

EPISODE 11: A REAL PATIENT STORY WITH JOE

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.

Today, we are thrilled to welcome Dr. Tom Donner, an Associate Professor of Medicine at Johns Hopkins University and the Director of the Johns Hopkins Diabetes Center. With Dr. Donner today is his patient, Joe, who has graciously agreed to share some of his experiences living with type 1 diabetes and some of the tips, tricks, and technology he's been able to use to help him manage his diabetes. Welcome, Dr. Donner and Joe. Thank you both for being here today.

Tom Donner, MD: Rita, thanks so much and Joe, thanks also for joining us today. We're going to focus today predominantly on diabetes technology. But I think it would be nice to hear, [and] put things into perspective as to when your diabetes was first diagnosed, how you learned about diabetes, and also how your diabetes was first treated? Could you share that with us?

Joe, a patient with T1D: Sure. And thank you, Dr. Donner, for inviting me to participate in this podcast today. I always find these to be very informative. And I hope that that's what will come out of the one that we're doing today. Yeah, I'll be brief, but I think it's important. Diabetes juvenile type 1 occurred with me in 1974, when I was 19 years old. Diabetes has been through the maternal side of me, my mother and my aunts, my uncles all had diabetes and I thought I would be able to escape it. I've been very active my whole life, not a bit overweight, not a real big sweet eater. And yet, I ended up in a summertime after a trauma to my body triggering off the diabetes, lost a lot of weight, and was diagnosed with diabetes. 48 years ago, it was tough getting accurate blood sugar readings, they were difficult to obtain, and effective treatment really was dependent on my knowledge of diabetes and methods to accumulate data, see patterns, figure out trends – they just weren't there.

TD: So Joe, how did you manage your diabetes after it was first diagnosed? How are you assessing your blood sugar levels? How were you giving insulin back then?

J: Yeah, that's a great question. I remember as an older teenager, 19 years old, being signed up to go to diabetic camps, which were really big back then. And the whole idea of a diabetic camp was to learn how to get basically one large dose of morning insulin (I think back then they called it NPH), but it was long-lasting insulin that would cover the peaks for lunch and dinner. And you basically had to build your schedule around the delivery of that insulin [and] new blood sugars to be able to kind of tweak that and take additional shots where you ate. I did learn to count carbs back then, and also learned what foods groups were friendly for a diabetic and which weren't. It was not what it is today.

TD: Joe, were you doing fingerstick blood sugar testing when you were first diagnosed at that point?

J: Funny, you should ask that. I actually remember peeing on strips that would always be yellow. You would never get an accurate reading through the strip. I eventually moved to pricking finger and doing probably four to six checks a day, to see where my blood sugars were. Back then, I was subject to the release of the NPH insulin, the long lasting insulin, so I would have to time my lunches for four hours and then dinner for eight hours when that insulin would peak. And that's not a natural way to live life, that truly isn't. So, I remember not only doing a lot of finger-prick, but also doing a lot of supplemental adjustments with regular insulin before meals to try and stay within range. And I do believe back in those days, I wasn't even aware of what an A1C was at that time.

TD: So you were age 19, so a little bit older than many. We kind of consider this as a childhood onset disease. But we now know that you can develop type 1 diabetes at any age. And you know, I've actually diagnosed patients in their 60s and 70s with type 1 diabetes. So, it does really span the spectrum of the ages.

J: I also have heard that traumas to the body can set off the genetic composition of diabetes. I remember at 19, I had an appendicitis attack, and I really wasn't diagnosed with spilling sugar or having diabetes until that week I was in the hospital and then came home and started losing a lot of weight.

TD: A great question and a lot of people can identify especially a more of an illness, say than an infection or something that was significant in the months or so preceding the diagnosis of diabetes but honestly, we still do not know what the trigger is. It's been largely speculated as being viral or some other trauma. If your pancreas was not functioning adequately at the time of your trauma, the stress that trauma may actually have brought the blood sugar levels up higher and may have brought the diagnosis out at that point. But trauma we don't tend to think of as a stimulus of type 1 diabetes.

So you were on injections for a number of years. Describe a little bit how having diabetes changed how you were able to live your life, especially those early years.

J: You know, as a 19-year-old, you're in, you're in a hole... you know, you're in senior proms, you're graduating, you're looking to go to college, I felt like I wasn't in control of my life at the time. And I'm a control freak. I want to be aware of everything that's happening to me and kind of forge my own destiny. However, with diabetes, I did not feel that I was in control. I felt like I was a victim. I felt like my blood sugars were hit-and-miss. And had I been doing A1Cs at that time, probably would have been extremely high I bet. I do remember that it wasn't until the 1990s when I got my first insulin pump that I had some sense of control over my diabetes. And that control allowed me the freedom to be able to get together with a group of people over the weekend to actually not feel dependent upon having to know 'do I have resources there to deal with a sugar low? Or did I have insulin available and a syringe available that I was going to be able to find a spot to duck out of the way?' And I can remember taking shots in McDonald's bathrooms and stuff because back then, all you had was a bottle of insulin and a syringe and an alcohol pad.

