

0:00:03.5 Brooke Pelczynski: I never would have taken the medication because I'm not about to stick myself with a syringe. Are they crazy that they think that's completely normal to expect someone to be able to do that right away?

0:00:17.5 Announcer: Hey there and welcome to Meducate Me where we talk to healthcare providers, patient advocates, educators and healthcare industry experts who may see things from different perspectives but who share one common focus, better patient treatment and outcomes. Join us where the meeting of minds gets to the heart of it all – with your host, Joe Blechl.

0:00:44.1 BP: Hi Joe.

0:00:45.7 Joe Blechl: Hey, Brooke. How are you today?

0:00:47.5 BP: I'm good, thank you. How are you?

0:00:49.8 JB: Good, I'm good. So for everybody out there on the podcast, my name is Joe Blechl, I'm with One World Design and Manufacturing Group. I'm here with Brooke Pelczynski, we're gonna talk about patient education and patient advocacy today. Brooke, do you mind introducing yourself?

0:01:08.3 BP: Hi everyone. My name is Brooke Pelczynski, I'm a Multiple Sclerosis patient advocate. I've had MS for almost nine years now. I'm also an artist and live a pretty normal life.

0:01:20.5 JB: Okay, so Brooke, what brings you to the podcast today? Can you talk a little bit about your patient experience that made it interesting that you'd be a part of this?

0:01:33.0 BP: Yes, so I'm here mostly today to talk about the lack of patient training I received with my injection devices and pre-filled syringe medications and all that jazz.

0:01:46.1 JB: Right, okay. So you had mentioned once before that sometimes patients on these therapies, they can feel isolated and overwhelmed, what is it about these therapies that creates that feeling for patients?

0:02:02.8 BP: I think that when you're first diagnosed, it's already quite terrifying and unless you are completely given every supply and tool you need to succeed in the beginning, you struggle along the way. Even if you have Google and you have a great neurologist and all of these things, sometimes there's still a puzzle piece missing and I think that as a patient, even when you're just missing one tool that could help you have a perfect situation, you're gonna fumble along the way and I think that's what makes things feel so isolating.

0:02:38.8 JB: That's interesting. Okay, so could you describe a specific experience when you were first on-boarded to a medication that really... It wasn't a good experience for you.

0:02:51.2 BP: Yes, I can. So when I was 21 years old, I was diagnosed and the first medication that I was prescribed was Avonex. My neurologist had told me that it would come to my house in a pre-

filled auto-inject pen that I would take once a week and what had happened from then on was completely different than what I was told. I received my first couple of doses through a regular pharmacy and they came in a vial and I was handed a syringe, and the pharmacist at the time was just like, "Here you go, take your medicine, titrate up." And I didn't know what that means. I don't know what that means, nobody knows what that means.

0:03:31.2 JB: Titrate up.

0:03:33.2 BP: Titrate up. What is that? 'cause I've always heard titrate down, you take less to wean yourself off of a medication but I had never heard the phrase, titrate up. So I was a very...

0:03:42.4 JB: It does sound like something somebody in a chemistry lab would know.

0:03:44.8 BP: Yeah and I was like, "I'm already so scared. I hate needles and you're really not setting me up for success with this 'cause I was told I'd get a pre-filled auto inject pen in the mail like when you have an allergy attack." So I was very lucky at the time of my life, I had an aunt who was a nurse and she kind of just took the reins for me and did it all for me and thank goodness for that because otherwise I never would have taken the medication because I'm not about to stick myself with a syringe. Are they crazy that they think that's completely normal, to expect someone to be able to do that right away? So that was the beginning of that medication journey and then I was told, "You're gonna receive the pre-filled auto-inject pens in the mail and once you receive them, you should call this nurse assist hotline and get that set up because the nurse will come to your house and show you how to take your first dose." And I was like, "Okay, that feels a little invasive. I don't really want someone in my house but okay, this is what you have to do."

0:04:49.8 BP: So I had called and scheduled the appointment and I was sitting in my apartment one day waiting for the nurse to show up and five minutes late, 10 minutes late, nobody showed up, and I started to freak out because I'm just like, "This is a scheduled medication. This already has a set schedule that I didn't make up, that you guys told me, and I'm trying to do my best to follow it so if the nurse doesn't show up, am I just..."

0:05:17.7 JB: Am I gonna miss my dose?

0:05:20.0 BP: Do I miss my dose? Do I wait? Do I call again? So I spend a few hours on the phone with the Avonex customer service people and they were not helpful because at that point, there was only so much they could do. They could call the nurse, see where she's at, but then she was already at another patient and it just was what it was. So I went to the internet and I just kind of ran with it myself, and the first... The Avonex medication is once a week so the first is three weeks of me taking this medication, it was a disaster. I figured it out but I definitely fumbled along the way and I was probably not getting the full dose and the booklet that they give you in the medication box is not helpful. How do you hold this flimsy newspaper booklet and my needle and...

