



What Does Normal Mean When Living With Myeloma?

Cynthia Chmielewski
Living With Myeloma

Amy Garofalo
Living With Myeloma

Brenda Jenkins
Living With Myeloma

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Cynthia Chmielewski:

We'd heard that we now have this new normal, the new normal of our life now living with cancer because myeloma has become part of our lives. And as we all know we're not going to be cured of myeloma right now. Maybe in a couple years from now we might be cured, but right now we're not going to be cured, so it's always in the back of our mind.

So let's start with, how about with Brenda. How has myeloma impacted your life? What challenges have you had? What are some things that are different now with your life than before you had myeloma?

Brenda Jenkins:

Good question. Cindy, for me, my life totally changed. It is so different. I had to learn how to adapt to change. Talk about a new norm, because everything did change.

I have spoken sometime about originally before getting diagnosed I was on a fast train, express train, just going all around, you know, to different places. I was a speaker going around to different places, and then after myeloma I got on the slow train, you know. I just smelled the roses, and, you know...

...I take my time. And I love watching the scenery. I love the scenery, so it's really different and even my priorities in life. Priorities are my health, my family and friends, you know, they go in that order. And it makes a difference. I actually think things are better. I am having so much fun. I love it. The support groups, and I have to mention the support groups. The support groups really helped me from the very beginning.

And for me, I was fortunate you enough to join a support group within a month of being diagnosed, and I have learned so much stuff from my support groups, whether it's financial, you know, the Leukemia Society, or doctors coming in speaking or whatever. I have learned a lot from the support groups.

And I share. I share. I share quite a bit on Facebook or whatever. It's just learning about the disease. So, yes, things change, but it's a good thing. It's not bad. And I know so many people now, you know, especially being from Arizona to Michigan. I got friends in Arizona. I got friends in Michigan. It's just really good. And even being in Arizona is because of myeloma. It's because the winters in Michigan got too rough for me, so I had to go—after about three years my kids said, uh-uh. We got to get you in a warmer place.

Now, I can tell you a challenge I had, and really going to Arizona really helps with it. My challenge was being a single mom, independent, especially with that first transplant and I had--you know, I did my homework and read up on it, and I knew that I was going to need help, and that was sort of hard for me. I had to actually go see—and they do have them available—a social worker, and we talked, you know, and she told me I basically had to let others help me.

That was a big thing for me to learn, is to let others help me, you know, those that love me. And my caregivers and friends are great, and I let them help me. But I had to learn that. But being in Arizona I'm feeling really independent because now I'm 2,000 miles away, even though Steve, my primary caregiver, calls me every day, he knows everything that I'm doing. And if I need any help or anything they have no problem flying to Arizona to take care of me.

Cynthia Chmielewski:

You're very fortunate.

Brenda Jenkins:

Yes. But my challenge was that independence, that independent part of me.

Cynthia Chmielewski:

Yes, giving up a little. Amy, do you have anything to add to how living with myeloma has changed your life?

Amy Garafalo:

Well, yeah, it definitely changes your life, your whole routine. You have to figure out your new normal and a balance. You do have to plan around your doctors' appointments. You have to plan your schedules, your vacations around your chemo appointments. You have to plan around the days after chemo where you might not be a hundred percent or you might be nauseous or tired or fatigued. You do have to listen to your body and know when to slow down.

It's just hard finding a balance. I've continued to work, and that's been difficult as well, but pretty much just finding your new normal and accepting that and making the best of it.

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