TD: We find that there's certain times of people's lives when type 1 diabetes control is challenging. Adolescence is one of them, high school years and then college years are, can be challenging as well, because there are a lot of psychosocial stressors that people are being subjected to. So you would have gone to college presuming after diagnosis. Can you share with us some of the challenges you found in college with diabetes?

J: You know, I was accepted into a number of colleges in the state of Maryland and out. I think a lot of my decision to go to college was to stay local and stay home. I ended up going to University of Baltimore, and then I matriculated into Towson University. But when all my friends were going out of town and playing sports and getting scholarships, I really felt I needed to stay centered so that I would be able to come home in the evening for what I could control. And I was very worried about actually leaving and going into a situation where I didn't know people and I didn't have the doctors available to be able to deal with any kinds of consequences that would occur because of highs or lows.

TD: Joe, share with us then how your diabetes management has changed over the many decades that you've had diabetes.

J: The first use of insulin pumps for me occurred in 1990s; '87, I had my first pump, '94, I had my second pump. They were really for the first time I felt effective tools that I could use to deal with diabetes. They were good, but they weren't perfect yet. What really changed the scope of my life was the introduction of Dexcom, the continuous glucose reading device. That's really when I felt like I had the tools in my toolbox to be able to really, were to deal with diabetes. And I think that's sometime around that period, Dr. Donner, I also met you and I need to stress that the third ingredient in this whole attack... the third is an endocrinologist who is truly knowledgeable about being able to take the data and looking at patterns, establishing trends, and fine tuning the delivery of your day to day needs of insulin and really getting a sense for what it is you need. So those three ingredients I felt really gave me the tools that I needed to be able to really take control of diabetes.

TD: Yup.

J: And things changed after that. I was introduced to A1Cs. I learned all about current trends with insulin pumps. Insulin pumps did a whole lot of different things. But that was truly where I felt like I was in charge.

TD: So Joe, if I'm doing my math, right, you were diagnosed at age 19, and then you would have been about 32 years of age, I guess, with your first insulin pump. So, you mentioned that pump therapy made you feel more in control. How so? What was it about an insulin pump that made you feel more in control?

J: A whole lot of things. Insulin pumps basically do two things: one is to allow me to bolus insulin according to the intake of carbs and the meals that I eat. The second thing is – and that I think is really more and more important as I get older and older – is that you can establish basal rates, which kind of give you a certain amount of insulin over a 24-hour period. It kind of takes care of your metabolic rates and also keeps you even in terms of blood sugars. Those two

elements, at that point in time, really did a great job with me to become stabilized so that I wasn't always starting at mealtime with real high blood sugars. I was able with the closed-loop system to take a look at the insulin pump, adjust the insulin either up or down to compensate for the glucose levels. And it wasn't a matter now of having data. It was more of finding ways to be able to interpret the data to provide more accurate control. So, the focus wasn't always catch up. The focus now was 'how do we use this information to establish patterns and trends that work better to keep me even in terms of my blood sugar?

TD: I agree with you. Insulin pumps can be an extremely valuable tool because as you mentioned, they enable us to best match how the pancreas would ordinarily make, deliver insulin to the body compared to injections because we can on an hourly basis, adjust the amount of background insulin depending on what the needs are at that time, how active people are, how high their stress hormone levels are. The other component of that though is it doesn't take over the role of the patient, because you still have to be proactive if your blood sugar levels are running high or low. And so, it sounds as though you continue to do frequent blood sugar testing when you first got a pump. And were you at that time told how to adjust the insulin dose based on what the blood sugar was?

J: Sure. I was. But again, here's the difference. What I did for the beginning of my diabetes was not what a natural occurrence is for an individual. We don't wake up in the morning, take insulin, and then adjust our day's schedule based on the release of the insulin. Instead, I am a very active individual. I have a job that has all kinds of demands. And so, sometimes I can't eat at the release of insulin. And so, what the insulin pump did, is it let me control when I was going to eat lunch because I could eat lunch whenever I wanted to, and bolus the insulin at that time for the number of carbs that I'd eat. And that made, that was a game changer as far as I'm concerned. Because that is how we live life. We don't live life with something that controls when we eat, we live life with eating as a part of a day's activity. And so, that's how insulin should be working for us. That's how I think insulin does work in our system if you don't have diabetes. We eat and whenever we eat, there's a release of insulin that compensates for what we're eating. And that, that was a game changer.

