancer versus what we traditionally think of as caregiving in society sometimes.

Robert: Sure. I think one aspect of it, and this may be a little bit generational with my stepfather; he's in his 80s now, but he was used to being very self-sufficient. His parents had gone through the depression, and they taught him a very strong work ethic, a very focused effort on not wasting anything. And in the caregiver role, he had to give up some aspects of that lifestyle that he had become so accustomed to in the way he was raised. And I think there were times where he definitely was reluctant or resistant to doing that. He would even become emotionally angry, almost like a child having an outburst or having a temper tantrum. But then when you walked back from that, you realized quickly that he was having to compromise. He was having to give up an area of his life and control of his life, and he wasn't ready to do that or wasn't ready to do that freely. And he needed time to adjust and time to process in those areas.

So, I think it's okay as a caregiver while you're directing your family member and supporting them, realizing that some of their emotions aren't really directed at you. They're directed at the process and the changes in life going on around them and sometimes they just need to let go and release it. And it can feel like it's pointed at you, but it's not. It's not personal. And oftentimes after those situations occurred, we were able to let some time go by and then go back and discuss, "Okay, what do we need to adjust? What do we need to do differently to help you better?" And he would be able to explain his feelings more or where those frustrations were coming from.

And then the other aspect of it was he wasn't so sure that he wanted more people engaged with him early on. He wanted his circle to be small, he wanted his support team to be small, and then wanted myself and some of the family members to kind of handle the peripheral communication and interaction. And as he got further into this journey, he realized the more people that were part of his life and part of this journey, the more they could give to him in different ways that I could not and the way that they could enliven his day, encourage him in different aspects, be there at different times than I could be there, and it made a more well-rounded experience for him. And he would even say, you know, "I'm glad that his friend Joe could spend that time with him yesterday afternoon," because he knew I was focused and needed to be in a different area. And it felt like he was unburdening me and freeing me up to do things that I needed to focus on. So, again, that's part of being able to let that family member see and realize some control about their life and the way they're interacting with others.

Jennifer: You continue to give us such good advice. Just this idea of being able to look at a situation through someone else's eyes is so important in the caregiving role because, you're right, often the anger, the sadness, those big feelings aren't necessarily directed at anything the caregiver is doing but at that situation. But it takes some deep maturity to really understand that.

And this other idea that one person can't be everything. The need for different people to play different roles.

And that piece you ended on of needing to control something, there's so much that's out of control for patients. And so, as caregivers, being able to find the pieces that people can control, whether it's who's coming over, what they're eating, how they're getting places if it's safe, just finding these little pieces that folks can control can be so important.

So, Rob, thank you. Really appreciate all this incredible information you're sharing with us.

Robert: Thank you as well.

Elissa: Hello and thank you for listening to the 3rd episode of Cancer & Caregiving: Navigating my Parent's Cancer.