



How Self-Advocacy Improves Patient-Doctor Communication

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Living with Multiple Myeloma

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Cindy Chmielewski:

Jenny, I'm going to put you on the spot. She's laughing. You have had relationships with lots of myeloma specialists over the years. You interview them on your Myeloma Crowd radio. How do you think that has helped improved research, helped improve everything, the relationships that maybe the doctors develop with patient advocates?

Jenny Ahlstrom:

What I realized in doing that show is that the doctors are so busy, they're doing research, they're seeing patients, they're attending meetings, they're trying to stay up to date on their own practices, that they didn't have time to really market what they're doing or share it with the patient community because they're more focused on writing the scientific papers.

But being able to translate it for patients into patient-friendly language I realized that there was a real need for a patient advocate to step up and do that piece because they just didn't have time. They wanted to share information with patients and they were excited to share the information with patients about their studies or what they were working on or new discoveries that were coming out. They just didn't have time for it.

So I think it's changed the way that myeloma specialists believe that they can communicate with the patient community because they jump at the opportunity to do that. They're excited about doing that. We're coming to ASH, the Myeloma Crowd is coming to ASH, and we'll be saying if you want to share your clinical trial in a video you can do that. And it's a three-minute video and it's short and it's sweet, and it's a great way to get the word out to patients. So it's just really important.

And what we've been talking about, I've been actually teaching my kids this, that there are people who are submissive and not really self-advocates. There are people who are aggressive and who are really bullies and rude about things. But what I want my kids to learn how to be is assertive, and that's standing up for yourself, asking questions, being kind and being respectful and being advocates of the work that these experts are doing.

The people that we are talking with and are working on myeloma research are incredible people. They are incredible, and the work they're doing is truly amazing. So I am thankful every day for all the amazing work that's being done to design the studies, to run the studies, to push the research forward. We are so blessed.

Cindy Chmielewski:

Thanks so much. Because of the work of the Myeloma Crowd and Patient Power and CURETalks, I learned so much about the trials that are up and coming. Researchers have been more than willing to share their work, and it just gives me a sense of hope and it gives me a sense of connection, connection with the research community which makes me feel very good.

Matt, do you have anything to add on this topic before we move on?

Matt Goldman:

Yeah. First I'll add that I learned early on that I needed to be my own advocate. My first nephrologist, my first kidney doctor just based on numbers alone wanted me to start dialysis, and my wife and I, we didn't feel like I was symptomatic. I was struggling with just dealing with my cancer, and I didn't want to add dialysis to the mix when I didn't feel like I was symptomatic. And it was a real education because that doctor was really angry at me and really upset that I wasn't following the direction that she was giving.

And so I learned early on to, like everyone is saying to speak up for myself and advocate myself and that it's actually okay to even fire your doctor and get a different doctor if you're not clicking with that doctor.

And then the second thing is I think what makes this disease confusing and challenging for folks, for everybody and including me early on and even now, there's really not one standard treatment that works for everybody, and it's hard when you're diagnosed with something that you've never heard of to choose a path to go.

Where I live I had a handful of different options of doctors I could see or centers I could go to, and we also considered flying somewhere to take the treatment just because we were having some challenges early on, and that really required me to get a little bit more educated about what these options mean and what they mean to my health and to my survival and to my quality of life. It, you know, again it was sort of an education that I really needed to learn about the disease and my disease and what treatments are that are out there and choose a path and go with it and stay educated.

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