**qual test**

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Date: September 9, 2025

Time: 11:00 AM

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, we're like, can we really talk to each other for an hour and fifteen minutes? 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, ma'am.

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 at 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 and 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 though I think about HR as people-focused, 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. 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: The upsetting part of that story is that it wasn't part of the panel of original things that they tested you for. 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, did the neurologist even know when you said you wanted to get tested for SMA?

Patient: He was pretty open to it, but 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 before the interaction with the pastor's wife?

Patient: I had seen a doctor for some lower back pain, and they attributed it to maybe childbirth. I 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, and when we got to our new duty station, I was going to try to continue care there, but she intervened before then. I just chalked it up to maybe gaining some weight because I was always really thin before kids. I lost my ability to run and noticed 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 pounds is a big change.

Patient: Mhmm.

Nancy: So you thought your weight was causing some of your issues?

Patient: Yeah. I thought maybe I was too heavy for my body frame or something like that.

Nancy: It's so interesting. Somebody attributed it to childbirth.

Patient: Yeah.

Nancy: It's just a female problem.

Patient: Right.

Nancy: How did you feel when you were diagnosed?

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 had to dive in and try to research. I was scared. I have three young kids. I'm married. What is my life going to look like? 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, just part of processing it all.

Nancy: Like, was there a genetic thing?

Patient: Mhmm.