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0:00:06.2 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.

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0:00:36.3 Joe Blechl: Welcome back to Meducate Me. I'm Joe Blechl. This is part two of a discussion between Heidi and Brooke. For those of you who didn't get to listen to the first segment, we'll repeat their introductions and then jump back into the conversation where we left off in part one. Today we have Heidi Holden and Brooke Pelczynski with us. Heidi, tell us a little bit about yourself.

0:00:57.7 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.

0:01:13.1 JB: And Brooke, could you also introduce yourself?

0:01:16.2 Brooke Pelczynski: Hi, my name is Brooke Pelczynski, I am the patient.

0:01:22.9 JB: A lot of patients are gonna get their initial dose in a healthcare provider's office, in a doctor's office or something like that. So what's that experience like for a lot of patients, and what's missing, and then what do they do after that initial dose is given in a professional office? What do they do after that, like when they get home the next time they have to administer? Can you both talk a little bit about that? Maybe Brooke, you can start.

0:01:56.2 BP: As a patient, I did not receive my first dose in the doctor's office. I think I would have liked to have my first dose in the office with a really nice nurse, but it didn't happen. And I get like maybe they don't have the time to have patients, yada yada, but I don't know. And I wonder if... Is there a weekly training session in the doctor's office for all the newly diagnosed? I would have attended that, that's cool. Then I would make friends who are sick and become part of the community. But it wasn't part of my story. I'm not sure what Heidi's stories are like.

0:02:35.8 HH: Well, I'll tell you. I have different feelings about training in the office. It really depends on how well the person was trained... Train the trainer. How well that nurse was trained on that device. A lot of them are on all sorts of... Or teaching all sorts of medications, so how... When was the last time they trained that one? How much time do they have? That's the other big problem, it's really how much time do they have. Sometimes they come in, they got just a few minutes and that's it, and pats you on the back, wish you well, and that's it. Also, they really don't have the time to explain to the patient why they're taking the medication, what it does, so that's a problem. Now, on the other side of that coin, I have offices that are fantastic. I just... I can't get over how great they are at training. So you have those kind of two different experiences that may happen. But now let's

say they're trained at the office, they go home, what kind of support do they have at home?

0:03:45.7 HH: So to me, the best trainings in the office are the ones that immediately they have an educator go and help that patient the next day, or just let the patient know there's somebody out there. Brooke, you didn't have anybody to help you at all.

0:04:03.9 BP: I was definitely sold the idea that somebody would come to help me, and that I would really have no reason to be nervous, but like you said, that doesn't always happen, nurses are busy, people get backed up.

0:04:16.6 HH: Well, that's the thing. They need to have at least an 855, 800 number that they can call, something like that, or some papers and all that. Again, my favorite trainings are the ones that they trained a little bit in the office, or maybe they didn't even inject, and they're gonna inject the next day with me, that's fine, but it's when we are partners that I think it works the best. And also follow-up calls, oh, my gosh, they are perfect. When somebody for you Brooke, would've called you in a week, "Hey, how are you feeling about this?" or the next time you have to do it, really talking to you personally about your feelings and your, I wouldn't say anxieties, but what's going on with your feelings about this medication, I think that's really, really helpful for me.

0:05:12.4 BP: I'm sure that there was a phone number on my medication box that I could have called and been like, "I need to speak to a nurse," and I'm sure that exists, but I had one nurse for each of these meds that I was trying to... I mean they were trying to build a relationship with me, but it was difficult because I was busy, and I was just like, "Oh, this would be nice, but I don't have the time to chit-chat right now."

0:05:36.1 HH: That is hard for us as educators on the other side of just trying to make it convenient for the patient, but...

0:05:41.8 BP: Yeah. Yeah, and I could imagine you have a boatload of patients you have to deal with, everybody has different schedules, and I'm sure it comes to the point where like you have to use your best judgment and help the people that 1000% need the most help at the time. So I get it. But I think that I wouldn't have been so quick to be like, "I can't talk right now, I'm sorry, click," if it could have been a little bit more scheduled.

