**qual test**

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Time: 3:00 PM

Nancy: How's it going?

James: It's going okay.

Nancy: You look so cozy in your blanket.

James: It's been getting colder.

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

James: Colorado.

Nancy: It's hot here today. I have to give you the same intro I gave you last time. Everything you say is confidential. I know your first name is James, but I don't know your last name. We're recording for research purposes. There are no right or wrong answers. I have more questions about treatment. If you mention a less than ideal experience on a medication my client makes, I might have to ask you a few questions about that and write up a report. Are you good with all that?

James: Yep.

Nancy: My brain is a little wobbly, so remind me of some basics. How old are you again, James?

James: 42.

Nancy: Do you live alone, or do you live with your parents?

James: I have a roommate at the moment. That's going to change in February.

Nancy: What's happening in February?

James: The roommate's moving out. My mom's moving back in.

Nancy: Is this where you moved when you came to Colorado?

James: This was my family's house. I had a fiance, and then they moved out so we could live here. That didn't work out. Then I have a roommate that turns me at night.

Nancy: Why is the roommate moving out and your mom coming back in?

James: Because my needs have elevated since then.

Nancy: Would you mind telling me a little bit about how your needs have elevated?

James: Just the natural progression of the disease. I got a cold a little over a month ago, and it affected me more than it should have. It decreased my swallowing capability a little bit. Even before that, my movement capabilities have been slowly on the decline.

Nancy: Sorry to hear that.

James: It is what it is.

Nancy: So you've been seeing a natural progression. Did it start a month ago, or do you feel like the progression started earlier?

James: It's probably been going on for about a year or so.

Nancy: What other declines have you seen in that year?

James: Mostly just arm mobility and muscle loss, which is expected with SMA, the atrophy of the muscles.

Nancy: Remind me when you were diagnosed with SMA, how old you were?

James: A year and a half.

Nancy: What have you been told about that? Do you know anything about how that went when you were diagnosed?

James: Well, it was a year and a half, so I don't remember much. But mom's told me they did a spinal tap and genetic testing from that, and that's how they knew what it was. They didn't tell her not to move me for a half an hour because the spinal fluid was low. So she picked me up, and I screamed my head off.

Nancy: Poor kid. Something she remembers maybe more than you do.

James: Yeah. I don't remember any of it.

Nancy: What are your memories about care from a medical professional in your childhood and younger adulthood?

James: Probably the earliest I have is maybe around five. We would go to Saint Louis Children's Hospital, where the MDA clinic was. I would see the same five or six different doctors, and they would poke and prod and test reflexes and muscle strength. It was just a yearly checkup kind of thing. I became friends with a few of them.

Nancy: Of the doctors?

James: Yeah. They would also run the MDA camp that I would go to every year.

Nancy: So you went to an MDA camp? How many years did you go to that?

James: Like, eight maybe, nine, something like that.

Nancy: How was that camp experience for you?

James: It was a blast. It was a week away from the parents, so that was fun. I made some bonds with counselors. I was a huge flirt back then, so I would always let the girls paint my fingernails so I could spend time with them.

Nancy: How old were you the years you went?

James: I think I started going when I was 11, maybe 12, something like that, and then up to when I was 19.

Nancy: What impact do you think that had on your life?

James: It was a good opportunity for me to see what it was like in the outside world. I grew up in a very country area, so there wasn't a lot around. It was fun just to be away from that. I was relatively social, so being around people that liked the same things I liked was great. My favorite parts were swimming every day and the midweek dance.

Nancy: Coming to the present, to what extent do you feel connected to any kind of SMA community now?

James: There's not really one here where I am. There was an MDA call center here for several years. I would go down and visit them and hang out. I sort of became their mascot. Whenever they had an event in the area, I would get invited.

Nancy: How did that make you feel being the mascot?

James: It was fun. I got to be around people.

Nancy: When was that you were involved with the folks at the call center?

James: Probably ten plus years ago.

Nancy: Otherwise, do you have any connections to the SMA community, like online or in person?

James: Not particularly. I'm still friends with my counselor. I had the same counselor for four or five years in a row. I'm friends with him on Facebook. We don't talk, but I see his life events.

Nancy: Does he have SMA?

James: No. He was a counselor, so he was able-bodied.

Nancy: Have you ever looked into or involved yourself in any of the online SMA stuff?

James: No. Not really. I find it more depressing than anything.

Nancy: Tell me about that. I'm really interested in that.

