



# A Myeloma Patient Café: Best Practices for Coping With Side Effects and Symptoms

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**Cindy Chmielewski:**

Hello, everyone, and welcome to the Myeloma Patient Cafe. We would like to thank our sponsors, AbbVie, Celgene, Sanofi and Amgen for their generous support.

Today we're going to be discussing ways of coping with and managing side effects from treatment and some of our symptoms from multiple myeloma. Before we begin I want to make sure that you understand that this is in no way going to replace your conversations that you have with your physicians, but you could use this as a springboard to start some of those conversations.

I am delighted that today we're going to be joined by other myeloma patients who have found some successful ways of coping with their side effects and are willing to share. So before we get started, let's just introduce ourselves and tell us a little bit about yourself, where you live, when you were diagnosed, and maybe one or two of the two most challenging side effects.

My name is Cindy Chmielewski. I live in Laurenceville, New Jersey, and I was diagnosed with multiple myeloma in July of 2008. And some of the challenging side effects that I feel the most frustrated about are the fatigue that I have and chemo brain. And why don't we go next to Sarah.

**Sarah Frisbie:**

Hi, I'm Sarah Frisbie, and I am from Nebraska, Omaha, Nebraska. I was diagnosed in November of 2011 after a hip fracture. My hip broke. And I think the most challenging side effects I've dealt with, probably digestive issues with lenalidomide (Revlimid) and some nausea, so that's probably been the most.

**Cindy Chmielewski:**

Okay. Great. Lynn, how about you tell us a little bit about yourself.

**Lynn Worthen:**

I was diagnosed in a routine physical in April of 2010, and the doctor there confirmed the diagnosis. He was a GP, but he confirmed it and sent me to Little Rock, and so I started treatment there. I've had the routine side effects, the fatigue you talked about, no appetite, no energy, that sort of thing that all kind of went with the transplant phase that I had, but beyond that I wasn't severely bothered by too many things. I didn't have neuropathy. I didn't have a lot of nausea. They gave me a lot of pills for that, and so those things worked pretty well.

I think—I don't know how everybody else had it, but they gave me 40 milligrams dexamethasone (Decadron) a day four days and stuff like that, and it was interesting to negotiate that. The lack of sleep, the retention of water. I gained 17 pounds in four days, you know, all that kind of thing. But those passed after a while when we stopped with the extreme level of dexamethasone and I got it out of my system. But pretty much the routine kind of side effects that people have.

**Cindy Chmielewski:**

Okay. Great. I can't wait until we get into the conversation of ways people managed dealing with some of their side effects and negotiating their dosage of dex. Paula, how about you?

**Paula Waller:**

I live in central Virginia, and I was diagnosed in April 2014 and had a transplant in November of that year, did consolidation, and I've been on maintenance ever since. The first side effect I really noticed was some neuropathy, not the painful kind but the kind that's more bothersome, numbness, just weird feeling. And I do have some nausea, which is now very well controlled that's associated with nemoro(?) that I take as part of my maintenance routine.

**Cindy Chmielewski:**

Okay. Jill, a little about bit yourself.

**Jill Zitzewitz:**

Yes, I'm Jill Zitzewitz, and I live in Massachusetts, and I was diagnosed in March of last year after a series of compression fractures in my spine. It took them a while to figure out what was going on, but once they did we got into treatment. And I think my major side effects have been still the back pain from the compression fractures. Even though they've healed I still wear out as the day wears on. I need to sit on my heating pad at the end of the day. And then the major one probably for me, I'm rashy girl. Every drug, I get rashes everywhere, and so that's been a bit of a challenge to deal with.

**Cindy Chmielewski:**

Okay. Steve, introduce yourself a little bit.

**Steve Simpson:**

Yeah. I'm Steve Simpson, I live in Tea, South Dakota. We're just outside of Sioux Falls, South Dakota. I was diagnosed in November of 2015. That was actually brought about through an MRI that showed up having six vertebrae that were pretty much completely destroyed by the tumor. Spent the next morning in about six hours of surgery and have gone from there.

Side effects, I'm going to say the worst ones are obviously neuropathy was a big one. Syncope was probably the biggest one I had to overcome, and then the digestive issue, I feel your pain on that one. That's just not real enjoyable, but we're getting there. So those are the things that—that's just a few of the many we have, but those are probably some of the big ones for me.

**Cindy Chmielewski:**

Hi, Melissa, welcome.

**Melissa Vaughn:**

Hi.

**Cindy Chmielewski:**

We're introducing ourselves, where we're from, when we were diagnosed and some of the major side effects that you have experienced.

**Melissa Vaughn:**

Okay. Want me to go ahead?

**Cindy Chmielewski:**

Sure.

**Melissa Vaughn:**

Okay, Melissa, and I was diagnosed 18 months ago, back in February of 2017. I have to think about that. And I'm from Dallas, Texas. And some of my symptoms were a lot of neuropathy in my hands and in my feet, some numbness. And I definitely had some spine issues as well, some pelvic lesions and so pelvic pain. And so I also have lesions in my hip and then I had a hairline fracture in my leg, so.

**Cindy Chmielewski:**

Okay. So it sounds like we have a lot of issues to deal with. Some of them are caused by the disease itself like back pain causing some of the compression fractures, and neuropathy I heard can be either caused by the myeloma or by the drugs that treat myeloma. And then we have side effects from the treatment itself.

