

EPISODE 14: A REAL PATIENT STORY WITH JOANNA

Rita Kalyani, MD: Welcome to *Diabetes Deconstructed*, a podcast for people interested in learning more about diabetes. I'm your host, Dr. Rita Kalyani at Johns Hopkins. We developed this podcast as a companion to our Patient Guide to Diabetes website. If you want a trusted and easy to understand resource for diabetes or to listen to previous podcasts, please visit hopkinsdiabetesinfo.org.

For today's podcast, we are thrilled to introduce Joanna who will tell us her story of living with type 1 diabetes. Also joining us is Caitlin Nass. Caitlin is a certified registered nurse practitioner and is a Director of Intervention for Diabetes Self-Management Training Programs, [a] diabetes prevention education program at Johns Hopkins. Caitlin is also a member of Joanna's healthcare team. Welcome, Joanna and Caitlin.

Joanna, a patient with type 1 diabetes: Thanks for having me.

Caitlin Nass, MSN, CRNP: Good afternoon. Thanks so much.

RK: Caitlin, I wonder if you might want to kick off the conversation with Joanna since you've been working together so closely for so long – in terms of Joanna's story and how the experience has been living with type 1 diabetes.

CN: Terrific. Thank you. So Joanna, I was reflecting... I met you just about five years ago when I joined the Diabetes Center. But I know you had been a member of the community for much longer than that. I wonder if you could talk to us about some of your journey and your work with us?

J: Yes, I've been with Johns Hopkins for a while. And I've had one of my endocrinologists moved on to do another project and I had to find a new one. I have to admit, I went through a couple. Someone said to me, "I know who to put you with." And I had my first appointment with you and I was like, "That's it. That's my endocrinologist" and truthfully, I've been doing well ever since. And I think that's part my hard work and part your hard work.

CN: That is lovely for you to say. And I would say 100% your hard work. I remember being struck when I met you – just how diligent and focused and conscientious you are. I said something, "Oh, it looks like you always use the bolus calculator on your pump." You're like, "well, why wouldn't I? It's technology. It's going to help me." <chuckles>

J: I remember that. <chuckles>

CN: <chuckles> You're working hard using all your energy and smarts and you get great results for yourself. And then you also had a special connection with one of the educators over the last several years.

J: Gene Arnold, my nutritionist...

CN: Yes.

J: Who you suggested I should go to and I said kind of, “well... okay fine,” because you know in my mind, I knew everything I need to know. It was a good decision to go. He's really helped me a lot. I eventually got a diagnosis of gastroparesis, so I had to rethink my diet. And basically, everything that I'd known about eating for diabetes got flipped around. Like, no, you don't necessarily want the brown rice, you might want the white rice because by the time it digests, it's not going to give you that spike that it gives people without gastroparesis because it's not digesting immediately. And I just had to rethink things and gave me some things to get my digestion going. And but I still know... and he was like, just kind of like, “looka here.” He was much nicer about it than that. And he's like, “this is what you're going to need to do. And I can help you tweak it. But this is what it's going to be. I know it's difficult for you. But it will get easier when you see the results.” And he was right, of course.

CN: I think one of the things that really strikes me because coming to Hopkins was really when I started to work with a large number of people with type 1 diabetes which is very particular and uniquely challenging. So I'm meeting people who've been managing their condition for 10, 20, 30 years. And I realized the most important thing out of that first visit is trust because you are the expert and until you know that you can count on me and that I'm listening hard, I don't expect you to take my advice. I think I did push on the Gene question <chuckles> only because I was so sure that he had that knowledge set that you needed, and but I know that trust was really what got you to the next level with him as well. We have to earn it.

J: I've had type 1 diabetes for 37 years. It will be 38 in November. So pretty much most of my life. Having someone who can back you and when you're not where you're supposed to be... You're not punished. You don't feel like you're being attacked. You don't feel like you're being a bad person. Because you know, I feel like that myself sometimes. And I come in and I'm like, “it's just not right.” And I come in and I'm kind of sulking and by the time I leave, I'm smiling, and I've gotten a pat on the back and some instructions or you know, some advice I can work with. So I felt like I had a cheerleader in you and that has made all the difference.