James: I've never particularly seen myself as disabled. It's just something that I live with. I find that is a unique mindset among the disabled community. Most of the time, they're like, "I'm so crippled. I can't do this and I can't do that." I'm like, yeah. And you've been that way your whole life. Talking and whining and complaining about it isn't gonna change anything. So I've never really found anything that would be worth my time to be a part of as far as Facebook groups or anything.

Nancy: That's really helpful for me to understand. Do you feel like people almost adopt a victim identity?

James: Yeah. Basically. And it's just not how I see it.

Nancy: How does it make you feel when you see some of the posts that people are posting on Facebook around SMA?

James: The posts I see are not usually around us. I follow a lot of content creators that have ADHD, but that's mostly because they also do Dungeons and Dragons or comedy skits. The couple of posts I do see on SMA are from a charity called Wheels Up. They're looking at making air travel more accessible for a wheelchair.

Nancy: How do you feel about that?

James: I mean, it would be great. I've heard dozens of horror stories of disabled people getting on planes and watching their terror get thrown in the luggage, and they get to their destination, and it's just destroyed.

Nancy: It's upsetting, actually. Are you interested in finding out information about things happening in the SMA world, like developments in SMA?

James: I don't really have a drive to. If I come across new information by happenstance, that's fine. But I don't go looking for it. It's not part of my daily routine. If I happen to see that there's been a development, then that's fine, but I don't actively seek it out.

Nancy: If new information about treatment happened to come across your screen, would that be something you'd actually wanna learn about?

James: If it's something I came across and it wasn't one of the four I already know, then I would be interested to see what the differences were. Unless it's like a miracle cure on the horizon, it's not something that I would consider taking.

Nancy: What are the other treatments that you know about?

James: Spinraza, Evrysdi, Zolgensma, and I've recently heard of another one, but I don't have it written down. Maybe it's only the three I know.

Nancy: When did you first hear about Evrysdi?

James: That was through Rare Patient. I took a survey, and it was one of the options. I was like, oh, I haven't heard of that one yet.

Nancy: What was your reaction to learning about it in the research?

James: It was good to see that they weren't just stopping with Spinraza. It was more accessible application. As I took more surveys, I learned more about it. Essentially, it's nearly as effective, I think, as Spinraza. It's just in a different form. Mostly, I was just glad to see that they were continuing with trying to find different ways of combating the disease.

Nancy: What did you think about the possibility of you and Evrysdi? Did that ever cross your mind?

James: No. It wasn't either one of those slower, halt progress kind of thing, and they never talk about side effects in the surveys. So the benefits didn't outweigh the potential cost in my mind.

Nancy: Can we just make a list? What do you perceive to be the benefits versus the cost of a treatment like Evrysdi specifically?

James: Well, I didn't know what any of the side effects were. I still don't really know. It's not a reversal. It's just a plug in the hole kind of situation. With my swallowing capability decrease, taking a pill is a bit more difficult than it used to be.

Nancy: Do you know what forms Evrysdi comes in?

James: I think it comes in a tablet and a liquid, I think.

Nancy: So the tablet might be difficult for you. Any thoughts about the liquid?

James: In a hypothetical situation where I was actually interested in taking the drug, that's the way I would choose to take it.

Nancy: What do you perceive as the potential benefits of taking Evrysdi for you?

James: In a hypothetical situation, I would need to know that there wouldn't be any side effects. Currently, as I am, not particularly.

Nancy: Why isn't stability good enough given that you're having some progression?

James: Because the chance of losing quality of life is an unknown, and I like to know the variables before I make that decision, all of the variables, or at least as many as I can. I'm not really afraid of death. So I kinda would rather live my life the way I want to live it and not be tied to and or have my quality of life affected by something that would drag out the inevitable.

Nancy: When you say losing quality of life, what would it like, how would taking a medication like Evrysdi specifically in your mind potentially impact your quality of life?

James: It depends on what the side effects were, what side effects presented while taking it. I think the liquid form needs to be refrigerated. That would be another thing to add to the list of if we were gonna take a trip somewhere, finding a way of keeping it refrigerated. If there was any interactions with alcohol or something, I'd I'm a wouldn't say an alcoholic, but I enjoy my drink every night.

Nancy: What is it about the potential side effects that makes you concerned?

James: Essentially, I like routine. So it comes down to if I take something that's gonna mess up my routine, it's going to mess up my entire day. Some of the side effects that I've seen that are possible are pretty unpleasant.

Nancy: Like, can you give me an example?

James: I think one of them was diarrhea, nausea, internal bleeding, migraines, headaches, something like that. The diarrhea alone is just not something that I can handle very easily or quickly.

Nancy: Are you aware of any other treatment that's in the pipeline that are potentially coming out?