Just to begin with, were you surprised by the side effects you were experiencing, or were you prepared to deal with them? Anybody want to...

**Steve Simpson:**

I will. I don't think you are because you really don't know what you're getting into.

**Cindy Chmielewski:**

...right.

**Steve Simpson:**

You walk into this blind to begin with, thinking—you know, they can tell you what they want, and that's fine, but everybody reacts different. And I think that's the big thing everybody needs to understand. From my standpoint, when we got into the chemo, you know, the bortezomib (Velcade) and all that stuff, I didn't have anything really from that I had to worry about other than neuropathy which is—you know, Velcade is a big factor in neuropathy and that being nerve damage doesn't go away. You can manage it, but it's going to be with you until, you know, whenever.

So, yeah, I would hope that most everybody is surprised for the most part because you don't know what to expect. You don't know what's coming from any of it. They can talk about the chemo brain, which, I don't know about the rest of you but when I heard that I kind of laughed. Well, I don't laugh anymore because it's sad but it's there. So from my standpoint, yeah, I think they're all kind of unexpected. The biggest one probably aside from those was the heart damage that I had that was the beginning of the syncope from the start where the left ventricle, the damage down to 35 percent, and so we had to kind of fix that problem first and then go from there, so.

**Cindy Chmielewski:**

Anybody else? Anybody knew what they were getting into, or was everyone else surprised?

**Melissa Vaughn:**

Well, I've been a therapist for 15 years, an occupational therapist, so I was familiar with multiple myeloma and kind of had a feeling I had it before I was diagnosed it before I was diagnosed. So going into it I kind of knew a little bit about neuropathy and some of the side effects, but just like what was just mentioned that it's so unique to each patient, and it was very unique to me, my side effects. So like he said, you can imagine, they can tell you what the experience may be but until you do it yourself it's difficult to predict.

**Cindy Chmielewski:**

Yeah. I think that's something we need to stress. Every patient is going to respond to treatment and their myeloma differently, so whatever we're saying today may help, may not help, may be something you're experiencing, it may not be, but it's just good to hear from each other.

We keep on hearing about neuropathy. Has anyone found ways of dealing with or managing their neuropathy?

**Steve Simpson:**

Well, I'll be honest with you. With mine, I'm on 2700 milligrams of gabapentin (Neurontin) a day, which is about as much as you wanted to take because that's nine pills a day. Plus I'm on duloxetine (Cymbalta), which is an additional drug for that, but in that I had to take away my amitriptyline (Elavil) for sleeping at night because those two contradict each other.

And then we just recently in my last thing, it wasn't yesterday, it was the last month going in for my monthly we dropped my dexamethasone down because that's another factor in neuropathy. My hematologist just decided to take the once-a-week dex and cut it down and see what that does, and that has helped a little bit. But even that sometimes isn't enough because my feet are continually numb on the bottom. I refuse to walk around barefoot anywhere in the house. I mean, it's just—there's little things that drive you nuts and you can manage to a point, but that's about as far as it goes.

**Cindy Chmielewski:**

We talked about some drugs like gabapentin.

**Steve Simpson:**

Gabapentin, yep.

**Cindy Chmielewski:**

Who did you work with those drugs? Was it your oncologist, hematologist?

**Steve Simpson:**

Yeah, all of this is through my hematologist, correct. Everything I've done drug-wise related to that part of it where it's related under that section of the cancer is through my hematologist. I have some other things we do obviously through cardiology or pulmonary and those types of things, but that particular one was with the hematologist, correct.

**Cindy Chmielewski:**

Anybody else have ways that they worked with their neuropathy?

**Jill Zitzewitz:**

I think for me my neuropathy was much worse before I was diagnosed, and actually it cleared some, which was surprising to me because that was supposed to be a huge side effects of the medications that we take so I was expecting it to just get worse and worse, but that wasn't a side effect for me. It was more of a myeloma issue, so.

**Cindy Chmielewski:**

So as your myeloma was getting better your neuropathy was getting low.

**Jill Zitzewitz:**

Yes.

**Cindy Chmielewski:**

Anybody else about neuropathy?

**Melissa Vaughn:**

Exercise, exercise helps me most.

**Cindy Chmielewski:**

Yeah. I was told a long time ago that maybe a vitamin B6 type of supplement may help with neuropathy, so I asked my doctor and he said it couldn't hurt so I've been taking it. I don't know if it's helping, but it's not hurting according to him, so that's something else maybe that you could consider. Any other body doing anything else there?

**Paula Waller:**

I take supplements. Actually, I have three things that I do for neuropathy. My neuropathy isn't terrible, it's more bothersome, but I do take a B complex vitamin which my doctor recommended soon after I was diagnosed.

I was stunned when my feet went numb within a week of my first Velcade shots, and I began researching, and one of the things I found was people were using acupuncture. And I was skeptical but decided to give it a try, and it has really helped a lot. What I find is I need to keep on a somewhat regular schedule with that. If I go a few months without it then the neuropathy worsens.

The other thing, someone said exercise, and I found that Dana-Farber's website has an online health library with a wonderful slide show of very simple exercises that can be done for feet, legs and fingers, and again something that I find I need to keep up with regularly for it to really help, but if I do it does help.