And today's pumps are phenomenal because it really is easy to determine the ratio between your carb intake and insulin portions. Today's pumps let you program this in. I've worked with you. Again, it's essential to have a good endocrinologist who really can figure out what your insulin is in relation to your carbs. And once that formula is in today's pumps, then really you end up having the control because you constantly know what the Dexcom talking to the insulin pump, what your blood sugar is, and you constantly have a calculator on the pumps today, that actually let you add up the number of carbs that you're consuming. That unknown that was there for so many years is now known. It's no longer hidden. And so, you basically get a much better sense of how much insulin to take so that you can target in the next couple of hours where you're going to end up being and the idea is to be someplace in a good range with blood sugar.

TD: I think many patients are actually hesitant to use pumps because of the unknown. They don't like to have things attached to them. "If can I shower with a pump on. Can I swim with a pump on?" Can you touch on some of those issues with respect to insulin pump therapy?

J: I don't mind telling you all that I'm a principal in a high school. And so, I believe knowledge is power. And I see so many teenagers come into high school today and they have the same apprehensions that you just described. Many of them want to play sports, they want to play football, they want to play lacrosse, they want to be on the swim team. I can only share my experiences with them because you can lead a very active life. I am an avid hiker. One of my goals still is to hit the Appalachian Trail. But I have done all the local trails. I play baseball. I've done a number of things. I hike on weekends. I have always fought change. I've always felt like I want to be in total control. But I have found a good balance to be able to let the insulin pump kind of mandate, dictate what I should be doing and where I should be. The conversations I have with students, I make it a point to tell the nurse when like a diabetic comes in, to allow me 10 or 15 minutes. Is this student wearing an insulin pump? You know, do they have a Dexcom? Over my 30 years of teaching and being an administrator, it's great to see that more and more kids are coming into the building with Dexcom, with continuous glucose feeding mechanisms and also with insulin pumps. The conversations I have with them, you know alleviate a lot of fears. They see me as someone who has walked their path and has been very active and that takes some of the apprehension away. Granted, there are tricks that you learn along the way. They should come up with a gorilla glue to stick you know, some of the mechanisms that you need to wear on your body. You know, I swim regularly, you know, you find a way to make these things work, you truly do.

TD: So when you swim, you keep your pump on?

J: I do not. I take the pump off. You know, I keep all of the contacts with the skin in place. Just simply because the amount of time I swim and the amount of time I'm in a hot tub or something like that, or the ocean is not long enough to truly cause a decrease or an increase in blood sugar. And you learn that over the years. You learn how long you can stay away from a pump and you also learn what you need to do to adjust your system a little a bit. It's amazing.

TD: So what we found from our end is that pumps really do allow patients to manage their diabetes better. We have seen better control with insulin pumps. And through better control, we do see fewer diabetes complications. And Joe, you have mentioned hemoglobin A1C which many of our listeners may know is a marker of three-month average blood sugar control. And we care about that number, because over time, we know that where the A1C is on average helps predict the risk that somebody has developing diabetes complications, which remain focuses is to try to prevent them.

You also mentioned the Dexcom, and not at all of our listeners may be familiar with the Dexcom. Could you share with us what the Dexcom sensor is and what it provides for you?

J: Essentially, you put a patch on your arm that has a [transmitter]. It has a mechanism that actually reads the fluids in your system. The recommendation is to keep it on the stomach. I prefer to keep mine on the arm, as long as you have good contact and you're using Bluetooth and it's connecting to the insulin pump. And now the iPhone, which is really become a blessing. You can put it almost anywhere you want. But what it does is it gives you a continuous read of your blood sugars. When I look at my phone right now and access the Dexcom app, I can see that my blood sugar now is 101. It also sets trend. Are you

increasing? Are you decreasing in blood sugar? It has a number of bells and whistles associated with it. So, that is really become essential to me, because I used to have all kinds of lows at nighttime. And instead of just adjusting basal rates and waking up sometimes with a real, real low blood sugar and getting myself into trouble, there are alarms that can be set along the way to indicate that your blood sugar is dropping. And you can set it up right now so it will tell you, you have about an hour before you ended up with a significant low and then it'll come back and say basically 'just told you this, now you're really in trouble, so you need to take some carbohydrates right now.' Conversely, it also does the same thing with highs. There are mechanisms and alarms that will go off if your blood sugars, whatever reason, increase dramatically.

