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0:00:06.2 Speaker 1: 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.

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0:00:36.2 Joe Blechl: Well, hello everyone. Welcome back to another episode of Meducate Me. I'm Joe Blechl, and today we have Heidi Holden and Brooke Pelczynski with us, and I thought I would just introduce Heidi Holden. Heidi tell us a little bit about yourself.

0:00:55.1 Heidi Holden: Thank you, Joe. Again, my name is Heidi Holden. I'm a registered dietician, and I'm also a certified diabetes educator, and I've had the most wonderful joy of educating patients on self-injectable medications for about 25 years now, it's been a great, great job because it's so fulfilling, and thank you for having me here on this podcast now, I'm gonna really enjoy this. Thank you Joe.

0:01:21.0 JB: You're welcome Heidi, and Brooke, could you also introduce yourself?

0:01:25.2 Brooke Pelczynski: Hi, my name is Brooke Pelczynski. I am the patient, and I was not fortunate enough to have a Heidi during my injectable journey. So that's why I'm here today.

0:01:35.9 JB: Well, I'm looking forward to talking with both of you today, so Heidi, could you start us off by sharing one of your patient's experiences that illustrates the challenges initial therapy onboarding?

0:01:50.2 HH: Sure, Joe, I've actually had many patients that... They had a lot of difficulties with doing a self-injectable, one really comes to mind that was, Oh my goodness, she was so afraid and she couldn't think straight, she couldn't sit, she was walking around and it just took a long time of talking about things that really weren't about the medication or the injectable, just to calm her down and get her focused on something else and after a few hours, we finally figured out what was going on, she was just so afraid of just the injection, sometimes people are afraid of other things, like side effects or whatever, but we finally got to the root of it and through some meditation and just getting her heart rate right down, she took the injectable and she was doing great, and I'm really, really proud of her, because I... Well it's about a week ago, I did a follow-up call with her and she finished her full course of treatment, the full 18 months. Wow. Again, I couldn't be more proud of that patient, because she overcame all that fear, it was great.

0:02:58.8 BP: That's really impressive.

0:03:00.2 JB: It's gotta feel good to get her through that, right? Help her through that. Fantastic.

0:03:03.9 HH: Oh, yes. Definitely Joe. Thank you. Yeah.

0:03:08.1 JB: Good, so Brooke, you probably have a couple of experiences, you mentioned that you didn't have a Heidi with you at the beginning, so you can probably relate to what Heidi was saying.

0:03:20.5 BP: It's so funny the way Heidi described, that this woman pacing about her apartment or her home and I'm kind of just thinking about it, like my very first injection, I spent four hours just starting the whole process, the medicine has to come out of the fridge, half an hour before you take it in my case, but I took the medicine out half hour before it, but there were three hours before that, I just organized my home, I set my mood lighting, I set the music, I called a friend, I got all my YouTube videos up, getting ready to take my meds, because my nurse had not shown up, but it's very impressive that Heidi did some meditating with this woman. That's a cool thing, I never would have thought of that. I never had somebody to suggest that to me, it might have been nice to have it as an option.

0:04:01.6 HH: Well, Brooke whatever works for you and whatever works for that particular patient.

0:04:06.0 BP: These headphones worked for me at the time, so I'm definitely a sound person, the sounds of the injection...

0:04:13.0 JB: Music track, right Brooke?

0:04:15.5 BP: Yeah, definitely music. Loud music, loud music.

0:04:17.7 JB: Yeah, yeah. [chuckle] Well, that illustrates a really important part of everything that we're gonna talk about today, and that is that every patient is a little bit different, and how do you reach the patient. It talks a little bit about how do you find out where that patient is at, and Heidi, I think you could really explain a lot about what you do and how you learn what's going to make the most impact and help the patient the most.

0:04:47.8 HH: Well, I think just listening is number one, asking a lot of open-ended questions, just really, really active listening is so important. And I think the number one thing that needs to be used when you're talking to a patient is don't assume, don't assume anything, because what you think may be the problem, may be completely opposite, so that's the first thing is just listening, finding out and then talking them through it, whatever it may be, it may be, again, side effects. All right, it's side effects, let's really talk about it, how many people actually got that side effect versus how many people didn't, and never poo-poo, I always say I'll never poo-poo anything, but just talking it through and finding out about that particular patient.