**Cindy Chmielewski:**

That's good to know. And talking about acupuncture. Has anyone else used acupuncture or any of the other like mind-body type of interventions, maybe yoga, meditation, anything like that that may help with certain of your side effects?

**Jill Zitzewitz:**

I definitely have been doing a lot of mindfulness since then and I think it has helped just with overall anxiety that comes along with disease and everything to kind of keep that under control. So just spending a few moments at the start and end of every day just being mindful and peaceful.

**Cindy Chmielewski:**

Can you describe a little bit about what a mindfulness practice looks like?

**Jill Zitzewitz:**

So for me it's just—really just a centering moment where you just really focus in on, maybe my finger, my knee, maybe the—oftentimes it's the tree outside my house that I can see in the yard and just kind of really just noticing that. Just noticing the tree or sometimes noticing the birds singing but just letting everything else go away while you focus very much on one particular item.

**Cindy Chmielewski:**

Okay. I did some mindfulness training at one of our support groups, and it seems like something that would be very beneficial. I really need to try a little bit more of that practice. Maybe that would help a little more.

How about pain? Ways of dealing with whether it's back pain or any type of bone pain. Anyone have suggestions?

**Jill Zitzewitz:**

So mindfulness definitely has helped with my pain as well. I seem to be able to kind of forget about it for a bit. Another thing that really for me, I'm in love with my heating pad, so I find for my back at the end of the day I just need to sit on it, so I'll have the air conditioner blaring so I can actually sit on my heating pad and kind of get some relief that way.

**Cindy Chmielewski:**

Anybody else have ways of dealing with back pain, bone pain?

**Sarah Frisbie:**

I've had quite a bit of back pain and hip pain. Those are areas. My back I had compression fractures, and so even after they healed it kept hurting. But after I had the fractures they gave me a brace, and I just wear that. If I know I have to sit or walk for a long time I just wear the brace and that helps a lot. Because I try--when I first had the fractures I had to take the hydrocodone, but I try to stay away from that if I can. I don't like the side effects.

**Cindy Chmielewski:**

And you said they gave you a brace. Who is "they"?

**Sarah Frisbie:**

Oh, my gosh, I can't—it was ordered. I saw like a neurosurgeon.

**Cindy Chmielewski:**

Okay.

**Sarah Frisbie:**

And he ordered it, and I can't remember the name of the company, but like I was fitted for it, and it's bulky and awkward to wear, but if I'm going to go somewhere and I have to fly and sit upright on a plane or something I will wear that. It's kind of like an exoskeleton or something. It holds me up and makes it hurt less.

**Jill Zitzewitz:**

My cane does that for me too. For a while I was barely able to walk and was using a walker and then a cane, and I don't need it anymore, but if I need to stand for any length of time I am in a lot of pain, and I find if I have the cane I can at least stretch up a little bit and do a little stretching and manage to get through that pain.

**Sarah Frisbie:**

Yeah.

**Cindy Chmielewski:**

Anyone else have to deal with some back pain or bone pain?

**Steve Simpson:**

The back pain came from the surgery, and that's going to be an ongoing thing for me. I don't think I'm ever going to get completely away from that. It's more like, when we're sitting right here I'll tell you right now, after so long the position of the neck or the support back here because of where the surgery was will create that bit of discomfort or pain.

Now, again, I can't remember who just said hydrocodone is a big no, and it is. In the beginning when I went through this and put up with it for three and a half months before I even did anything I refused any pain medicine whatsoever, so I've got a pile of hydrocodone sitting, hidden away because I won't take it. What happened was we went to tramadol and a lidocaine patch to just kind of simplify that problem.

Lidocaine patch is nice just because it's simple to put on, it's quick, and it does provide enough relief for me to not have to worry about taking anything else. Now, again, it's more of a—I don't want to say now a pain as it was initially. It's more of a discomfort because there are muscles and nerves that didn't quite heal right, so I've got two vertebrae that actually stick out back there where the scar is at, and through all of the weightlifting that I do now on a regular basis that gets pretty tender pretty quick. So I rely on those lidocaine patches and Tylenol every once in a while to get through that.

**Sarah Frisbie:**

You know, I was going to say another thing that was really effective for me that I use sometimes but it's kind of awkward to get it in the right place is a TENS unit, the little electrical stimulation. And where it's at, where the pain is on my back it's kind of hard to reach, but if I can do it I've done that and just worn it all day and periodically turn it on, and that will help me if I have to sit somewhere for a long time. Because the only thing that really, completely relieves it is leading way back in a recliner or just laying down in my bed, but, you know, I can't do that all day, so.

**Cindy Chmielewski:**

Right. I find that my pain is worse if I stand in one place for too long, so I try to move positions, not stand in one place. Sometimes just sitting down for five minutes, getting off your feet and restarting whatever you're doing helps with my back pain.

**Lynn Worthen:**

You know, you all—I haven't said anything. I'm listening because, as I said earlier, I haven't had a lot of issues with side effects. Pain, I don't have an explanation for this but I don't—I feel pain like everybody else I guess, but I don't—I don't necessarily experience it like everybody else. I haven't had much pain at all through this. I had, as Melissa said, I have pelvic lesions and a pretty good size one on the left iliac wing. I learned that big term through all this.