0:06:11.9 JB: Right.

0:06:12.8 BP: It's just not... It just wasn't very efficient and I think as a new patient, the most

important thing is for things to move seamlessly, and this process didn't move seamlessly for me.

0:06:28.6 JB: So here you are, you've got this medication. Now, you had had one in the doctor's office already, right?

0:06:33.4 BP: No.

0:06:36.4 JB: Oh, this was your very first...

0:06:37.3 BP: Yeah, I had no dosing in the doctor's office. I believe that my neurologist showed me an example of what the pen could look like, the auto-inject pen, and she let me hold it and she put it to my leg. It was like, "Push this button, everything's gonna be great." But there was no medication in it and it's completely different once there's a needle in there, and the whole stress of all of that just starts to boil up into a big snowball.

0:07:04.3 JB: Okay, so here you are, you've got your medication at home and you don't have the nurse show up. What would have made it better at that time? What would you have fallen back on that could have helped?

0:07:21.0 BP: I think that at that time, it would have been great if there was a video platform that I could go on to the computer and just watch somebody else take their medication and know that it was approved by this company, right? Like they verified this, they gave it the check mark, they're like, "This person takes their medication the right way, you should follow their lead." But at the time, I didn't see that, and if it existed, it wasn't easy to find so I think that would be helpful. And it probably exists now, times are different.

0:07:54.4 JB: Right. So you've got a lot of fear, you're talking about fear and anxiety, right? So what are the best ways to help patients overcome them?

0:08:09.3 BP: [chuckle] A glass of wine. No. Yes, a glass of wine to settle your nerves a little bit, I personally...

0:08:15.1 JB: So that should come with the box that should come from the pharmacy.

0:08:20.2 BP: If every month that you got your box of medication, it came with a wine subscription or a coupon to some grocery store wines, Trader Joe's wine supermarket, that would be great but...

0:08:29.6 JB: Pretty hard to figure out which type of grape people like at that point, right?

0:08:34.3 BP: What wine pairs best with the Avonex intramuscular injection? What's really gonna loosen you up? But for me personally, when I had to deal with self-injecting, I found that these headphones were great. I bought these headphones specifically because my pen was so loud and it would give me so much anxiety and I was like, "I don't even wanna push the button. I know I need the meds but I don't wanna push the button." Everything boiled up and just became more the things that feel so small to normal people. My mother at the time would be like, "Just push the button and

everything's okay. It makes a lot of noise, it's two seconds. Yap, yap, yap."

0:09:09.9 BP: And I'd be like, "I know that to you it's just two seconds." And to the observer, this should be quite an easy thing to do but there's so much other anxieties on top of just pushing that button. It's the anxiety of, "What if I pull it out too early and I don't get all the meds?" The anxiety of, "What if it jams as I'm pushing the button and it kind of stops half way. It's supposed to go in and it didn't go in. Do I throw this out? Do I use a new pen? Do I waste an entire dose and then is the insurance company and the medication company gonna send me a replacement? And what if that doesn't come on time?" So it's all of those anxieties building up into the whole process.

0:09:52.6 JB: You actually had a time where you thought you pulled the medication out. You thought it was a full injection and you pulled it out. Can you talk about that?

0:10:03.8 BP: Yeah, definitely my first two injections, the booklet that you get in the Avonex box would say count to 10 but I'm already nervous so my count to 10 is super fast. Where it should have been like a one Mississippi, Mississippi count, not even one Mississippi, double that Mississippi because you'd count to 10 and then you pull the injection out and then there's medicine squirting all over the place and you're like, "What do I do?" And then one time I had pulled the injection out too early, so the needle didn't retract all the way back into the pen and I ripped my leg a little bit and that was disgusting. And it's kind of just like, "Was that my fault?" I don't even know if that was my fault 'cause even when the medicine had finished, the needle never pulled back into the pen so is that a design flaw and did I just happen to have a bad pen out of a batch of thousands and thousands of pens? I have no idea and the people on the customer service line weren't. They don't know either, right? So who do you speak to then if nobody knows the answer?

0:11:11.0 JB: So they didn't have anything that available to help you and if there was an error, to say what to do... What do you do next, right?

0:11:21.4 BP: No, it was just the... With every medication that I've been on, you have a designated... A nurse that reaches out to you every couple of months to make sure you're on the right track, the whole nine yards. And every nurse that I've had that just has to call and have a chat with me, has been very nice but they're nice over the phone, do you know what I mean? They can't be there walking you through the experience and the best they can do is be a verbal support for you and it's... A verbal support is great when I can hold the... Hello, injection in one hand but it just kind of doesn't play out that way. And especially when your lifestyle doesn't fit into the nurse's 9-to-5 jobs, and then if I'm taking my injection at 8:00 PM, there's nobody there to speak with at that point so you're left to the internet.