0:06:05.6 HH: True, and that's something that didn't happen for you, And that's what we try to do. We try to schedule, or a patient says, "I'm more available after 5:30," or whatever it is, and that should be documented for the educator to help the patient. Because the whole point is, getting a communication, a live communication with your patient and seeing how they're doing, and you can't do that when they're saying, "Can't talk to you right now..." "

0:06:31.6 BP: [0:06:31.6] it's **not** gonna be a great conversation. But wondering if moving forward, we're talking about how technology is... Telehealth is so important. I would love to Zoom with my nurse, right? Like Heidi, I love having a chat with you. I know what you look like, I can see your facial expressions. I can see that like, "Oh, I'm doing this the right way." Your face looks calm. My face looks calm. We're meeting in a mutual space together. You're not a stranger. You're

not a fantasy woman on the phone anymore. I know who you are. This is my friend Heidi. She calls me every other month or whatever it is. And I think it's something that as a patient, I would look forward to more rather than what feels like a spam phone call sometimes. 'Cause the number comes up as potential spam or a mystery number, and I'm like... And I'm checking the number on the phone, I'm checking the number on the box and like, these numbers don't match. So I don't know.

0:07:31.5 HH: That's a good point. We are doing a lot of Zoom-ing with telehealth right now obviously 'cause of what we've been going through the last few years or so, but it's... And personally, I just... I love it. It's working well. But for some patients, they really need that live trainings and so on. But I like the idea of what you're saying, Brooke, about even with follow-up calls, doing Zoom, even if someone needed a live training, and then further follow-up calls doing Zoom. 'Cause I agree with you, once you see their facial expressions, you get so much more out of it than just, "How are you doing?" On a phone call. So I think that's a great idea, and I hope that's something that we can do.

0:08:25.0 BP: Fingers crossed. I definitely as a patient, just want to feel like I know the person in my corner, right? I want to know who's sitting on my bench there to help me out. I know my neurologist, I know that I can send her an email and she's gonna get back to me. And it makes me feel good to know like this little blonde woman is sitting at her office and she's like, "Brooke sent me an email. We have to get back to her."

[vocalization]

0:08:46.4 JB: So one of the things that we've talked about in the past Brooke, was when errors happen in an injection. Can you talk a little bit, just a tiny bit about your experience?

0:09:04.6 BP: Where do you go, Joe? [chuckle] What do you do when there's an error in your injection right?

0:09:10.6 JB: Yeah, yeah, exactly.

0:09:12.6 BP: Who do I call? Who do I try to talk to? Do I call the neurologist and get put to the front desk because it's 8 o'clock at night and then leave a voicemail? I'm like, "Hey, I messed up my medicine. I know it's a weekly dose, but do I take the next dose?" There was nobody to speak to about that. I probably could have called the nurse. Yes, Heidi. But I don't know, I probably didn't. Or probably did, didn't like the answer I was given because they don't know the whole situation, and my frustration probably just chose not to take the next dose. Because medication is so expensive at the time of my life, it was so difficult to get it on time, that it was more important for me in my head to keep the schedule going. Because if I have five doses, they're not gonna mail medicine out for another five weeks, and then if I take an extra dose, I'm gonna be a week behind and have a gap week. And it was really scary to think about.

0:10:07.0 BP: So I just went to the internet and did my best Googling, and it led me to a new... It just led me that the medication ended up not working and I had to take a new medicine.

0:10:20.9 HH: Wow, Brooke. Sounds like you had absolutely nowhere to go. You were trying to figure it out, and you didn't have a helpline number you could call at that time, and the frustration, and you did what you could do, and so you did a great job because you really looked into it and you could only do what you can do at that moment. That's a terrible story though, because it just makes me so sad.

0:10:49.8 BP: I think it probably happens more often than...

0:10:51.4 HH: You're probably right.

0:10:53.7 BP: I think it happens more often than people wanna talk about right?

0:10:55.9 HH: Well, they're embarrassed too.

[overlapping conversation]

0:10:56.6 BP: [0:10:56.6] You call these help lines and your put on hold.

0:11:00.1 HH: They're embarrassed to call too sometimes. That's why I like being that touch point with my patients periodically, because if they have a question, they feel more comfortable if I call them and that, "Oh yeah, this happened, oh yes... Whatever." But they need to have... I will not be off the line till I know they have that helpline number down somewhere. They have me, but they have a help number. Because no patient should be by themselves in that situation.

0:11:34.2 BP: Right.

0:11:34.8 HH: It's just not... Because it's not good for anybody. It's not good for the company that produces this or the patient, or the educator trying to put out that fire. But yes, you did a good job because you did what you could do.

0:11:51.7 BP: Thank you, Heidi. I remember that I was on a medication and I had taken it and the booklet said, "Take your medicine and count to 10." Okay, so I count to 10. I take my medicine, I count to 10, afterwards I pulled the needle out, and it didn't... I don't remember if it was supposed to retract or if I was just anxious we pulled it out too early, but pulled it out, cut my leg, medicine and blood all over the floor, and it was disgusting. And I cried because I... Did I not get my medicine? Did I not take this the right way? And my first move was to call the neurologist because we had a relationship and I felt comfortable speaking to her, and that's why she's my first move. So I think the whole moral of the story is that a patient is more willing to have a conversation with somebody they feel comfortable and have a relationship with rather than a mystery person on the phone or a help hotline. Because I call the help hotline, I am already frazzled and upset, I have to start from the beginning, tell the whole story again, give myself more anxiety, more stress.