And I've had—been curious as I've travelled and spoken at support groups to ask people how many like bone marrow biopsies they've had or fine needle aspirations they've had. In Little Rock they do them in abundance, and in eight years I've probably had, oh, I don't know, 30 or 35 bone marrow biopsies and fine needle aspirations. And everything is done—you're awake. Unless you have to be sedated you're awake, and so I just lay there, and they do what they have to do. And I feel certain things but I don't—it doesn't hurt me that much. I just lay there and do it.

Like right now, see, I wear boots quite a bit, and my right toes on my right foot are a little bit numb, but if I take these boots off and walk around, the exercising part, that little bit of neuropathy will go away. But it is helpful to hear what you're saying because all that could change. All those things could be different.

And as I talk to people around the country everybody—you said earlier, Cindy, everybody experiences this stuff differently. It's just there are commonalities in all that we do, but it's never going to be exactly the same for everybody. It just doesn't work out that way, and we can encourage one another and help each other with information that we're gathering in places like this to know what to do when you have certain kind of things happening to you.

So I'm grateful that I don't feel certain things, I haven't experienced certain things. And I've had lots of Velcade, I've had lots of dexamethasone, and I was in remission. And I had a small, truly was a small relapse, and then I had three years of treatment that ended back in May, and through all of those things from the beginning, the stem cell transplants—I had two of them. I had two stem cell transplants in a span of about 10 weeks, and that again is part of their protocol here. And they worked for me and—but I did have a small relapse that put me back, and now I'm in a stringent complete remission situation, which is great.

And I enjoy hearing other people because they help me to understand some of the things that I did experience, and I'm grateful for that. But all those things can change for anybody, and so I thank you for what you're sharing today.

**Cindy Chmielewski:**

The one thing about neuropathy I didn't hear anyone mention was I know sometimes you can dose reduce. You could take maybe a smaller dose. That's something that you may be able to discuss with your physician if that's something they're willing to try. Or sometimes you can take the full dose but spread it out a little bit longer, you know. Instead of twice a week getting a treatment once a week or one every other week.

So I think the important thing is especially with some of these side effects that you experience when you're taking some of the medications is that open communication with your physician, telling them exactly what is bothering you and how it's bothering you. Because together you might be able to make some time of decision so that you don't have to live with the pain, that there might be some way to reduce it or to manage it in the best way possible.

Let's get into these GI issues and nausea. It sounded like something that people are experiencing. I know the most times I had that was during my stem cell transplant, so why don't we maybe talk about transplant first and then maybe talking about ongoing and maintenance therapy later on. Ways that you got through your—how many people have had transplant first?

**Sarah Frisbie:**

Yes, I did.

**Cindy Chmielewski:**

And, Lynne, you had two. Paula, have you had a transplant? Yes. And Jill?

**Jill Zitzewitz:**

Yes.

**Cindy Chmielewski:**

And, Steve, did you have a transplant? Melissa?

**Melissa Vaughn:**

I actually—I chose not to do the transplant because I plan on doing IVF, actually?...

**Cindy Chmielewski:**

Okay.

**Melissa Vaughn:**

So—I plan on having another baby.

**Cindy Chmielewski:**

That's important. Actually, that can be something we talk about in a few minutes. Let's talk about transplant. How did you manage some of those severe side effects that comes with stem cell transplantation?

**Steve Simpson:**

Some of the what? Could you repeat that?

**Cindy Chmielewski:**

Some of the severe side effects. You know, I mean, I'm sure you didn't have any?

**Steve Simpson:**

You know, that's kind of weird because transplant, and again, it just goes back to everybody reacts different because this is one of those where you sit in your two-hour consult meeting and they drill you with everything you're going to

supposedly—you can anticipate, I'll put it that way. Your time in there, what to expect, this may happen, that may happen.

And I'll be honest, this is one of the most surreal things I've ever seen because the eight or nine hours to take out your own stem cells, that was probably worse than the actual two days of the transplant process because that's, you know, you've got to sit there. You don't get to go anywhere.

Transplant itself was, I said surreal for me. It was, you know, they come in 24 hours from the time you had the chemo the day before, and had no issues from that. I sat there in total for an entire day. They came in and within 12, 15 minutes you're done. And I looked at my hematologist, I said, really, we're done? That's it? He goes, yeah. I said, okay. You know, two-and-a-half, three hours later I'm walking out of the hospital—or out of the cancer center, excuse me, and I never went back until day 98.

So side effect-wise the worse thing was, what, five days later when your white count goes down to zero and the four buses run you over all at once, you know, you can't prep for that. So from my standpoint that was probably the worst of it right there, just that normal, okay, you watch your white blood count, have fun now because you're going to be out of it and go to it. So side effect-wise I really didn't have anything.

I was very fortunate through the whole process again, number one, to be able to leave that same day because nothing really changed physically for me at all. I just kind of sat that and I'm like, okay, Dr. Kelly came in I said, okay, can I go home? You know I live 12 minutes, 15 minutes away. I have 24-hour care if I need it, and everybody in this hospital is what, they're sick, right? So how about we just go home and we deal with it, and it was fine.

I left, and I felt perfectly fine for the first three or four days like nothing happened, but then once your count drops it's kind of like, whoa, here we go, but that was about the worst. Other than appetite, but that's part of the process. So I guess I got lucky from that standpoint. Very lucky.