0:12:10.5 JB: Obviously, patient education and training is filling in a gap and there's still gaps even today, right? So how is patient education actually related to your decision to use or to stay on a certain medication or a therapy?

0:12:35.0 BP: As a patient, I rarely am given a lot of options when it's time for a new medication, if I'm being honest. And I think that if we spent more time educating people on like maybe, "Even though this medication has the best results, it might not be the best medication for you and I think

that there's not enough effort put into that, right? Every time I've had to have a new medicine, the doctor is kind of just like, "This is the next medicine." And they don't really ask for a lot of input. They'll give you two choices and be like, "You could have this or you can have this."

0:13:10.0 BP: But it would be nice to know everything about a medication before I have to be on it. And right now, I have a great neurologist but in the past, I haven't had great neurologists and because they're so busy, they'll just throw a bunch of pamphlets at you and be like, "Here are your options, read them, tell me what you wanna do." And I think that if they spent more time letting me know, what are the side effects? How do you take this medicine? There's actually three different versions of the Copaxone because they have a generic version and that pen will be different and if I knew all of those things as I was being given a new medication, it might change my choices.

0:13:52.9 JB: So there are instructions for use, there are quick start guides, there are starter kits. How do those contribute to what you're saying in terms of being able to really just not have a bad experience when you start something?

0:14:08.7 BP: Personally, I find that the instruction book, the big paper that has the how-to with the tiny type and all the FDA's... I don't even know if it's FDA but I kept saying FDA. All of the guidelines and allergy information, those papers are not helpful. They definitely get tossed into a box of stuff I will one day use as wrapping paper and I never look at them...

0:14:36.3 JB: Not even if they're full of illustrations, instead of words?

0:14:40.0 BP: I've never received one that has beautiful illustrations. And I think maybe that's a whole... A whole other problem. It's like I'm a visual person, I want to see it. I'm an illustrator, I like illustrations whereas someone like my mother wants to read it and wants it to be like, "This is exactly what it is." [chuckle] So I think that... I don't know. When I pick my new medication, maybe they can tailor your box, right? Your box of medication comes with a drawing booklet and it shows you how to take your medication step-by-step or, I'm a reader, and maybe your box full of your medication comes with an actual book but these flimsy pieces of paper that I keep receiving... And I receive them with every medicine that I'm on. I'm on Tysabri now and they're still sending me this stuff in the mail and I'm like, "Why are you wasting all this time and effort sending me papers about a medication that a doctor gives to me? I don't even take this one myself."

0:15:39.0 JB: Right. Right, interesting, okay. Okay so was there anything else that we didn't talk about that you wanted... That you thought was important for people to know?

0:15:51.7 BP: Let's think. We covered the frustrations of not getting proper training. [chuckle] We covered... Oh, this is something else that I think is useful, I think, to patients in general. What I find as a patient is that I go to an appointment and I'm receiving an overload of information especially when I'm starting a new medication or leaving a medication because it's not working and I find that because I'm already so stressed hearing this news, whatever a doctor says to me, I'm not processing it and it's just not coming into my head completely.

0:16:31.0 BP: So in the beginning, I used to take my mother to my appointments but I find that if

you bring family to an appointment, they tend to care too much and talk over you and the doctor ends up talking to your family instead of you. And I think that as a patient, you should have a dedicated friend who cares but they don't... They care for you and they're just gonna sit there and listen and maybe sneaky record the whole visit so that later, you can go home and listen to the visit again. And I wonder, is it bizarre to think that my doctor visits should be recorded so that at a later date I can watch it again? Is that crazy? I don't know, but if it was a telehealth visit, I could record my visit and save it to my files.

0:17:22.0 JB: Did you wanna share anything else?

0:17:24.0 BP: I don't know. I don't think so, Joe. I think we covered a lot of stuff.

0:17:28.0 JB: I think so too. So Brooke, thank you so much for sharing your experience. Thank you very much for... I really do hope that, and I do think that this can be a big help for all the other patients that are going through... That have experiences that are similar to you.

0:17:46.0 BP: Thank you Joe.

0:17:48.0 JB: So really appreciate the time you spent with us.

0:17:49.1 BP: Of course, it was a pleasure and I do hope that one day this falls into the right person's lap, and they take that extra step. It's like a side shuffle, it's not really a step forward. It's just kind of like, "We gotta go a little over and then keep going straight." But...

0:18:02.8 JB: Well, let's send it out into the universe and let's ask the universe to do the best.

0:18:10.0 BP: Fingers crossed, fingers crossed for sure.

0:18:12.7 JB: Yeah. Okay, thank you, Brooke.

0:18:15.6 BP: Thank you for having me. You guys have a good day.

0:18:18.1 JB: And you too. And thanks everyone for listening.

[music]

0:18:34.4 Speaker 2: Thanks for listening to Meducate Me, where the meeting of healthcare minds gets to the heart of patient care. For more on this series or for great patient compliance and medical training materials, go to our website at patientcompliance.com.