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Time: 12:00 PM

Nancy: Samantha, my name is Nancy. It's so nice to meet you.

Patient: Nice to meet you.

Nancy: How are you doing today?

Patient: Good.

Nancy: Good. Before we begin, I just want to give you a quick introduction. I really appreciate you joining today, and we're going to be talking all about SMA and SMA treatment in particular. Everything you say today is completely confidential. I don't even know your last name, so let's just keep it that way. Please try not to tell me the name of any doctors involved in the SMA treatment. I do have a few colleagues listening in. They don't know who you are either, and we're recording just for research purposes. If by any chance you mention that you've had a less than ideal experience on a medication my client makes, I have to write up a little report called an adverse event report, and I might have a few questions to ask you about that. Also, I think you agreed to give seventy-five minutes of your time. Is that correct?

Patient: Yes, ma'am.

Nancy: So even though that seems like a really long time, every once in a while, I still need to interrupt folks just to hustle things along because I do have a ton of questions. Are you okay with all that?

Patient: Yes.

Nancy: Will you tell me, are you the person who has SMA, or are you a caregiver of someone who has SMA?

Patient: I have SMA.

Nancy: You have SMA? Okay. Can you tell me a little bit about yourself, if you live with anybody else, how you spend your days, just so I have a sense of who you are?

Patient: Sure. I live with my children and my husband, and we have two dogs. I work part-time for a local school, and I am enrolled in school to earn my bachelor's. I do all the other daily things in between.

Nancy: That's a lot going on there. How old are your kids?

Patient: I've got 19, 17, and 15.

Nancy: Wow. Alright. You're full on. I have one 16-year-old and two 14-year-olds, so just behind you. And what do you do when you work part-time for the local school district?

Patient: I work for the front desk. When the kids come in late or need to check out, I ensure that they're safely checked in or out and then input some data into the system, whether it be attendance or other various things that are assigned.

Nancy: That's great. And amazing you're getting your bachelor's. What are you majoring in? Sorry, these are just nosy questions. They're not crucial, but it helps me get to know you a little bit.

Patient: You're good. I've got my associate's in medical coding and billing, in medical office admin, so I thought it'd be fun to get my bachelor's in human resource management.

Nancy: I mean, there's a lot of detail in both. Right? A lot of systems stuff. Even like, I think about HR as people, people, people, but it's a lot of systems too. Right?

Patient: Yeah.

Nancy: Well, good for you. So you're type three SMA. Is that right?

Patient: Yes, ma'am.

Nancy: Okay. And when were you diagnosed with SMA?

Patient: October 2012.

Nancy: Wow. I never asked you how old you are. How old are you?

Patient: I'm 43.

Nancy: Okay. So interesting. You were diagnosed at, like, 30 years old?

Patient: Mhmm.

Nancy: Wow. So interesting. How did the diagnosis come about?

Patient: Our pastor's wife is a physical therapist. She noticed my gait and told me I needed to see a neurologist. They tested me for a couple of things, and one of our friend's daughters actually has SMA type zero or one, and something told me to get tested for it. I had never really heard about it, didn't know anything about it. But when the testing came back negative for MS and a couple of other things, I just said, hey, test me for this.

Nancy: So the upsetting part of that story is that it wasn't part of the panel of original things that they tested you for. Like, if you hadn't asked...

Patient: Yes.

Nancy: Sorry. That's just a little heartbreaking there.

Patient: Yeah.

Nancy: What a remarkable physical therapist to know that you should see a neurologist.

Patient: Mhmm.

Nancy: Wow.

Patient: Yeah. Just watching me walk on Sundays and the little bit of interaction we had, she said, there's something going on with your gait. You need to get in, and so I did.

Nancy: Wow. So all the testing came back negative, and then you said to the neurologist, what was the reaction when you said, actually, I want to get tested for SMA?

Patient: He was pretty open to it, and he wasn't very well-versed on it. He had to do some research. I was sent to a muscular dystrophy clinic in another town once I got diagnosed to help me learn some more about it. He was very limited in his research. Basically, what he found on the Internet is what he knew.

Nancy: Sorry. I don't know why I just giggled, but it's just intense.

Patient: Yeah.

Nancy: Had you been seeing a physical therapist or had your own physical therapist before the interaction with the pastor's wife?

Patient: I had seen a doctor. I had some lower back pain, and they called it a limp at the time. They were attributing it to maybe childbirth. I'd had my third child by then, and they wanted to do an epidural to block some of the nerves and the pain. I didn't have it done. My husband was in the military, so we moved. When we got to our new duty station and got settled in, I was going to try to continue care there, but she intervened before then. I just chalked it up to maybe gaining some more weight because I was always really thin before kids. I lost my ability to run. I was slowly noticing a few other symptoms, but not being knowledgeable, I just chalked them up to being fifty pounds heavier than I had ever been.