And that's where I stress so hard with people that everybody reacts different. Nobody reacts the same, and as we do this and we get on the social media pages of people asking questions they got to understand that everybody is different. And that's why I like these because you can hear all the different things that go on. Again, I feel very fortunate that I've been able to kind of just glide through this whole process with not a lot of issues to deal with, so.

**Cindy Chmielewski:**

Anyone had like GI issues they had to deal with transplant, fatigue, ways that they?

**Lynn Worthen:**

I learned to pay attention to what the doctors said. They gave me a sheet of paper and they said take these medications in the morning and these in the afternoon and all that, and I looked at it where it said laxatives and stool softeners, and I said I'm not going to become dependent on those things. I'll make it just fine otherwise. Well, two days later I was asking at 8 p.m. what we could do about the problem I created.

And I learned to pay attention to what they said because I had no background to understand how steroids and chemo—one lady she called it the concrete maker, I mean, how it could really create issues for you. So I learned to pay attention and to know that they've been there before and they know a lot more than I do about this sort of thing. And that helped me all the way through.

But, anyway, I just learned to negotiate it by doing exactly what they said about use of laxative, use of stool softener, all that kind of stuff so that you didn't create a much bigger issue.

**Jill Zitzewitz:**

I had a lot of problems with nausea, and I found that—I mean, they did give me medication for it, but I really didn't want to eat anything, and I finally found a couple of foods that appealed to me, canned peaches and yogurt and oatmeal, so that's all

I ate for about 10 days. Literally, that's all I ate. And then I went through this phase of egg sandwiches when I got home. I just wanted egg sandwiches on toast, you know, fried egg sandwiches. I'm not sure why.

But I didn't really worry about not getting all of the nutrition I needed just to figure out what I could tolerate, and figuring that out and just going with helped a lot.

And then I also walked every day. When I was in the hospital I forced myself to walk up and down the hallway carrying my IV pole, dancing with my IV. But—and then at home I paced my driveway outside, tried to get a mile in every day, but it would be in like little blocks. Maybe I can do a quarter mile and then after I rested I'd do a little more. And that really helped I think. I got my energy back a lot quicker.

**Sarah Frisbie:**

I was hoping—I had watched videos and different things of people who had gone through transplants, and I was hoping that I would be one of those people that it wasn't too big of an issue, so I kind of went into it with a hopeful attitude. But I was really, really sick, and it lasted quite a while. I did it in the—I stayed in the hospital, so I was there maybe I think about two and a half weeks, but it was just—I could barely keep anything down.

But I did eventually—because in order to leave I had to start figuring out how to eat. But I did find some things like you said that I could keep down. And so I developed this love of Wendy's frosties and I would just eat those. Because I needed calories, you know, and same as you, Jill, I wasn't worried about nutrition. I just needed to keep something down. So I had frosties for like two weeks I think, pretty much lived on that. But I was—I had so much nausea, and they gave me stuff too for it, but it just seemed like nothing would get rid of it. So that was my experience.

**Cindy Chmielewski:**

I was more like you, Sarah. I tried to keep on top of it because they told me if I kept on top of it with the medications it was best, but I just couldn't shake the nausea and the diarrhea every time I ate. And odors were a big thing. There were certain smells that I just couldn't tolerate just smelling those things. It was strange because some of the things that I'd loved before I had my transplant I couldn't even stand the odor of.

And you had frosties, I had custard ice cream. That was the thing that got me through, you know, at least being able to eat because I was too in the hospital and they wouldn't let me out of the hospital until I showed them I was able to eat something. So everyone is so different.

Paula, how was your transplant experience?

**Paula Waller:**

My transplant was inpatient, and I think nausea was probably the biggest challenge and also mouth sores. Not in my mouth so much but in my throat, and that made eating really difficult. I survived on popsicles for several days.

**Cindy Chmielewski:**

For mouth sores. Did you do anything else for those mouth sores?

**Paula Waller:**

The medical team there gave me pain medicine, but basically just had to kind of wait for them to go away. And I did do the ice before the—and during the melphalan (Evomela) but still got the sores.

**Cindy Chmielewski:**

Still got the sores even with the ice. For those of you that don't know, some of the online support communities encourage you to suck on ice and to eat ice the entire time of your melphalan infusion in hopes of not getting the mouth and throat sores. And once again it was something I spoke to my doctor about and he said, can't hurt so if you want to try it give it a try, so, you know, I did. I didn't get mouth sores, but, Paula, you did, so I guess there is no rhyme or reason for some of the things that we do.

**Jill Zitzewitz:**

At my hospital they had us eating popsicles because they wanted you swallowing it too to keep your throat cold, and so apparently I almost beat the record. I ate 24 popsicles during that week. But I didn't have any mouth sores, so it worked for me.

**Lynn Worthen:**

The nurses told us to eat ice two hours before until two hours afterwards, and being who I am I decided if it worked that way I would just start when I got up in the morning and I would eat it until I went to bed at night, and it worked okay for me. Got water in me and also it kept my mouth and throat cold so I didn't have problems with it. But I was around people who have had some severe problems like all of you said, and it can't be a very pleasant experience.

**Cindy Chmielewski:**

Melissa, would you mind speaking a little bit about your choice of not going for a transplant and why you made that choice?