CN: That's terrific. I know that you do more to care for your health by lunch than I might do in a week or a month. I have nothing but respect. The last thing any healthcare provider wants to be is a negative voice in your head. But sometimes we let our worries intrude on the relationship, and people come away feeling judged, and that's definitely on us.

J: I had one before that I was so excited, my A1C was down and I was so proud of myself. I was excited. And she began speaking to me, and was like, “well, we need to get that down because you know, 14% of blah, blah, blah, blah, blah... and 70%...” and started spouting off these statistics about complications and this, that and the other. And I was like, “Oh, that's not happening anymore. I can't do that.” When I'm proud of myself, I need you to say, “Yeah, that's awesome. It's down. Now maybe what can we do to help you get it down even further?” As opposed to saying, “That's not good enough,” which is what my brain heard at the time. And it's discouraging. Yes, there are technical things you have to do. But diabetes is a mental game, too. When you're down – besides the fact of being depressed and stressed out can affect your

blood sugar – when you're down, you're just not motivated to take care of yourself like you should. And no one should have to experience that.

CN: That's one of the things that's so interesting and challenging to me working with people with diabetes... the science is just a piece of it. And so much of it is about communication and understanding a person's motivation and self-care behaviors and self-care beliefs. You know, you've been dealing with this for such a long time. How do you ride out these challenges? What are the tools that have helped you sustain this concerted effort day after day?

J: Encouragement. I belong to a Facebook group. There are people there and people will say things like, “Who's had surgery for a detached retina? Or “Does anyone else have ‘frozen shoulder,’” or different things. And some people will complain and need encouragement. We celebrate our diaversaries; everyone congratulates each other. There's a lot of encouragement. There's some real talk like, “Get it together, man,” “Pull yourself together.” <chuckles> So having people who know... because things start going wrong sometimes no matter how well you take care of yourself. You start to think it's just you and then you find out oh, wait a minute, these musculoskeletal problems... that's kind of typical. People do have that, or they have this or they have the other. You realize you're not alone and you're not weird and there are people you can talk to. You know, I'm a firm believer in having a team.

CN: Yes, no doubt. It really struck me there are many patients that I work with who don't know another person with type 1 diabetes. That'd be like living in another country and no one speaks your language is how I think of it. And you have a real need to connect that you've described for yourself, just as you just explained about this Facebook group. But you also feel a need to connect with others to try to help and to reach others. You shared a beautiful essay that you wrote recently that you wanted to put out into the world. And that's, of course, why I thought it would be wonderful to have an interview with you that you could share to the community, as well.

J: I used kind of hokey sports reference, but it is about creating a team of professionals and others. I feel like you need a good endocrinologist. You need a dietitian or nutritionist. These are the three minimum.

CN: This is the core team.

J: Yes, this is a core team. This is the... what do you call it... the ‘A String’, And you need what I call a ‘person’. Someone who understands you, somebody who will walk it with you, someone that you're so close to about it that they can tease you and you don't get offended. I always say, “My husband is in it with me.” We'll be talking and he'll say, “What's your sugar, Sugar?” It's silly, but it just warms my heart that he knows that this is... that he *feels* that this is *our* journey. And so it can be a friend, it can be a family member. You need at least one of those people. And then you need to get your diabetic eye exam. So you know, keep up with cardiology, podiatrist, and those sorts of people that you can add on to your team. But you really got to start with those three, because this is really not something I feel like you can successfully do alone. There are too many moving parts and changes.

CN: No question, and you mentioned that, you mentioned, “I can be consistent and get different results.”

J: Yeah.

