



Coping With Cancer: Tips for Newly Diagnosed Myeloma Patients

Cynthia Chmielewski
Myeloma Patient and Host

Lynn Worthen, Paula Waller, Melissa Vaughn, Jill Zitzewitz, Sarah Frisbie and Steve Simpson
Myeloma Patients

Please remember the opinions expressed on Patient Power are not necessarily the views of our sponsors, contributors, partners or Patient Power. Our discussions are not a substitute for seeking medical advice or care from your own doctor. That's how you'll get care that's most appropriate for you.

Cynthia Chmielewski:

Any other words of advice, anything else we didn't talk about you think it's really important for someone maybe even newly diagnosed with myeloma should know, should think about, should explore?

Steve Simpson:

I'm going to bring this up. The biggest thing that we pushed is that we, my wife and I, have I guess pushed ourselves as advocating for yourself, and I'm going to say that because again being on social pages and reading, there's a lot of people out there that don't realize that they can advocate for themselves in more than just your own health. My perspective on this was you went in to a visit, like when I go see a hematologist, if I walk out with a question unanswered that's my fault. That's not his, that's mine.

We have a very busy cancer facility where I'm at, so these guys see a high number of patients every day and they're busy, but they take the time that they need. My visits can go anywhere from five minutes, 10 minutes to maybe 20 depending on what I have going on. I'm usually the short version of a visit. They like that. I'm in and I'm out, everybody's happy. But you have to advocate for yourself.

And the biggest thing that came about for this with us is when it came time for the stem cell transplant the insurance that we had at the time told us that you are not going to have it here at Avera in Sioux Falls because they were now what they call a center of excellence, which is a piece of paper. I could go to Omaha, I could go to Mayo, I could go to the U of M. I said no, no, and no. Now, the lady who was dealing with this was in Florida, so she had no idea not only where I was at but didn't even know really what was around there.

So on call number one we got a little vocal with her and said okay, take your hands off the key board, listen very carefully. I'm going to tell you where I'm at. I'm going to tell you my four options, and then as we went on it went down to where they'd only cover certain percentage of the transplant, then all of a sudden I was told if I was going to stay here they wouldn't cover any of it. And I said, well, guess what we're going to do. We're going to stay here.

So we spent two and a half months between myself, my advocates in my cancer center and my hematologist dealing with these people at the insurance company saying, look, there's a reason we're doing here and here are the reasons. And after two and a half months and delaying the transplant I think two weeks I stayed here. I didn't have to go anywhere.

Now, you get into this issue of money and all these things with insurance obviously that comes with all of this, but in the long run I didn't stay in the hospital. I went home, so I look at it as I just saved you guys some money because I was in there for the day and a half and out of door and gone. So had I been somewhere else I would have had to stay there, and that wasn't going to happen. I had parents who at the time were 81. They can't travel. We have kids. My wife has to work. She can't travel. So you lose your support group.

You now go to a different doctor who doesn't know you. He doesn't know you from myself knowing any one of you guys stepping up saying hi, how are you other than having pieces of paper in front of you, so you're basically starting over. I told him I would not do that. I did not just spend all these months going back and forth every day to have you tell me I have to start over just for this process. I said that's not going to happen.

So that advocating for yourself becomes a really big part of this process. And there are a lot of people who I don't think understand that, that you can do this. And there's nothing wrong with doing it. Don't stand there and let them say you have to do it this way because you don't. Push yourself and push them to realize that this is about you. This is your life, this is your future, this is your family's future, and anybody else you have as caretakers, caregivers, whatever you want to call them, this is what you guys have to deal with. So we pushed and we pushed hard, and we've always done that and we will continue to do that. And you know, that was—that was stressful when you get to that point. It's not any fun doing it, but you have to do it. That's just the bottom line.

Cindy Chmielewski:

Have to learn how to become your own best advocate. Some of us know how to do it in the beginning and some of us need to learn, but you do need to be your own best advocate.

Steve Simpson:

Right. And we're fortunate because we have advocates for about everything in our camp. We have advocates for the insurance. We have advocates for the LLS and all of these little things you can get. We have people that do all that for us, but you still have to be there for yourself and you still have to voice yourself and just voice your opinion and not be afraid to do that because nobody's going to yell at you for it, but you've got to be able to do that.

Cindy Chmielewski:

Exactly. That was one thing I learned, that no one will yell at me for saying my opinion. That was what was I was afraid of, that if I disagreed with someone they won't like me or they won't take care of me the way I should be taken care of, and I learned that that was wrong, that I needed to advocate for myself. And people actually respected me when I started advocating for myself and kept becoming that empowered patient. So that was a long way for me, but I agree. You do need to do that day in and day out.

So final words of wisdom. Everyone think of something final to say and words of wisdom to the people who are going to be watching this video.

Lynn Worthen:

None of us picked having myeloma. We didn't choose that, but we can choose how he handle it mentally, our attitude about it, all those kind of things. And it is very, very important to have as positive an attitude every day as do. Sometimes it's hard because this stuff can drag up into a dark hole, but whatever it takes to keep your spirits up and to be positive about things will help a great deal even in the treatment process.

Cindy Chmielewski:

Good.