**Melissa Vaughn:**

Yeah. So originally when I was first diagnosed we planned to do the transplant and then after four months of treatment my body responded pretty well and then after talking to my oncologist about having another baby because I did—I did IVF prior to treatment because just in case I would need the transplant we decided to do IVF. And after I responded well to treatment I decided—I made the decision with my oncologist to hold off on the transplant so that we could try and have another baby because my IVF was successful, and I knew that it would take a long time for my body to recover after the transplant.

So even if I had just got close to remission the plan was still to hold off on the transplant as of yet. Just because of the current medications that there are I could keep it under control even with steroids. So after seven months of long treatment I did get full remission and so the plan was still to have another baby. Unfortunately, I've had some symptoms again, so I don't know if it was a good decision to hold off on transplant or not, but we'll see here in the near future, but that was still what I decided to do.

And my hope is still to have another baby. So whether I have to go back on treatment for a little while or if I have to keep it under control with steroids. Of course while I'm still having bone pain and things like that, especially in my pelvis, I don't know want to have a baby and have a pregnancy with that added pressure on my pelvis. So we'll just see what the future holds. But that was my decision, that was my reason why.

**Cindy Chmielewski:**

And a good reasoning, and best of luck to you. I do know another very young myeloma patient who had one child and now is pregnant with her second child so, you know.

**Melissa Vaughn:**

I have a 3-year-old little, boy so I'm hoping to give him a sibling.

**Cindy Chmielewski:**

Great. Wonderful. Okay. So now that we're over our little transplant, how about some of the side effects you have—treatment or maintenance therapy? Someone? Okay.

Okay. Was that you, Ruthie? No, it was just somebody's phone went off or whatever, but we can just restate the question and try.

**Cindy Chmielewski:**

Okay. Now that we've gone over some of the side effects and how to manage them through—let's try that one more time. See, this is its chemo brain that kicks in. I'm in the middle of a sentence and I forget what I'm saying.

So now that we've discussed some of the side effects we were experiencing through our stem cell transplant and how we went ahead and managed them, now that our transplants are over and right now I guess maybe some of us are doing some continuous therapies, some of us are in maintenance therapy. Are your side effects as severe? Are they any less? Any tips,

any discussion?

**Jill Zitzewitz:**

So I am now doing maintenance therapy with Revlimid, and I'm having the same kind of issues with the rashes and my skin is just—I don't know if it's partly post-transplant as well, your skin is just kind of not the same or if I'm just—that's where I get lots of problems. So I'm still trying to manage that by modifying the dose. You know, instead of going 21 days and then a week off we're trying two weeks on, two weeks off. We keep dropping the dose to see, and it's getting better.

And so I think what you mentioned earlier about working with dosages to try and help, that same thing happened to me during induction therapy with Velcade. I got a terrible rash, went to a dermatologist, and he said, well, I'll give you an EpiPen just in case, but you need the drug, so. And—but we were able to modify it by modifying my schedule of when I got the dex. I got some of it after my Velcade shot and not all of it before, and doing it once a week instead of twice a week without taking a week off, but there were ways to kind of modify the dosage to deal with the skin issues that I'm having.

**Cindy Chmielewski:**

Were there any ways you treated the skin issues besides..

**Jill Zitzewitz:**

Oh, yeah. So there was sort of like a steroid cream on my skin to try to help with that. I found that especially post-transplant if my skin gets dry at all or if I get in the sun at all then things get worse, so I'm pretty religious about Eucerin skin calming lotion to keep my skin moist and definitely using steroid creams when things flare up.

And also I'm trying to work on diet to see if that can help, if maybe, you know, maybe I'm already a little bit sort of—my immune system is a little out of whack and I'm taking an immunomodulator which is partly throwing it out of whack a little more. So I'm trying to like limit dairy and gluten and things like that to see if it has an effect, but I don't know yet.

**Cindy Chmielewski:**

Okay. Anybody else had to deal with skin issues or rashes?

**Steve Simpson:**

Kind of an interesting thing because coming out of a transplant obviously you didn't pick up any Revlimid until after the 100 days or whatever, and I was still back on the original 25 milligrams, and as soon as we started that back up the rash, literally it just took off and it was just—it was brutal. But the oddball thing is we did drop Revlimid down and right now we're at 10 milligrams, but the steroids I take on Sunday are also for the purpose of keeping that rash down and nothing else. That's the only reason I went onto that was simple for that purpose, and it's worked fine since then. We've dropped that steroid down to maybe, probably eight milligrams a pop because instead of 20 on any given Sunday I take just eight, and that part helps the neuropathy but it's also kept the rash down.

Now, could I stop that entirely? I don't know. I might be able to, but obviously the rash wasn't as severe as some of the other people have, but that was??that was the hematologist's decision to try that steroid because at the point nothing else was working anyway, so that was kind of that worked so, but, you know, it's been fine since, so.

**Jill Zitzewitz:**

Another thing that I heard at Dana-Farber and I've heard a lot of other people that said this, either loratadine (Claritin) or ondasetron (Zofran) or some 24-hour antihistamine type for allergy medicine, and I've been taking Claritin, and that actually seemed to have helped too.

**Cindy Chmielewski:**

With the rash? Okay.

**Paula Waller:**

I took Claritin also. I had a rash just a couple of times during induction and either the rash was self-limiting or the Claritin really did help.