CN: And for a long time you thought that was a mistake you made – maybe a miscalculation – as opposed to having to ride the wave of the challenges of type 1, which are so unique. And that's why I was grateful that you were open to seeing an educator because as long as you've had it and as much as you know, you're at a different place in your journey. As it turned out, there was a stomach issue that was aggravating things and making extra challenges for you. I feel like everybody needs that support that you described. That's why I was so moved by your... you know, ‘Who's On Your Team’ essay because I can't imagine asking people to do this alone. I always tell people, “I want to see you every three months, no matter what. If you're doing great, it can be a short visit. If you're really struggling, we'll dive in. If you're on the cusp, but you for all the work that you do every day, you deserve that minimum level of support.” And if so, for a lot of people, their spouse isn't the person. It's different. Everybody's... you know, the boundaries and what's safe and like you said, to have someone you trust enough to tease you when you've probably been teased before... that that's very different than what every family member can do or provide.

J: Another thing I've done... I've collected anecdotes from people in that Facebook group about the horrible things people have said to them – the stupid, the mean, the ignorant, the ugly – and I've made a slide presentation that I'd like to eventually... I haven't gotten up my nerve to do it but I want to do like a little interactive webinar kind of thing on that. But you'll just be shocked at some of the things people say. Like we've always heard like, “Oh, I don't know why you don't you know, if you just eat cinnamon every day and eat exactly five goji berries, <chuckles> you will... you won't have diabetes anymore.” Or people say “Yeah, my grandma's cat had it and she went blind and died.” Thanks...

CN: Yeah.

J: I appreciate it. “My aunt just takes a pill and goes on with her life. I don't know why it's such a problem for you to deal with it?” They just don't get it. Or the ones we call the ‘Type 0s’. People who do not have diabetes but are complete experts on it; they know everything there is to know, they know better than you.... Yes, we call them Type 0s. We have our own language.

CN: Yes, apparently, apparently.

J: We terminology for different things. Yeah.

CN: This is inside baseball that we're getting today, Dr. Kalyani? <chuckles>

RK: Joanna, I have to say, I haven't heard that term before. Type 0s...But thank you for sharing that inside scoop. I'm sad to hear that people will sometimes say things off-handedly – not really thinking about the impact it could have. Have you ever felt discriminated against because of

your medical condition for having type 1 diabetes? Or it has it held you back from doing things that you've wanted to do?

J: Yes and no. There was a time when I was interested in possibly the CIA or different groups or police department. And they generally... I don't know if laws have changed now or the rules, but they won't take you. I was very interested in the Peace Corps. And naturally, it makes sense. They're sending you into a hardship location where back then you really need to keep your insulin refrigerated. And if the local temperature's 110 degrees, and there's not a refrigerator or ice, you can't do that. So I understand that it's a liability. So it does provide some limitations, it has. I find almost every time I go to the airport, I have trouble because there are lots of Type 0s running around. You cannot or you're not supposed to go through the X ray equipment with a CGM, continuous glucose monitor, or your insulin pump. So I tell them, I need a pat down. I have an insulin pump. "No, it's okay, you can go through" "No, I can't go through." "Yeah, you can. People do all the time." Well, if you've got about \$10,000 to replace this, I'll go through. And then they say I'm being uncooperative, and they get an attitude and sometimes I have to pull out my blue paper saying that I cannot go through and I keep a note from Caitlin saying that I have to carry these supplies. But it's really frustrating. What makes you think that after my 37 years, you know more than I do about my health condition and my equipment? It makes no sense. But it's a struggle every time and I think that's why a lot of people just risk it and go through. They don't want to be bothered with it. But I'd rather not be wherever I'm going that's not home, and have a pump that's not working in a potentially dangerous way. I'll just have to get frustrated and they'll have to learn a lesson.

CN: Yeah. But especially because you present yourself upfront. "Here I am. This is what I need. Here you go. Here's the documentation." So you're doing everything you can to help people come towards you, right? And recognize and understand what you need. You do a tremendous job with that so that's got to wear you down.

So speaking of pumps and sensors, you've used a couple different combinations over the years and it's been quite some time now that you've been on one. Can you talk about the difference with the current pump that you have or just the difference when you went from injection to a pump use because I think that's something a lot of people navigate and have to think a lot about. That's another leap of faith.