0:05:42.2 BP: Yeah, that's funny, Heidi, because definitely when I was first injecting myself, I think my hesitation was that everybody else was just pigeon-holing me into this like, "you are just scared of the needle," and it's never the needle. I am terrible to my skin sometimes, right? It's not the pain, it's not the needle, it's the build-up to taking the injection for me, and trying to explain that now I can do it very well. It's an anxiety thing, or trying to explain that as a new patient, nobody

understood that, and they were like, "put an ice pack on your leg half an hour beforehand, it's gonna be okay," and I'm like, "It's not the ice pack, it's not the pain of the needle, it's the pushing the damn button and getting ready, and all the sounds that come with self-injecting for me." I don't think that anybody wanted to hear that, they're just like, "we have offered you the easiest thing in the world, you don't have to go to the hospital, you can do this by yourself, we deliver it to your front door," and yes, you do all those things, and that's great, but I didn't have the comfort zone that I needed, or I don't even know if I would call it the comfort zone, but like the, "Hello, please help me" that I needed at the time.

0:06:51.9 JB: And that's important Brooke, because these companies that provide injectable medications, they really do a lot of work in the background to make it as simple as possible. It's a really monumental effort that they put into researching it, they do a lot of patient studies and things like that. So it probably does come as a surprise to some people that there are still gaps and there are still things that patients need to help them get through this. So Heidi, what do you do when you're training someone, what do you do to help them get past some of those anxieties that Brooke talked about and maybe some of the things that you've seen in addition to what Brooke talked about?

0:07:43.5 HH: Well, again, I think with Brooke's case, I don't think anyone was listening to her, and I think that gave her way more anxiety than she needed to have. So that's the first thing. She had a problem with pressing that button. So that would say, "Alright, what bothers you about pressing that button, is it the sound, and can we make something in your headphones when you do it?"

0:08:12.2 BP: Right.

0:08:13.8 HH: Is it, for example, I had a patient recently that she was just so worried that she wouldn't keep it in long enough, you know... wet injection. So we worked on a walk-up song, that's what I call it or an injection song, that would last that amount of time or just different ways of going about it. If she's really afraid of the actual injection, there's Emla. There's ways of numbing the skin that might make it better for them, but again, it's just really talking to the patient about what their problem is and then addressing that particular problem. That's how I feel. Now, Brooke, and you sound like they weren't listening. Did you find a way that they listened to you, eventually? [chuckle]

0:09:00.9 BP: No. I had always kind of felt like I am very young. You're very capable. You can do this. You don't need that much help. And I felt like that was the path I was pushed towards, and I definitely played it off like, "Yeah, I am really young, I am really capable." But I feel like even when I did try to reach out for help, it wasn't there when I needed it, and I am very much like, "I can do everything alone, I don't want your help anyway," but there were moments when I was like, "I just want someone to answer the phone" and I couldn't get in touch, so it led me to my sister, [chuckle] and my best friend, and YouTube, and the videos that were out then are probably not even anything compared to what's out now. But it was a lot, and I think now, I would have behaved differently to get different results, and I think that people that are diagnosed really young, want to feel independent and want to be able to do it themselves, and even though they want to know that the Heidi exists, they want to be able to problem solve on their own first for a little bit, and then turn to the Heidi.

0:10:13.9 JB: So Brooke, you did talk a little bit about things that are out there. You talked about the videos. You talked about YouTube, you talked about your sister. I wanna get back to that a little bit in a minute. [laughter] So there's also IFUs, Instructions For Use, Quick Start Guides, starter kits, they're all meant to make it easier to get started on an injectable. How much do those help and what kind of a role do they play in making it easier to stay on an injectable?

0:10:53.4 BP: I know that Heidi and I have different opinions about these things, and I think that's okay. They're coming from different perspectives and different age groups, I'm sure Heidi deals with patients of all ages, but at the time that I received my injection and they handed me a booklet with instructions, but at that time, I was so highly stressed out, so overly stressed out that the idea of having to hold a book and learn to take my injection, it just didn't work. And in the beginning of my MS, it was not great, and my hands were like, sometimes they wanted to do what they were supposed to, sometimes they didn't, and having to hold an injection at a 90 degree angle and hold this paper that tells you how to take it, was very difficult for me. So it led me to look for other methods.

0:11:39.4 JB: So Heidi, what's been your experience with those materials that have come with the injectables, and talk a little bit about how patients receive them and maybe how they could be improved or what's missing, if there is something?