RK: Joe, it's been so great to hear about how continuous glucose monitoring has really facilitated control, as you said over the management of your diabetes. Just to mention, I don't know if you've tried other kinds of CGM, but in addition to Dexcom, we also have the Abbott Libre, and then also, the Medtronic insulin pumps have integrated CGMs, as well. So just to ensure that we include all the models out there. But, I'm so glad to hear that the Dexcom has helped you.

J: I think all of them are very effective. It really becomes a personal matter of what you prefer, and what you like. And unfortunately, sometimes what the insurance companies are willing to pay for. But I think to explore any of those continuous glucose monitor reading devices puts you in a much better situation. Because again, I think the goal of a diabetic, and more so as I'm older now, is to achieve excellent control because I think that's the formula that really gives you a better control of your life. Right?

TD: To add on to what you've said, Joe, about these continuous glucose monitors... So these devices are inserted. There's a small filament that's about two hairs thick that goes underneath the skin into what we call the subcutaneous tissue. And so, it's continuously monitoring the sugar level in that fluid and provides every five minute updates in terms of sugar values. And what I think is useful that you alluded to, is that not only do you see what the blood sugar level is, but what direction it's headed. And that is important because people act very differently if their blood sugar is 90 and stable, or 90 and rising or 90 and falling, especially at bedtime. As you mentioned, you can set at what blood sugar level the device will alert you to both highs and lows. What happens if your blood sugar gets low? What does the device tell you?

J: It will tell you, in other words, how far out do you want to know that it's falling significantly. Sign set, for example, so that as it's starting to fall, and the pattern truly is to a significant decrease in blood sugar levels, it will send a beep out and then when you take a look at the glucose monitor, it will say, "You have about one hour, take some carbs now to compensate for it." However, you can also set that for 30 minutes or 10 minutes, for 5 minutes. [You] want to make sure that it's set in a place where you can eat some carbs, eat some foods, so that it compensates for that. It's a phenomenal device. It truly is.

TD: What will it do if your blood sugar gets really low?

J: I believe there's a cut-off point. So in other words, the insulin pump will actually cut itself off and stop. But the alarms get more significant and more annoying as the blood sugars

drop. And you know people, especially the kids that I'll talk to, don't like that. They'll be in a classroom and an alarm will go off. There are ways that you can disguise them. You can bring them to vibrate, you know whatever you are comfortable with. I actually keep mine pretty active. I have a whole set of administrators who work with me now. And when I have an alarm that will go off, they'll either tell me, this is not a good time to be eating with me, or they'll pull out a Snickers bar or something and give it to me. <chuckles>

In my mind, I think that you create a circle of friends who are aware of what diabetes is, and who can joke with you and can recognize when you're having a low, that you're having a low. And more and more, I think that's easier for an adult to do. I think it's tougher for teenagers. Once you start to kind of show teenagers that this is something that you live with, it makes a better situation I believe.

TD: So as a physician, I like when I hear that the alarm is very loud when it gets when the blood sugar gets, you know, below 60 or so because that's when it becomes more concerning that you could have a more severe low blood sugar reaction. And what's also remarkable about the technology these days is that this sensor can share the information with other people, especially parents who are extremely worried about their five- or six-year-old who is away from home; the parents can now monitor their child's blood sugar levels on their phone and be reassured that they're in a safe range.

J: One other thing that I have discovered is that over the years with the diabetes, I don't recognize lows as well as I did when I first got it. And so I can surprisingly drop as low as 50 or 45 before I start to recognize a low in some instances. What the insulin pump does is compensates for that and will let me know when I'm at 70 or at 65 that the trend is my blood sugar is going down and to do something with it. And I find that to be extremely useful having had diabetes for 40 years right now. I also find it to be extremely useful when I'm sleeping and I'm not monitoring my blood sugars or I'm in touch with the feelings. Many times I've had a low in the middle of the night and the Dexcom has alerted me that I'm, you know, moving in that direction and I need to do something. When I've gotten in trouble with diabetes and I've had a significant low, there's only been a couple times in my life where I needed to have on call placed to 911 and it was years ago. It was always because of a late night low of some sort that I didn't recognize because I was sleep.

TD: Have you had any severe lows since you've been on a continuous glucose monitor?

J: I'm not going on low right now. No, I have not. And I think that's again, the whole goal here is excellent control for better quality of life. Last thing I want to do is spend a night in an emergency room or have 911 come with all the Pomp and Circumstance.

TD: That's I think been one of the biggest innovations and helps us in the sensors that alert patients to lows to help prevent more severe lows, because that's a limiting factor with insulin. We can give a lot of insulin, but we also have to be careful that we don't cause problems with low blood sugar levels.