J: Life changing. Game changing. I'm sure there are good reasons people still like to use syringes and give injections, but I just don't know what they are. Everyone knows diabetes is a 24/7 job; it's never not present. But I thought my first pump was game-changing just because I wasn't giving injections and it made adjustments and things.

The one I'm on now I adore it. If they call me and said, "Would you do a commercial?" I'd be like, "Yes, yes, whatever you need, I will do it." It's been accurate. It doesn't beep at me all the time. And it takes the guesswork out of everything. I'm not gonna lie, I had a rough time transitioning to this new CGM and pump because I didn't have to prick my fingers. And for 36 years, that's what I had to do. And when I was being really conscientious, that could be God knows how many times a day and in the middle of the night. And I didn't know what to do with myself. I felt like I was being bad. Like I was not taking care of myself even though the pump

and the CGM were telling me everything was fine. I just felt like I was not doing the right thing. And it took me several weeks to adjust.

CN: I remember you talking about that.

J: Yeah, it was a real adjustment. Now it took a couple of weeks and now good. <chuckles>

CN: <Chuckles> No looking back.

J: No. And you know, if it asks me – which is very rare – if it asked me to calibrate, I calibrate or whatever. Or sometimes if I'm scared, it might be off, or I'm not feeling where it is...

CN: Yep.

J: I'll check to see but this five-, six-plus times a day... not happening. And you get a huge chunk of your life back.

CN: Yes. Yep.

J: It's amazing. You get... I don't even want to think about how much time I've lost or calculating how much insulin I should have or whatever. You need to know about how many carbs you're eating and that's all you got to know because it does the rest for you.

CN: I still know that you're working hard <chuckles>. Not to contradict you.

J: No, I am. I'm working.

CN: Absolutely. But I thought as a bystander, I thought about that, as you were describing letting go of finger sticks. It's that vigilance had been so necessary for so long that it wasn't just a switch that you could turn off. It was a huge emotional and psychological adjustment – for the better, which is fantastic. But I think that's what I tell people I said, “It's not just time that it can potentially open up for you in every day, but energy and focus that a little bit of that diabetes workload is being picked up by the technology. And then maybe you can just focus elsewhere and glance at that sensor and feel a little bit lighter.”

J: Now that I think about it, people who do not want to use a pump or a CGM... I think that loss or loss of control might be too much change. You don't always feel in control with diabetes because you're just not. I don't care what your A1C is. Sometimes, it's going to do what it wants to do. And it has nothing to do with you not being vigilant and doing what you're supposed to do. And when you let a pump or a CGM control those parts there is a loss of control. So you want to see, “Well, what is it doing? Well, what does it saying? Well, what is it?” You know, when you first start because you got to trust that this piece of machinery is not giving you too much insulin or is not malfunctioning or knows which way your blood sugar is going so it knows to scale back on your bolus or whatever that may be. And that's a real trust issue. I know, I think I may have let you touch it one time. No one touches my pump. That's like asking, “Can I hold your pancreas a second?”

CN: Not a chance.

J: No.

CN: Not a chance.

J: Hold my... did I ask if I could hold yours? <chuckles> No, it's the same thing. And most of the time, it's people who don't know what they're doing and they want to start pressing buttons on your pancreas. No, thank you. Yeah, I've had some choice words with people about that, you know, for different... if I was in the hospital for procedures or things and I'm like, "I control this. This is what's gonna happen." And they're like, "Well, let me see that." No, no. And I had to sign-off that there I have it or you call my husband to come in and do what he needs to do and sign-off that I'm responsible for whatever happens because you know, there are various settings for carb ratios and all sorts of things. You mess that up. I may never find it and know what's going on. Trust issues are real.