0:11:54.5 HH: Well, I can totally understand Brooke, why you are down on it. [chuckle] I think if I got your starter kit, I would be really, really disappointed. I've seen a lot of good ones, not so good ones. I believe that the ones that I really am glad to give to the patient has maybe a tri-fold page that you put on the table and look at.

0:12:17.7 BP: Like a stand.

[laughter]

0:12:19.3 HH: A stand.

0:12:20.4 BP: Like it stands up by itself. That would have been cool. That would have been cool.

0:12:24.5 HH: You know, they have different little things, for example, maybe a diagram, so they can put a little date on it, so they rotate their injections. That's kind of fun. Maybe a travel case or some of these medications, they have to be kept cold, so some of the starter kits come with, like a cooler bag that they can travel with and so on.

0:12:49.0 BP: It's not practical all the time, right?

0:12:51.7 HH: Well, that's true. It might not be sometimes, but it might other times, so it's kind of a little perk for them, they get a few needles, but what I really like is not so much the IFU, Well, I like the quick start guides and so on, I don't want something that's really, really small print and so on. I like the ones that they can actually see, that's colored. That comes sometimes with the starter kits, that they might not get when they're getting their injection training. That kind of stuff is, I think,

really good. When you're training somebody too, if they have these papers and they're actually writing their own notes on it, that really helps them to cement it. Even if I tell them it's all written down, they say, "Oh No, let me write it too," and that's perfect. So they can go home. They can see what they have. They can see what they wrote. I like all that stuff. It might not be for everyone, and some are a lot better than others, but I think it will help quite a few people.

0:13:58.3 BP: I do understand that there are thousands and thousands and thousands of people with problems, and they need to make it easily accessible to most people, but I think that there could be a little tailoring in some areas.

0:14:11.9 HH: Brooke, you're making a really, really good point, that it should be tailored. "I want a written copy," or "I want it sent to me," or "I wanna have it digital." That is a very, very good point.

0:14:22.3 BP: Yeah, well, I understand that you need to give this information out, but there are certain things I think should be tailored a little bit, like this is crazy, but what if I was visually impaired and would still have to do this by myself, like How are you training me then? And the nurse didn't show up. How are you training me? How does that happen? I can't even fathom that.

0:14:44.1 HH: Very good point, Brooke, and again, it goes back to listening to the patient. What does that patient need?

0:14:51.2 BP: Right.

0:14:51.6 HH: You might need digital, where my 93-year-old needs...

0:14:56.6 BP: He wants the paper.

0:14:57.0 HH: A page that is really blown up and we can Xerox and make it bigger. So, really listening and finding out what that patient needs is important.

0:15:04.6 BP: Or maybe you can perfect your font size.

[chuckle]

0:15:08.3 HH: True.

0:15:09.5 BP: Right. That would just be the icing on the cake.

[chuckle]

0:15:13.0 JB: Sounds like digital is the best way to go.

0:15:17.3 BP: I think that my 86-year-old grandma has an iPad and uses it religiously, and I think that there are people in the world that will remain wanting paper stuff, but the majority of the world

is moving forward digitally, and everyone kinda has to keep progressing, otherwise things fall stagnant. And then you hit problems with like, "Why does my medication routine feel like I'm living in 1975?" That shouldn't be the case.

0:15:46.0 JB: You can provide printed materials. They're easy, but if you want something that's more individualized, then it has to be on a media that can be dynamic like that.

0:16:00.4 HH: And also the languages can be changed. We had problems with getting hard copies in different languages sent, and I think the digital. But I think it's a little bit of both. Like I said, for a lot of people I know, they want that paper in front of them, and for Brooke and others, digital.

[overlapping conversation]

0:16:18.3 BP: Yeah. So they can keep it in their junk **draw** and pull it out whenever.

0:16:22.1 JB: Well, certainly with illustrations and diagrams, right?

0:16:25.0 HH: Right. Right.

0:16:26.3 JB: A lot of pictures on a printed page is very, very helpful.

0:16:30.9 HH: Very helpful.

0:16:33.5 JB: Hey listeners, that was part one of this discussion with Heidi and Brooke. Wanna hear more? Check out part two in our next episode of Meducate Me.

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0:16:43.5 S1: Thanks for listening to Meducate Me, where the meeting of healthcare minds gets to the heart of patient care. For more in this series, or for great patient compliance and medical training materials, go to our website at patientcompliance.com.

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