



Patient Power

Jenny Ahlstrom on Dealing With Myeloma As a Mom

Jennifer Ahlstrom
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Andrew Schorr:

And hello from Dallas and the HealthVoices fifth annual conference. I'm Andrew Schorr. 140 patient advocates, e-patient advocates here, and with me is one of the best in multiple myeloma, Jenny Ahlstrom from Utah. Jenny, thank you for being with us.

Jenny Ahlstrom:

Yeah. Thanks for having me.

Andrew Schorr:

So, Jenny, you have six children...

Jenny Ahlstrom:

We do.

Andrew Schorr:

...back there in Utah, and you've been living with myeloma, what? Eight or nine years?

Jenny Ahlstrom:

Yeah, almost nine years.

Andrew Schorr:

So nine years. Some of your numbers have been changing, as they do over time, so like what's next. So what I want know is how do you do it as a mom, and how does your family deal with the uncertainty of living with myeloma?

Jenny Ahlstrom:

Well, I think it's an easy answer. I think--and I've been really, really fortunate that I haven't had multiple relapses, but we've been very open with our kids. We sat everybody down at the beginning, and I remember where we were sitting and had a conversation with them about what we were going to be going through as a family.

We were fortunate because--well, we were living in Mexico at the time, so I ended up staying in Utah and getting treatment while my kids went back. And we were fortunate to have a big family, so we had some help down with the kids. And I had support where I was, so they felt supported. I think it would have been harder, actually, had they stayed with me

and then—you know, six kids is a lot of—you know, compromised immune system with kids coming home from school with germs and things, so it was—it all ended up working out, and it was the best way to do it.

But I think it's, it's tough to know how to address your own needs, and it was almost better for me to be away from them at that time because I just was trying to heal.

Andrew Schorr:

Right. But now it's years down the road.

Jenny Ahlstrom:

Yeah.

Andrew Schorr:

And, as I said, you're living with the uncertainty. I mean, myeloma history is being rewritten while you've been living with it.

Jenny Ahlstrom:

Yeah.

Andrew Schorr:

And I know you've lost friends.

Jenny Ahlstrom:

Yes.

Andrew Schorr:

But here you are and hopefully for many, many years with newer and better treatments that work for you, and now you have this family, a large one, and everybody knows nobody knows what's next.

Jenny Ahlstrom:

No, yeah, there's a lot of uncertainty, and it's a mind game. Every time I go and get labs you feel like Cindy, my friend, talks about it. You get this red card or this green card, you know, which card are you going to get? And when you get the red card you kind of—it's very stressful to know how to handle it.

I think what's helped is that we've involved our children in all of our advocacy, so last year we had this software tool that we developed called HealthTree. We went on a 50-city tour as a family. We brought four of our boys with us. It was very empowering for them to see how we handle adversity, so it helps them be not as stressed about it when we feel like we're doing something about it.

And at some level we feel like we're just going to give it our best shot. We'll go down swinging if we have to, but we're going to do everything in our power to make that happen.

Andrew Schorr:

Wow. Wow. So it's a family affair.

Jenny Ahlstrom:

It is.

Andrew Schorr:

And so having this transparency within the family rather than whispers between mom and dad, you—has been a good thing.

Jenny Ahlstrom:

Yeah. And if my numbers go up significantly or are not, I keep the kids abreast of it. I'm not trying to stress them out by it, but we believe in being very transparent with our kids about what's happening.

Andrew Schorr:

Okay. I want to mention that what Jenny and her husband do is they've been devoted to educating people worldwide. We've been partners over the years, and really besides dealing with your own situation in your own head and at home you've made it a mission to help people worldwide, and that must feel great.

Jenny Ahlstrom:

Well, that helps me. I do it because it helps me. It helps me, but it helps everybody else too. So we created that software tool that I talked about called HealthTree, and it's to help patients find treatment options, understand clinical trials. It's what I wanted when I was diagnosed. Here I am, a 43-year-old patient, and why can't I see the data about treatment A, treatment B, treatment C? Which one's helping people like me live longer? That's what I wanted.

Andrew Schorr:

Okay.

Jenny Ahlstrom:

And so that's why we created it.

Andrew Schorr:

Well, thanks from thousands of people, Jenny. Let's work together many years, okay? I want to give this woman a hug here. Thank you, Jenny.

And we're at this conference where we are learning best practices from patients with all kinds of conditions, and the goal is for the patient voice to be amplified throughout healthcare worldwide. And we're all trying to be part of it in our own conditions, and I'm drawing tremendous strength from people here, too. Are you?

Jenny Ahlstrom:

Yeah.

Andrew Schorr:

Okay. Well, thank you for being with us, Jenny Ahlstrom, normally from Utah, Andrew, normally from California, here in Dallas, Texas. Remember, knowledge can be the best medicine of all.

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