Interview Transcripts

# Interview with Sarah (Pseudonym)

## Selected Data from Pre-interview Survey

**Participant ID:** A-67

**Pseudonym:** Sarah

**Diabetes Type:** Type 1

**Gender:** Female

**Age:** 33

**Age Diagnosed:** 27

## Interview Transcript (Full)

INTERVIEWER: Hello, my name is Matt. Thank you for taking the time to talk to me today. Before we begin, do you have any questions about the informed consent form that you completed earlier?

SARAH: No, thank you.

INTERVIEWER: To be sure that we have an accurate record of today’s conversation, I am going to supplement my notes by audio-recording our interview, is this okay?

SARAH: Yes.

INTERVIEWER: Thank you. Today is March 26, 2015 at 4:30 p.m., and I am speaking with Sarah. Thank you for taking the time to talk to me today. I am going to be asking you a few general questions. If there is anything you do not feel comfortable answering or that you do not know the answer to, that is not a problem; just let me know, and we can skip that question.

SARAH: Excellent.

INTERVIEWER: First, in your own words, how would you describe diabetes to someone with no experience and limited knowledge of the condition?

SARAH: So, Type I diabetes is when your pancreas no longer makes insulin, and you need insulin to open up your cells to allow sugar to be processed by your cells. So if you don’t have insulin, your cells can’t process sugar, and basically you kind of end up where you don’t have any energy, and it affects your brain, and that sort of a thing. So you have to take insulin. They have synthetic insulin you can take, so you sort of have to operate as your own pancreas to administer insulin to yourself, to process food and to get energy.

INTERVIEWER: Thank you. You indicated you were diagnosed with diabetes six years ago at age 33...

SARAH: Yes.

INTERVIEWER: What do you recall (if anything) knowing about diabetes before you were diagnosed?

SARAH: I knew very little about it. So—yeah, I’d—Typically, in the past, it’d be something you’d be diagnosed with as a child or in adolescence, so I knew, you know, that it was something people had, and you had to take shots, but that was about all I knew about it.

INTERVIEWER: How do you recall feeling and reacting when you were first diagnosed with diabetes?What questions did you have?

SARAH: I was—First I was relieved because it explained a lot of the—unusual sort of feelings I had been having. The usual symptoms, you know.

INTERVIEWER: What were some of those feelings or symptoms?

SARAH: I was losing a ton of weight, I was going to the bathroom all the time, I was constantly thirsty—I had all the classic symptoms, and I was really tired. So, all of a sudden, all of that made sense. And yeah, it was a little bit of a learning curve. I had a lot to learn. But it was also—so yeah. It was unexpected, but not devastating, or anything like that.

INTERVIEWER: What were some the questions you remember having when you first learned you had diabetes?

SARAH: My first question was, so what is the treatment going to be? Are there any, sort of, long-term negative effects? Those were sort of the main—the main questions.

INTERVIEWER: What did you learn about those questions? The treatment and any long-term negative effects?

SARAH: I learned that it’s pretty easy; it’s a pretty treatable disease. And basically, you have to learn how to manage how much insulin you need to take based on your food, so you learn how many carbs—you have to learn to count how many carbs are in any meal you eat. Basically, you also learn it’s very treatable and that you just—if you eat a healthy diet and exercise, it’s pretty easy to keep a handle on. It’s not a particularly disruptive disease, at least in my experience. And then, long-term effects are if you don’t take care of it—yeah, you’ll have long-term effects. You can go blind, you can get neuropathy where you can’t feel your fingers or toes, and that can be dangerous if you don’t take care of it. Basically, it’s just a disease you need to keep on top of.

INTERVIEWER: How do you learn to do some of the things, like counting carbohydrates?

SARAH: So, there’s all kind of books that you can get that give you the carb counts of basic foods, fast foods, those sorts of things. Then you just get really good at reading labels. Luckily, there’s labels on pretty much everything. And then, after a couple of months, you pretty much—I’ve discovered most people eat the same things most of the time. When you’re not eating the same things, you can always look it up, and there’s all kinds of apps on phones now, and stuff. So it’s pretty easy to look things up and develop a sort of working knowledge of how many carbs there are and stuff. It takes time. It’s doable.

INTERVIEWER: You mentioned maintaining a healthy diet and exercise. Are those things you have to make changes in your life to accommodate?

SARAH: No. I was already pretty good about getting exercise, and then, like everybody else, I go through phases where I’m lazier than others, but on the whole that wasn’t necessarily a big change.

INTERVIEWER: Going back to how you learned about diabetes, what sources did you learn about the condition from? Where did you learn about diabetes once you were diagnosed?

SARAH: So, when I got diagnosed, the doctor’s office and the hospital gave me a big pack of, you know, “Your first year with diabetes.” “Tips about diabetes.” There’s a lot of great websites. The American Diabetes Association has a great website. There’s a—Shoot. I think it’s called Juvenile Diabetes Research—has a really good website. And they refer you. They have all kinds of exhaustive lists on information from the website and books you can read. And then there’s—American Diabetes puts out a magazine called *Diabetes Forecast*, and you can get all kinds of information there. Finding information was pretty easy.

INTERVIEWER: How many of those resources do you think you actually looked at when you were...

SARAH: Did I look at? A lot of them, just because I’m academic, so you know, I do the research. So, I would say for sure the American Diabetes website and the one that starts with a “J” that I can’t remember off the top of my head. And then there were a couple of really good books. I looked at one that had a really good title called, like, *Being Your Own Pancreas*, or something like that. And then there’s a *Diabetes for Dummies* book. My mom also loaded me up with books. So, yeah, I had no end to books. In fact, there were almost too many of these sources. You reach a certain point where you—they’re all sort of repeating the same things and answering the same questions.