**Cindy Chmielewski:**

Good. How about fatigue? Anybody have ways that they manage fatigue or help fatigue?

**Steve Simpson:**

Kind of a weird one. Everybody again being fatigued comes and goes, and for me I guess it's more or less how much I've done during the day. Again I'm—before this all started I was a hyperfit individual, 52, six days a week in the gym or whatever and, of course you can't give that up, and that's been a struggle. I'm finally back in at about that pace. That will fatigue me out. And to be honest with you for me now I haven't been back to work, started, so we're going on close to three years now. I'm trying to get back, but I guess the only way I can say this is you learn to listen to your body maybe a little better than you did before. I'm always 110 percent, 110 miles an hour, it's just how I'm wired, and you can't do that anymore, so now you start feeling that fatigue point, you almost got to just cave in and take a break.

I'm not a person to take naps in the afternoon unless it's one of those things where like over the recent past I can't control it, but just got to learn to listen to yourself. If it's time to take a break, you take a break. I don't know what else to say because sleeping on a regular schedule is virtually impossible. It doesn't happen anymore. I hope someday it does, but even with a CPAP I'm lucky to get five, six hours at best in a given night. And of course steroid days forget it. You're lucky to get two or three over the course of a couple days.

But for me again it's just listen to what your body is telling you, and if it's telling you better slow down, slow down. Because again if you don't, we all know that that's going to get you in the end, the stress, the fatigue. There are so many things that we don't—we didn't focus on prior, at least I didn't, they've now become a point to where if you don't you're going to get sick. And obviously we all know that getting sick is the last thing we want because that just multiplies to something we don't want to deal with. So it's just kind of one of those things.

But exercise I think is one of those that for me kind of helps with that because you start pushing yourself, you build the endurance, build that ability to do a few more things or more than you maybe were doing before. It's the same thing as after transplant, get out and walk, get out and move. I can remember after transplant if I was lucky to get two or three block is in on a walk that was good at the time, but at least it was something. You know, you had to build that stamina, you had to build that part of it back up. It's a continual process. You've got to keep going.

**Cindy Chmielewski:**

Right. So listening to your body, taking a break when you need to. I think that's great advice. Building up your stamina with a little bit of exercise at a time. Anybody else, ways of dealing with fatigue?

**Melissa Vaughn:**

As a therapist for a long time and actually working with patients it was interesting to be a patient myself, an interesting experience. And something that I'd always counsel patients to do was to exercise and to eat right. And before my multiple myeloma, before I was diagnosed that's what I did, and even back then it had an impact on how my quality of life was. And even as a multiple myeloma patient I realized how important those two things really are even as a patient and how I had to kind of eat my own words and really battle through the fatigue because that was probably one of my number one and most difficult symptoms was fatigue. And so even though I didn't feel like it many days, just getting up and walking.

And also I'll put in a plug for physical therapy because that's the realm I work in, and they work closely with your doctor, and they can devise a treatment plan based on your precautions, contraindications, things like that of that nature where you can exercise safely, and they can develop a treatment plan for you. They can also issue braces and things like that if that's what you need to exercise. But I truly believe that that can increase your quality of life, those two things. Post-transplant, pre-transplant, during multiple myeloma.

**Cindy Chmielewski:**

I agree. Unfortunately, I was not one of those most fit people like Steve was prior to my transplant, prior to my diagnosis, but I now know that whenever I'm starting to battle fatigue or not feeling right I go back and I look at what I was eating, if I'm not doing any exercise, and that usually correlates with it. Even if I just get up and go outside, take a walk, being outside in that fresh air, maybe doing some mindfulness out there, enjoying nature, just trying to get my mind off maybe all those stresses because stress sometimes causes that fatigue too, you know. And eating right, eating food that provides you with

energy, you know, I think those two are really good points in dealing with fatigue. Any other?

**Jill Zitzewitz:**

Related to exercise, so I did do physical therapy before I was diagnosed because of the compression fractures, and that definitely helped with building my core strength, and I kind of kept resorting to those exercises during the transplant process. But I was a little bit nervous about exercising vigorously because I didn't know how strong my bones were, I was afraid of—and so I actually joined the Livestrong program at the YMCA and I found that to be incredibly—I mean, I'm doing Zumba and things I wouldn't have done before. A lot more cardio, because you can do it in a modified way. They can work with you, we do it—and I learned how to do yoga, I learned how to trust my body more and take breaks when I need to, not to overdo it, you know, to set my own limits.

So I found that that was really helpful for me. It was also a support. There were other cancer survivors there, and it got me back exercising, and now I'm also back in the lab. I'm a scientist, so I'm on my feet most of the day in the lab, but it actually helps. It doesn't make me more tired. It helps me to keep moving.

**Cindy Chmielewski:**

I agree. I was part of the Livestrong at the Y program, and it really did help because you have the one-on-one trainer to help modify those exercises just for you. So I felt more comfortable than just joining a gym. And, like Melissa said, I went to physical therapy because I wanted to start exercising but I was afraid because I had so many compression fractures. What I should be doing, you know. I didn't want to hurt myself anymore. I lost three and a half inches in height throughout this process, you know, and when I went to the physical therapy fortunately we were able to do like aqua therapy in a pool and learning how to do Zumba in the pool and just many resistance exercises, so I didn't have all that stress on the body.