Nancy: Wow. 50, but it was a big change.

Patient: Mhmm.

Nancy: Wow.

Patient: Yeah. So I just thought my weight was causing some of my issues. Maybe I was too heavy for my body frame or something like that.

Nancy: Yeah. Wow. It's so interesting. Somebody attributed it to the birth. You're like, oh, let's just chalk it all up to childbirth.

Patient: Yeah. Yep.

Nancy: It's just a female problem.

Patient: Right.

Nancy: Wow. Okay. So how did you feel when you were diagnosed? What was that like?

Patient: It was a little bit scary. I didn't know much about SMA as a whole. I only knew what I had seen in our friend's daughter. I'll be honest. I didn't know much about it. So I had to dive in and try to research. Obviously, I was scared. I have three young kids. I'm married. What is my life going to look like? All those things crossed my mind. My biggest fear was, are my kids affected?

Nancy: Oh, what do you mean? Can you say more about that?

Patient: I was worried if my kids would have SMA.

Nancy: Oh, like, was there a genetic thing that was passed down to them?

Patient: Yep.

Nancy: And your friend's daughter, you said she had type zero, type one. Is she pretty severely impacted?

Patient: Yes.

Nancy: And that was your one example of SMA?

Patient: Mhmm. Yeah.

Nancy: So you were referred to a muscular dystrophy clinic. Is that what you said?

Patient: Yes. They referred me to a muscular dystrophy clinic in a city close to us, just to maybe get their insight on it and see if they could give me some more information. I took it into my own hands and pushed to actually see an SMA doctor.

Nancy: At the same place?

Patient: No. I pushed to go to Utah to see a specialist out there. That was the closest SMA doctor I knew.

Nancy: Without telling me your actual address, what state do you live in?

Patient: Currently, I'm in Alabama. We were in Kansas when all this was going on.

Nancy: How did you know about the doctor in Utah?

Patient: I joined a few SMA pages and heard that this clinic was well-known. I pushed my insurance to go out there because I did see the neurologist in Kansas. Well, two of them actually. They didn't really know much. Couldn't really give me much guidance. So I decided it was my right to see somebody who could maybe inform me a little bit more.

Nancy: When you say they didn't give you much guidance, can you say a little bit more about that?

Patient: I was being told things like live your life the best you can. I was told at one point I may end up in a wheelchair. While it's not horrible, to be newly diagnosed, not knowing what's going on, with three young kids, all these things are just spiraling. Like, what do you mean? Is there nothing to help me? Basically, go home and figure out the next wheelchair that you would like. That's what it's being presented to me as. It was a lot of, well, you're walking and you're moving. We'll see you in six months. We'll see you in a year. There was not a lot of, like, hey, try these therapies or do these things. It's we'll just keep watching.

Nancy: And you said you were on some SMA pages. Tell me about that. Did you go on Facebook or something?

Patient: Yeah. The one lady, whose daughter we knew, did a lot of research and found some pages. So I reached out to her. My husband and her husband were in the army together. I found some pages on Facebook. I don't recall exactly what the names were, and just got some information from there. At the time, I was told there were really no doctors that knew a lot about adult SMA. There was one doctor in Ohio that kind of knew a little bit about adult SMA, but I had heard there was a pediatric doctor in Utah, and that's where they sent me. I went to a children's doctor actually in Utah.

Nancy: And this is a neurologist who you were told was an adult specialist?

Patient: I think she is a neurologist. Yeah.

Nancy: How did that go when you met with her?

Patient: Very well. She was very insightful. I spoke to a dietitian there. They did some testing. I had by then lost my ability to climb stairs without a railing. But as they were testing me to climb the stairs, I could do it in her office. It's probably one of the most informational doctors I had seen. They broke down SMA for me, how they think I was affected, gave me more information about it, a better outlook. Here's some diet advice. Watch your calorie intake because you obviously are not as active as a normal human being.

Nancy: Okay. So I'm just gonna pause there. I want to understand where you're at now, and then maybe we'll fill in between now and then because it's a fascinating beginning story that you've told me. In terms of now, do you...

Patient: I have a neurologist that I see twice a year. I'm actually in the process of swapping, but I have a neurologist I'll see basically twice a year, every six months. That's more so because I asked to go every six months versus every year. And then just my primary care doctor.

Nancy: Why did you ask to go twice a year?

Patient: Just to maybe track my strength and things like that. Just to keep tabs on myself.

Nancy: It's interesting you're switching. What's your relationship like with the current neurologist? And do you have a new neurologist picked out?

Patient: I do. I just have to wait.