Sarah Frisbie:

I think, and someone mentioned this or maybe more than one person mentioned this before, but the idea that if you are having severe side effects or even just moderate ones talking to your doctor about maybe tweaking like how much or often the scheduling of your medicine because that's helped me too in the past.

Cindy Chmielewski:

Anyone else have some final words?

Jill Zitzewitz:

I would just say find your community. Don't try to walk this journey alone. For me I think that was a huge part of it. It was hard to say yes to the meals that people wanted to provide or to help with the kids, but be willing to accept people's help and don't try to walk it alone and just rely on people around you to help care for you when you need that.

Cindy Chmielewski:

Paula?

Paula Waller:

I agree completely about maintaining a positive attitude and outlook, but I would say see a specialist. I think every myeloma patient should see a myeloma specialist. Advances are being made so quickly that I think that's the best way to keep up with it and to make sure that you get the best treatment.

Cindy Chmielewski:

And Paula, just a follow-up question, for someone who might not know what a myeloma specialist is, what do you look into to make sure that the person you're seeing is a myeloma specialist?

Paula Waller:

A myeloma specialist who would be a physician who treats just strictly myeloma patients or myeloma patients and other patients with very closely related blood cancers.

Cindy Chmielewski:

Okay. Good. Melissa, do you have any final words?

Melissa Vaughn:

Well, I concur with everybody what they've said. I would just say just don't give up. Like it's going to be okay. Like multiple myeloma, even though I'm young, it was not the end of the world. I still have a long life ahead of me, and there's a lot of treatments on the horizon. There's a lot of information out there, and you'll grow into it. It was a little overwhelming at first and that can't be helped. You're going to feel those feelings of sadness, and it's a grieving process, but you'll be okay.

Cindy Chmielewski:

Good. Steven.

Steve Simpson:

I'm going to go back to what Lynn said, nobody asked for this, you know we didn't, and it doesn't do any good I guess to sit and wonder what caused it either because I know if anybody's on those pages you get all those conversations,

well, I did this, does this cause it? No, not necessarily, it happens and that's just part of life. Now, from my standpoint my whole goal from the beginning was to get to a point where you wouldn't know you had anything at all, you weren't sick. It's a struggle in the beginning. It was for me because I had lost so much weight and I came out basically skin and bones from the surgery and everything else.

It was a long haul after that surgery because after you have, you know, that nice 10-inch opening down your back and you've got 45 grand of hardware in your back, I spent probably two-plus months where I couldn't even take care of myself. It was complete 24-hour care with everybody else because if I tried to stand up and walk the left side was completely paralyzed so I couldn't even hardly do anything. That was from the nerve damage, and when they rip it open to repair all those—the pins, the screws, the rods, all that stuff causes wear and tear on the body. But from my standpoint it was okay.

As I told Kelly, your job is to do this, my job going to be to do this, and you do yours and I'll do mine. And that's kind of where I took it. I said, you know, I'll do what you guys tell me to do knowing that we're going to talk about medications and stuff like that, but I'm going to do everything in my power to get myself back to where I need to be to where things are basically more normal wherever that new normal might be. And that was just my push was that attitude where, okay, I'm going to go back to where I was or as close as I can get to where it was. And it if it takes an extended period of time, which it does, so be it, but you just have to keep yourself moving.

You know, I agree that the negative attitude doesn't really—doesn't do anybody any good in regular life let alone now when you got all these things going on because again you never know what's going to show up the next day. That's the joy of this, I guess. We can all be sitting here happy today and tomorrow three of us may be out cold because we can't stay awake. We don't know.

It's just an unknown, so you learn to take things in stride. I learn to take side effects to where unless it's at a point where I just don't like it or I can't handle it I don't even bring it up half the time anymore, and they know that. If we don't bring it up in a conversation in a visit we're not going to deal with it. Only going to deal with it once I ask for it because I try to manage a lot of that on my own. I don't know about the rest of you but I was—growing up out here in the Midwest in this lovely great white north as I call it you learn to have your body take care of a lot of the issues on your own. If you got sick, your body took care of it for you. I was fortunate as a kid if you got sick or you didn't get sick your body was able to take care of it. Well, guess what, that doesn't happen anymore. But you still try to find that diet or that exercise, all those things that aid in that part of it.

But it's just that attitude you take coming in and try to keep it going forward. And a big part of that is the support groups we have, you know, the families or people you can talk to. All those things kind of come into play, so.

Cindy Chmielewski:

Thank you. And I guess my final words of wisdom being a former fifth-grade teacher and myelomateacher on the Internet I think it's so important to educate yourself, you know. I believe knowledge is power, and if you're an empowered patient having discussions with your doctors and with your care team no matter what, I think you're going to have the best possible outcomes for your situations. So educate yourself and find support, and just like Steve was saying make sure your voice is heard.

There are issues with precision medicines but the main thing is not response rate but durability. And I think that's going to be the next iteration of the NCI Match study, which is a large precision medicine study, is stop doing just these small groups of people who are showing activity but then they relapse quickly. And I think it's going to look at systems analysis and how do we overcome resistance.

Please remember the opinions expressed on Patient Power are not necessarily the views of our sponsors, contributors, partners or Patient Power. Our discussions are not a substitute for seeking medical advice or care from your own doctor. That's how you'll get care that's most appropriate for you.