And from the physical therapy I was able then to join the local pool and take part in some of those classes that weren't putting the stress on my bones in the very beginning. I agree physical therapy could really help with getting to exercise, and then once you start exercising you might gain some more energy and the fatigue may go away. Anyone else? Okay.

Let's talk about online patients communities. Any of you belong to any of the online patient, either Facebook groups, Smart Patients, PatientsLikeMe? Any of those?

**Jill Zitzewitz:**

So I've joined some of the online Facebook groups, but I actually didn't when I was first diagnosed. I think I was a little overwhelmed and I didn't necessarily want to hear everybody's stories, but now that I'm feeling better I feel a little bit more like maybe I can offer some support. So I found them to be very helpful, things that you might not have even thought of, thing that you can bring up to your doctor come up, right, because people have different experiences.

I was kind of afraid to be on the web too much because there's a lot of things out there that you don't know how helpful they are and they can be scary. I have four kids, and first thing they did, they're teenagers, was go on the web and think oh, no, mom's got three to five years to live. She's not going to see me graduate. She's not going to see me, you know, get married or have children, and that's not necessarily the reality for myeloma patients today, right?

So I think finding good resources and finding support and hearing the stories of survivors who have been, you know, 15, years, 20 years at it, you know. It's starting to become very encouraging I think for everybody.

**Cindy Chmielewski:**

Anyone else on any of the online communities?

**Sarah Frisbie:**

I am on Facebook. I have—and I look at it. I'm just the opposite of you, Jill, because you said like when you were not feeling well you didn't, you know, you didn't want to hear like any scary stories, and when I was feeling good I didn't want to think about it. And then if something would happen or I'd relapse, then that's when I guess I was wanting to hear what other people did. But I agree it's very encouraging to hear people who have been successfully either in remission or at a low level for years and years. That's probably the most encouraging thing, I think.

**Melissa Vaughn:**

I think I'm the only one on Instagram. There's not a huge myeloma community there. However I did put myself, I tagged myself as myeloma in there, so I have connected with a lot of people actually a that have—it's a little more difficult when you're—I have to say when you're younger because there's not a lot of people with young kids with multiple myeloma or want to have another baby?

**Cindy Chmielewski:**

Right.

**Melissa Vaughn:**

Connect with other young people and so a lot of people, yeah. That helps to connect.

**Jill Zitzewitz:**

There is a Facebook group for myeloma patients who are under 50. They let me join even though I was 53 because I am a working mom with four teenagers, relatable. And I found that one to be...

**Melissa Vaughn:**

...very inspiring.

**Cindy Chmielewski:**

Yeah. And actually I was talking to someone in that Facebook group and he is in his 20s, so I think he is trying to start a Facebook group for myeloma patients who are maybe under 40, so there might be a totally different perspective even having more children. I'm on Instagram too, so I'm going to have to find you.

**Melissa Vaughn:**

Yeah, it's myelomamama. That's what I call myself.

**Cindy Chmielewski:**

Oh, I do follow you. I'm myelomateacher on Instagram so I'll follow myelomamama. Okay

**Melissa Vaughn:**

So I know you.

**Cindy Chmielewski:**

What? I'm having a hard time hearing you, Melissa.

**Melissa Vaughn:**

Oh, sorry. I don't know if my internet connection is kind of going in and out. I just said okay, I do know you. That's what I said.

**Cindy Chmielewski:**

Cool. I think I was more like Sarah with online communities. When I first got my diagnosis was 10 years ago. It was prior to most of the Facebook communities there, and Smart Patients was at that time called ACOR, cancer online resources, so it was a long time ago, but I knew nothing about myeloma. I was really an uneducated patient. I really didn't know much about what types of questions I should be asking my doctor or any conversation. So just being part of that community and working and seeing what people were talking about in that community, I would just write down questions that maybe I should be asking my doctor and, you know, or things that other people were doing to see if that was something I should consider doing.

So for me the online communities really helped first educate me as a patient to learn what I should be doing at a patient, how I should be engaging with doctors because prior to that I was brought up in that age of doctor knows best, and I just blindly followed whatever the doctor was telling me, and I soon learned that conversation was something that was important, but then also when different things were coming up I always had my list of questions that I wanted to ask if this was okay for me to do too, so. Anyone else on any of the communities online?

**Lynn Worthen:**

I'm not on online communities, but I just want to put in a pitch for any kind of communication between patients. That's particularly what I do when I go and speak to support groups, but I've watched the ability and the power of groups to help someone who is really struggling with some of the decisions about treatments and that sort of thing. If they can talk to someone else who has been on that journey already, it can make a lot of difference.

I'm thinking particularly of a group in Boca Raton, Florida, where one man was going to do nothing. He was as low as a snake's belly in his depression. And I watched that group who knew him talk to him and the lady who led the group texted me a few days later and said he's decided to go and be evaluated. You know, it was the power of that group to help that person make good decisions about their life. So things like this where people can talk to each other I think are really very, very good.

**Cindy Chmielewski:**

You bring up a good point. Any type of group, online, in-person. There's a number of myeloma support groups across the country that if you're fortunate enough to be in one of those cities could really help you out. Could pick you up, could provide you with lots of information. So, yes, definitely the power of the groups. Okay.

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.

Thank you all for spending time today, sharing your knowledge with us and hopefully inspiring some others.

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