James: I've gotten a couple surveys asking about product x kind of stuff, but I don't know any names of anything. So I assume there's at least one more in the pipeline.

Nancy: I guess they're doing research on a higher dose of Spinraza. Any thoughts about that quickly?

James: I mean, if it works for the people it works for, that's great. I think it also lowers the amount or decreases the amount of times they need the injection.

Nancy: Would you ever consider anything like a higher dose of Spinraza?

James: It's nearly always gonna be no.

Nancy: There's another medication being tested under the category of what's called an anti-myostatin that you have to take in combination with either Evrysdi, or Spinraza or Zolgensma if you're younger. It targets the muscles specifically.

James: I've heard of that. It's like a muscle growth or muscle enhancer kind of thing.

Nancy: What do you think about that?

James: It's a step in the right direction. In terms of me, if assuming for a second there were no side effects, and they could show me a mild to moderate improvement in motor function on someone around my age, then that would be a it would put it as a top of the list for me. It would at least put it on a list of this is probably something that I want to try to pursue.

Nancy: If it were something you would try to pursue, what would you want to take that anti-myostatin in combination with? Evrysdi or Spinraza?

James: Probably Evrysdi just because it would be easier, and I know I wouldn't have to leave the town to get it.

Nancy: If it did show, though, in combination with those two treatments that people your age tended to have mild and moderate mild to moderate improvement, what would you want or need to be able to actually feel good about pursuing that treatment option for yourself?

James: Insurance would be one of them for sure because there's no way that I could afford something like that. It would absolutely have to be covered by insurance.

Nancy: Are you on Medicare?

James: I am. No. Medicaid.

Nancy: It's probably joint. It's probably a dual program.

James: Probably. Although, I think it's changing at the end of the year. I don't know what's going on with insurance. I got a letter from an insurance agency saying that Rocky Mountain Health Plan's going away, and they're taking over the insurance. So I have no idea what my insurance is gonna do.

Nancy: I would probably want to talk to a peer, someone that is or has or was taking it, and talk about their experiences. And get honest answers, not fluff answers.

Nancy: Do you feel like if you spoke to the manufacturer, you would just be getting fluff answers, or do you feel like potentially you could get real answers?

James: It depends. I feel like if I was talking to a representative of the manufacturer that they would glaze over the downsides. They have a way of silver tonguing their way through things.

Nancy: Do you ever talk to your primary care physician about SMA at all?

James: No. Not really. I have a yearly checkup, but it is what it is. There's not really anything. I think he might ask, has there been any changes or anything? But it's not something I go in-depth with him about.

Nancy: If for some reason the primary care physician was actually someone who was a route to medication or a route to treatment, would that be of any interest to you?

James: Not entirely sure it would make that much of a difference. I use doctors as I need them, and they, in my opinion, tend to be bought out by the pharmaceutical companies anyways. So they push whatever they wanna push. If this treatment was covered by insurance and I was able to talk to a peer and get honest answers, I would go to somebody and pursue it. I wouldn't ask them for a recommendation. I would figure out who I need to talk to.

Nancy: So for you, the most trusted sources of information about treatment are peers. Do you trust any other sources of information about SMA treatment?

James: I mean, the raw data, but that can be cryptic sometimes. As far as information on the drugs, I would probably look at what the manufacturer had to say about it. But if I was talking to a representative, I'd be very skeptical of what they were saying.

Nancy: Was there anything else that you wanted to share? Was there anything about SMA treatment that you didn't get to share that you think was relevant to this conversation?

James: Not that I can think of. We went through a lot of this stuff.

Nancy: I learned so much. I was so excited when I saw your face. I was like, yes. I got to talk to you again. I love your sense of humor. Also, you mentioned Dungeons and Dragons. I was very excited to see that they now have stamps made by the US Postal Service, Dungeons and Dragons stamps.

James: No way.

Nancy: I may be the only person who still buys actual stamps, but I did find that out. And I was like, who can I share this with? You're my first person to share it with.

James: Well, if I buy stamps, I'll make sure I get some D&D things.

Nancy: It has been so helpful to talk to you, James. Thank you so much. I wish you the best with everything. We really are so grateful that you were willing to come back and put up with me once again.

James: Oh, yeah. No. There's nothing to put up with. You're a pleasure to talk to.

Nancy: Thank you so much. It was a pleasure.

James: Couple more of these, and we'll be close friends.

Nancy: Exactly. I'll be sharing with you all my recent stamp purchases. You'll be like, Nancy, this is so boring. Alright. Well, I hope you have a great rest of your day.

James: You too.

Nancy: Bye.

James: See you.