CN: It's so interesting the two sides that you described in terms of the challenges for pump – both for yourself and for other people. So one hand was, "Well, maybe I'm not working hard enough. And maybe it's cheating if I'm not testing my sugar four or five times a day." And on the other side, you're imagining people who are thinking, "I'm not going to trust that thing to do the job that I've done. I do my own math. I need blood to know that that's a real sugar. Nothing else will compare." There's so much like you said to the psychology of all this, and trying to figure out where you are, what questions you need answered, what would it take for you to be ready to take another step. You know, something that sounds interesting, but "mm. . . it's not what I've always been doing"

J: It was very difficult for me changing from one brand of pump to another. There's a learning curve because they're completely different. And as I was doing well enough, on the old pump, I was working way too hard to get the same result I'm getting now or I could be getting... actually, I'm getting better results. Actually, when you asked me if I was tied to my pump, I'd been thinking of doing different things. I was going to ask you at the next appointment what you thought about changing. So when you brought it up, it sounds to me like you didn't think I was gonna say yes. I'm so glad that you spoke to me about it so that I can try things out and see what I want to do. And it worked out well. It was a good decision. It's easier for me to manage. Plus, it's... the finger stick removal is revolutionary. And I trust the CGM I have more.

CN: Yeah, that was... Those are careful. It's like you don't give people opinions about their new boyfriend. <chuckles> You saw me coming.

J: I did. But it was at the right time. Because apparently, we were both thinking the same thing. But it's kind of like I said, your pancreas is like...so [are] we getting a transplant or what are we doing with this? It's a delicate procedure, redoing all of your settings and making decisions. But I can't stress enough how much it was worth it.

RK: Joanna, I wonder if you might provide us some background about your diabetes. When you were diagnosed? And I know it's been some time but how has that changed over time in

terms of the therapies that you've been on. I know the pumps you talked about. There's been many different models and [they're] game changing. What was it like when you were initially diagnosed? How has it changed?

J: So it's been 37 years, so I just turned nine. And I was diagnosed a few days before Thanksgiving that year. The good news is I was not very sick. Like I'd stayed home a couple of days. I was tired. My mother knew the signs. And my dad knew the signs. They decided I should get . . . I mean, they knew I was tired, a little grumpy and I was drinking a lot and going to the bathroom a lot and I'd lost a good amount of weight very quickly. But I went to the doctor, [he] checked me out and I thought he was gonna cry. He's a fabulous doctor. He said, "She's got diabetes. Take her home. Pack her bag. She's gonna be in the hospital probably about a week till we can get her settled. I'll call ahead let them know you're coming" and that sort of thing. So I don't know what my blood sugar was at the time, or my A1C or whatever. Clearly, it wasn't that bad, or he'd have sent me immediately, you know, by ambulance or directly to the ER. And my mom took me to my favorite pizza place. And she actually let me have a pizza sub. I love their pizza subs. So she let me have like half a pizza sub and I had my first Diet Coke. I don't know why I remember these little tidbits. But I had my first Diet Coke. And since I wasn't a soda drinker, it didn't taste strange to me. I was lucky that I was young enough that it didn't... you know, it wasn't a huge change. And we went to the hospital and I guess I was a little precocious because they did gave me my first shot. And after that I did all of them. And no one has ever given me an insulin injection. And they taught me about... back then it was the exchange like the car.

CN: For eating?

J: The food exchange...

CN: Yes, the food exchange. Sure.

J: And calculating my insulin and all of that. And so I was in maybe a little less than a week but I was blessed not to be sick. I didn't pass out. I wasn't in danger of anything. So that was a good experience. And my parents were wonderful. They should have taught a class on this: how to help your kid feel normal. I had no idea until I was an adult that they would get up in the middle of the night and see if I was breathing or check on me.

CN: Sure

J: And do those kinds of things because they acted like pretty much like nothing had changed. My diet changed a little bit, you know. But they didn't treat me any differently. They didn't hover. They let me take care of myself for the most part. And my dad said he remember talking to my first endocrinologist, you know, I had when I was a child. And she said, "You have to go to sleep. You're not going to be able to help her or be there for her if you're exhausted. Joanna will wake up if her blood sugar is low." And knock on wood, I always have. So he started to relax. But they never let on one bit that they were terrified.

CN: That's amazing.

J: And that helped me a lot. So I didn't feel... I never felt weird, or like I wasn't like the other kids or like I couldn't do the things I wanted to do. That never crossed my mind. I know people now I'm like, "Your child's 14 years old. Why aren't they doing this, this, this, this, this, and this?"

