



Patient Power

Navigating Cancer Together: Patient and Care Partner Perspectives

Mark Silverstein
CLL Patient and Advocate

Nelia Pacheco
Care Partner and Advocate

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Andrew Schorr:

Hello and welcome to Patient Power. I'm Andrew Schorr. We're looking at a couple, Mark Silverstein and Nelia Pacheco, that I originally met in 2015 when they were at a conference of people affected by chronic lymphocytic leukemia from all across Canada. And Mark had been dealing with it since 2010. But when you're dealing with it, it's not just the patient. It's the partner, maybe children, more extended family, I know as a patient myself. First of all, Mark and Nelia, welcome back to Patient Power.

Nelia Pacheco:
Thank you, Andrew.

Mark Silverstein:
Great to be here.

Andrew Schorr:

So we want to talk about navigating cancer as a couple. So, Mark, you've had a variety of treatments and most recently actually an allogeneic transplant, which is a big gun in fighting cancer. And, Nelia, you've been by his side this whole thing. So what would you want to say to care partners, if you will, on how you've survived? He's a survivor but how have you been a survivor?

Nelia Pacheco:

I think very early on, I think as a couple, you have to make a decision. Either this is a partnership in this battle or you need to decide how you're going to approach it. And at the beginning of Mark's initial diagnosis, I was not an active partner. As anyone who has experienced a diagnosis like this, it was overwhelming. And I wanted to run and hide and pretend it didn't exist and it was Mark's call and not mine.

I'm really happy. It took me a few months to kind of come around, especially because the diagnosis at stage IV, the initial one, and we were literally—Mark was receiving FCR within weeks. So it was just a bit of a rollercoaster. So after a couple of months of, again, just doing my own reading, listening to Mark, certainly made a decision that I needed to get on board. And so we took the approach as a partnership and discussed everything. And I went to as

many appointments as I could with Mark, of course, to try to get my education to the level where he was at and his understanding.

And so it really was a choice to be there to support him. Because it's his disease. Although I just—you know, it's like I'm just suffering that kind of as a consequence of the diagnosis. But it is about being involved in it and it gives me some control, too, and understanding. And it helps with my own fears and anxieties. And so we certainly took that approach and we talked about it a lot and how he wanted to do it, what he needed from me and vice versa, and that's how our approach was.

Andrew Schorr:

Now, Mark, I know as a patient, and I want to ask you about it, I, at different times, have censored what I would say to my wife because I didn't want to scare her. And maybe I was processing it myself so maybe I wasn't so scared. But I didn't want to trigger something in her. From the beginning, did you have this open communication? Here's what the doctors are saying to me or here's what I'm worried about. Were you always open or is that a process you've had to work on?

Mark Silverstein:

I think it's a bit of a process. There has been times that—yeah. There's been times that maybe I've been very scared and I didn't want to communicate that to Nelia because she already—I felt like she had a lot on her plate already and she was already fearful of what was going on and whether I felt my nodes getting bigger or there's something else going on. It wasn't something I would communicate all the time, especially at the beginning. \

But I realized that not communicating those fears, either of us—because she wouldn't communicate if she felt like I would have too much on my plate so she didn't want to tell me how her fears were. And I felt the same thing, too, right? And so you went actually in conflict because you both have these fears that you're not discussing and eventually that energy comes out and you end up in conflict. I can't—there's certainly a few times before, especially before a hospital visit, getting tests and stuff, where you both kind of got that fear jumped up. There's that hyper fear because of the testing. And if you're not talking about it, it just doesn't turn out so well.

And so I think, as time has gone on—and perhaps at the beginning, it was a little more like I would choose and pick what I would sort of discuss with her. I think as time went on, I think letting out all my fears was very helpful for both of us.

Andrew Schorr:

Right. Anything for you, Nelia? You were talking about being open.

Nelia Pacheco:

Absolutely. Absolutely.

Andrew Schorr:

Okay. So Mark is not cured. He's been through a variety of treatments for cancer. I can say that because, Mark, you may look back having had the allogeneic transplant five years from now, and say we look back and, Mark, it cured you. And that would be great. But we don't know that. So, Nelia, how do you deal with the uncertainty? You've been together 17 years. You hope to be together many more years and have a full life. There are two children involved that you've been raising. How do you deal with the uncertainty or do you even think about it?

Nelia Pacheco:

Honestly, I don't think about it now. At this point in the process. When Mark was admitted to hospital when he was failing on ibrutinib and we were introducing venetoclax, it was probably the scariest time in the whole process. And I

think that—we talk a lot about that. It totally changed everything for me. And it was that understanding, because I'd often get a lot of people—friends and family would ask me how am I gonna deal if Mark was to pass.

And after going through that experience, it was the first time I think I made peace with understanding that, if something did happen to Mark, I would be okay. I don't know when I would be okay. But I understood that life would have to continue and that's kind of the approach I took. So it has changed significantly for me from that experience. And it is just about trekking and every day is a gift and every day is enjoying each other as much as we can and laughing.

But that really did change everything for me. And then before, sure, you think about it. You have that sadness, of course. What would I do? We're very fortunate. We have a very pleasant, kind relationship and we are each other's best friends and he is my favorite person. But it was that kind of understanding and acceptance of it. So I made a choice. I don't want to spend—I don't want to waste that energy in thinking, "What if?"

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