0:12:55.0 BP: I call the neurologist and you get put on hold, or you have to leave a voicemail because they're very busy people too. Right? So what ends up happening is that this story of me messing up my medication doesn't really get handled until I'm back into... Back in for a check-up

and I'm like, "Oh, I messed up."

0:13:11.1 HH: Sounds that way, Brooke. I think for me, how to prevent... Like you have that wet injection, I think is talking to the patient in the beginning. I always do. What can you do wrong? Let me tell you what I've seen people do. And we talk it through, for example, maybe I'm not sure, of course, what happened when you pulled it out, but get a song that lasts for however long and sing that song, Mary Had A Little Lamb, whatever, or count.

0:13:44.8 BP: I think that as a patient moving forward... Currently, currently as a patient and in my past life, I would... I like... I like to know the worst case scenario. If I mess this up, am I gonna die? If I mess this up, are you gonna have to cut my arm off? Or ridiculous things like that. But what is the worst case scenario if I don't get my meds today? What happens? Does this make me have to start my whole treatment course over again? Which I don't know the answers to these things. Do I just come in tomorrow? Do I have to wait a whole month? Yada, yada, yada. But I personally like to know the worst case scenario of my medication, not taking it properly, taking it the right way, it doesn't work, still what is... What are all these outcomes? And I think it's not talked about.

0:14:30.8 HH: Brooke, I think what you're saying too, is that you like the worst case scenario, and it's the first thing that went through your mind, all the worst case scenarios. [chuckle]

0:14:39.9 BP: Yeah, yeah...

[overlapping conversation]

0:14:40.1 HH: But... In the same sentence.

0:14:42.1 BP: Thank you. It's just definitely all the anxiety building up in my mind.

0:14:45.4 HH: Yeah.

0:14:45.5 BP: 'Causes me to ask these preemptive questions. The hospital I go to now is pretty great.

0:14:51.1 JB: Okay, so let's talk a little bit... You had mentioned... There's a lot of people that are in the support role, right? Brooke, as a patient, you had mentioned your sister before, and I want you to talk again, talk a little bit about caregivers and what your experience was, and then maybe Heidi, you can talk a little bit about what your experience is and what should be done... What do caregivers need? What should be done for them?

0:15:20.4 BP: I think in a perfect world, a patient picks their designated friend or family member to also learn these steps so that everybody knows what the hell's going on. And in the worst case scenario, like my hands cramped up, I can't take this stuff myself, somebody can be there to do it with me or do it for me.

0:15:46.0 HH: So the caregiver is important, but I find there's a few different things with

caregivers, most of the time it's really great, like Brooke said, when the caregivers know what's going on, they know the more of the technical stuff of how to do it or troubleshoot with the patient. I love when a caregiver is in a training with me and really understands as well as the patient what's going on. The other reason I think it's very important to always have the caregivers in a training if at all possible is that they need to know why the patient is taking it because, and what the disease state is.

0:16:29.3 JB: Again, what's the worst case that could happen with a caregiver?

0:16:32.0 BP: That is the worst case, yes.

[laughter]

0:16:38.0 JB: So, Heidi, is there anything else that you wanted to talk about that we haven't covered already? Something important that we didn't get a chance to talk about from your perspective? And Brooke?

0:16:48.6 BP: No, I think we had a great chat.

0:16:51.6 JB: I think so too.

0:16:51.7 BP: I think we had a great chat today.

0:16:52.7 JB: Okay, well, thank you both for joining. Thanks for the great insights. And we will put this out into the universe and see what good things come.

0:17:02.1 BP: Fingers crossed that it gets picked up by the right people.

0:17:05.1 JB: That's right.

0:17:05.5 HH: Oh that'd be great, Brooke. I hope so too. I'll keep my fingers crossed.

0:17:09.0 JB: Alright, thank you both.

0:17:10.0 BP: Excellent. Thank you, Joe.

0:17:11.2 JB: And thank you audience for joining us.

0:17:13.2 BP: Thank you, Heidi.

0:17:14.9 JB: Take care.

[music]

0:17:19.2 S?: Thanks for listening to Meducate Me, where the meeting of healthcare minds gets to

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