INTERVIEWER: Actually, brings me to my next question. Do you ever recall receiving conflicting information from different sources?

SARAH: Nope. It was pretty consistent across the board. The thing I found to be wary of were there’s a lot of websites I found that were support group websites where you’d get people talking their own experiences, and sometimes those could get a little questionable, sometimes. Again, those are just individuals, not doctors, talking about it, so I kind of steered clear of some of those. But yeah, on the whole it was consistent, reliable, and yeah.

INTERVIEWER: In your experience, how much do people who do not have diabetes understand about the condition?

SARAH: I find it varies. It’s a little bit confusing because there’s Type I diabetes and Type II diabetes, and there’s not a lot of understanding what the difference is. To be honest, since I don’t have Type II, I’m not sure I even understand Type II, though Type II is often caused by, you know, if you’re overweight, or you don’t exercise, or you’re older. That’s where Type II is more associated with that. So there’s confusion that there are different types, and some people think that if you have diabetes you can’t ever eat any sugar. That seems to be the other big misconception. You can eat sugar. You just have to dose, give yourself more insulin if you eat a lot of sugar. And yeah, like any person should be eating a ton of sugar anyway. So that seems to be the main—I think people know more about it, but what they know about is Type II, which is different from Type I.

INTERVIEWER: What are some different ways that people react if they find out you have diabetes?

SARAH: They’re usually afraid about dietary restrictions, or they don’t want to give me something that I can’t eat. That’s usually the reaction I get. “I’m so sorry. I served you dessert with dinner.” But, yeah I’m pretty—I don’t have any food restrictions. I just have to just know how many carbs are in something, so that’s usually the main concern.

INTERVIEWER: How do you respond to these reactions?

SARAH: I usually just try to put them at ease, you know. It’s ultimately my responsibility to take care of it, not you. And if I eat sugar I’m not going to die, so that kind of thing.

INTERVIEWER: Since you were diagnosed six years ago, are there any ways in which diabetes has affected the way you live your life?

SARAH: Yeah, I just have to be more aware of what I eat, is the main concern. You know, the main thing you have to be worried about is having a low blood sugar. That’s when you can have effects, and that can affect your driving, and it can affect your judgment, and that sort of thing. I just have to make sure I always have a snack in my bag to ward off—luckily, if you have a low blood sugar, all you have to do is eat something with carbs in it, so it’s really easy to treat. Those would be sort of—yeah, being aware of food, and always having a snack.

INTERVIEWER: Have there been any other tangible tasks that are part of your life that weren’t before?

SARAH: Yeah, again, it’s mostly just I have to be aware, double check my blood sugar if I’m going to go exercise really strenuously or if I’m going on a long roadtrip, or something. It’s just making sure I check my sugar level.

INTERVIEWER: How do you do that?

SARAH: You just stick your finger and draw some blood. And then you’ve got this blood sugar reader that you have to test. So you’ve always got your little testers with you. So, I guess you have to be a little more organized and aware, which is a challenge for me as a disorganized person. Again, it’s a pretty manageable disease.

INTERVIEWER: Do you imagine that your life would be significantly different if you didn’t have diabetes, or do you think that it would be fairly similar?

SARAH: It would be pretty similar. The one thing it does is that it’s another kick to the butt to eat healthy and be active, and that sort of thing, so I’m probably better about that than if I didn’t, but I wouldn’t say it’s super—that it changed my life in radical ways.

INTERVIEWER: Is there anything you think the general public does not know about diabetes, or living with diabetes, that they should?

SARAH: I think it’s probably good to know about the dangers of having a low because sometimes if I’m having a low blood sugar I can’t always tell. The people who I spend a lot of time with, if I’m going on a trip or something, I’ll usually alert them to what the—but I don’t think that’s something the general public needs to know. Type II diabetes, it’s more important for people to have an awareness of, you know, not eating a lot of sugar and trying to be generally active, and I think with Type II it’s a lot more important because that’s something—No one knows what causes Type I. It’s sort of luck of the draw. It can’t be avoided, but Type II can be avoided. So that one I think is a little bit more important for the public to be aware of.

INTERVIEWER: Is there any specific information that you think would be useful for people to know?

SARAH: And I think it’s stuff that’s out there already, you know. Like, don’t eat a ton of sugar, and, you know, try to be active. All that sort of stuff that goes with being a healthy person. And I think that there’s—I think that people have a pretty good awareness about, you know, that those are things to avoid. So yeah, once you get Type I, if you get Type I, it’s pretty easy, like I said. It’s pretty easy to educate yourself about that.

INTERVIEWER: Thanks very much. My last question is: is there anything else you would like to share about diabetes?

SARAH: No. I guess it’s more of an issue with little kids who have Type I diabetes because, once again, there are so many other factors that come into play with—Again, if you’re teaching or babysitting or something, just knowing how to treat a low, or things like that. Those things are more important with little kids because at a certain point you’re old enough where, you know, it’s your own responsibility, but where you’re a kid I think it’s, maybe a little bit, you’re not entirely responsible for all of the things that are happening. That’s a whole different ballgame. Not one I really have experience with. I don’t have kids with diabetes. I can just imagine it’s a tougher ballgame. That’s probably it.

INTERVIEWER: Thank you so much for taking the time to talk with me today. I and everyone on our research team really appreciate your help. If you have any questions in the future, please feel free to contact us using the information on the paperwork we gave you earlier. Thank you again!

SARAH: Thank you.