CN: For themselves?

J: No... yeah for themselves. It's not a good look. And they're gonna have a rough transition when they go to high school, have more freedom; or they go away to college, and their parents aren't planning everything for them or fixing their food. Yeah. So I was lucky.

CN: Did your... either of your parents work in healthcare? Or did anyone else in your family have diabetes? They seemed so insightful right out of the gate.

J: So my uncle had type 1 diabetes. He was diagnosed kind of late with it. So I don't think my mom was living with... still living in the house with my grandparents and him at the time, but she knew about it. But he lived in St. Louis and we would talk all the time. And I would say, "Well, we're twins." You know I was little and then about a year after I was diagnosed, he had a pancreas, kidney transplant. He rejected it and he didn't make it. But I think just from knowing what he went through, my mom knew something's not right. My child's not right. And I hope this is what it is. But I know what this is what it is.

CN: So she went in eyes open, and then she and your dad were able to go with it. And yeah, I mean, I think all of us are sitting around here on this conversation, as adults are thinking, "Of course, they were terrified." And that they could allow you to not see that and to just shine yourself and go through the process yourself.

J: Mm... My dad's a college professor, so he couldn't kind of take off. But it occurred to me a month ago, I came to the realization when I was in fifth grade, my mom came to work at my new elementary school. [She] was in another classroom. It just occurred to me like a month ago, I'm like, "She came there to spy on me." <chuckles>

CN: Of course, she did.

J: Like I had never thought about it because when I was diagnosed, she decided to take the year off just to... you know, she would sometimes bring me snacks at school, or she would come in, instead of leaving my blood sugar equipment, which was a big old thing that folded up and down back then.

CN: Oh boy. Sure.

J: Yeah, it was a big monster. So she would come in every day and you know, in fourth grade and do that. But in fifth grade, she gave me the independence but somehow she showed up to help out. Um I think... was she working in this Special Ed classroom doing something not in her field at all? And I just figured it out.

CN: All these years later?

J: Yeah. Yeah, that she really had come to spy on me just to make sure I was okay.

RK: Look, Joanna, it's been so great to hear about your learning as a child, the realizations that are still occurring, even as an adult. <chuckles> The tremendous role that both your family and Caitlin as your healthcare provider, a central part of your health care team, has had in ensuring that you're thriving the way you are today. And in parting, what would you say to any of our listeners who have been newly diagnosed with type 1 diabetes? What would you say it's been like to live with this disease?

J: Challenging, but when you do something – when you're doing well – you can probably guarantee that you're healthier than most people. You got your diet under control, your blood sugar, your blood pressure... but I would say, don't hesitate to create your team. Get your lineup. And if someone's not working for you, or you're not comfortable, switch 'em out. You don't have to be nasty about it. But you have to have people that you are comfortable with and that see you... Yes, they know you're diabetic, but they also recognize that you're a human being and a person. And I know Caitlin always asks, “Oh, so how's the new job going? Or you and your husband have vacation plans?” or remembers that I'm more than my blood sugar. I think that's so important. Don't give up. Find your people. Life with diabetes is manageable. It's harder sometimes. It's easier sometimes. But you can do it. I'm still here and I'm planning on, you know, if I have anything to do with it, the diabetes isn't gonna get me.

RK: Well, thank you so much, Joanna, for sharing your candid experiences and so great that you've been able to find your person in Caitlin. And Caitlin, thanks for sharing the excellent care that you've given to Joanna and it's been so great to hear about the relationship you all have had over the years – how that health is key to Joanna to thrive as a central part of your healthcare team. So thank you. Thank you both for being here.

CN: Thanks so much

J: Thanks for having me. It's been fun.

RK: I'm Dr. Rita Kalyani, and you've been listening to *Diabetes Deconstructed*, a companion podcast to the *Johns Hopkins Patient Guide to Diabetes* website, which has all kinds of useful information about diabetes, including videos and animations, a lifestyle and nutrition blog, and a comprehensive diabetes glossary among other topics. For more information, visit hopkinsdiabetesinfo.org.

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