J: The other thing I like about the insulin pump is in addition to the alarms for low blood sugars and high blood sugars, they're also alarms for incomplete delivery of insulin, cartridge jams, "have you changed your site in the last three days?" They also want to indicate if the pumps not in sync with the Dexcom. So today's insulin pumps really far advanced in technology and all of those things... any of those kinds of things that could affect the delivery of insulin, thus affecting where you are in terms of your blood sugar.

TD: So Joe, you've touched on this already... you now have what we call a hybrid closed-loop insulin pump. And there are three pump companies now that have made such devices. And we call them hybrid closed-loop because the sensor is now communicating with a pump. And if the sensor is sending signals to the pump that says the blood sugar is going to be heading low, the pump now will decrease the amount of insulin that were even suspend in some delivery. And if the blood sugar is running high, the pump will automatically increase the amount of insulin delivered so that blood sugar level stay in a better range. Do you want to describe how starting that hybrid closed-loop pump has helped you with your diabetes management?

J: Sure. So it's been a game changer. And I think that, you know, we've talked about different components of that. To have that, I think replicates your own system in your body. When you think about it, for years and years, I wanted to know if there would be some sort of insulin delivery pump that could actually be inserted into your body to do the same thing that a natural pancreas does. But, that has huge risks connected to it also. And so, the closed-loop system really gives you as I said before, all of the tools that you need in your toolbox to truly fight the disease. And it's a tough disease because one of the things as you get older, I pay [for] surgeries for things that I've just had a replacement of my hip recently. I fell off a ladder a couple of years ago and crushed to heal. Dr. Donner, you know all about that stuff because you made some recommendations in terms of who to see. But I think diabetes is a tough disease, it truly is. And I think any of the tools that replicate what the pancreas does gives you better ability to control blood sugar. And I've learned it's so important when you get older and you have to have surgeries and things of that nature, that the best way to make a good recovery is to be able to have good level blood sugars. I think that a closed-loop system gives you the best of all worlds.

TD: One of the challenges is having Type 1 diabetes is exercise and its effects on blood sugar levels, especially causing low blood sugar levels. It sounds like you do some potentially long hikes and all. What do you do to help prevent low blood sugar levels from occurring with exercise?

J: So let's come back to the insulin pumps of today. They have options on them. Two I wanted to talk about, in particular. One is a sleep option. What it does is gives me excellent control in the evening so that I set it at 10 o'clock and it comes off by 5AM. And during the evening, I find that it does a phenomenal job of keeping me at an even blood sugar that is right around 90 or 100. The other thing that is an option on the pump is the exercise option. Previous to this, this mechanism on the insulin pump, I would try and pump myself up with carbs before I go to the gym or before I can take a hike because I was going to do strenuous exercise, and exercise lowers blood sugar. However, the pump would kick off and say, "hey, you've just taken a whole bunch of carbs, so, we're gonna give you some insulin to compensate." So it's kind of counterproductive in terms of what I was trying to achieve. But the exercise option gives you the

mechanism to be able to load carbs that as you exercise, you've got kind of good baseline and through the exercise period, it reduces that without a lot of insulin necessary.

RK: Joe, you are clearly so knowledgeable about these new technologies. And it's so great to hear about your experience. I was just curious if you could share how did you learn about all this? Was that from your interactions with Dr. Donner's, as you know, excellent endocrine care during your visits? Or were there other resources that you use to really learn how to do this on a day-to-day basis?

J: That's a great question. Knowledge is power. And so, as someone who has been involved in education for over 40 years, I try and read everything that I possibly can. But as I said a little while ago, having the right endocrinologist makes a huge difference. The relationship that you established with the right doctor makes a huge difference. Dr. Donner works with my regular doctor, [who] has also made recommendations when I've needed assistance, really can make a decision in terms of do I need a nutrition specialist or not. Like I said before, I understand that the insulin pumps today produce more data and create more patterns and show trends. I would never be able to read all that, but a good sit down with a good endocrinologist will make huge differences. The technology today truly eliminates the need to have office visits. Dr. Donner is an extremely busy individual. And so, he can set up Zoom meetings where he can actually take a look at the readings and calculate where I need to make adjustments for the delivery of the insulin. I was always very concerned and one of my huge goals was to achieve a really good A1C somewhere below seven, you know, in the mid-six range. Once I've achieved that, now what we do is try and find some continuity and some patterns where there are still peaks so that we can adjust those also.

TD: And from a physician's standpoint, the technology is extremely helpful to us. We are very data-driven... not only glucose meters, but now that continuous glucose monitors allow us to download the data and I can see trends in blood sugar levels very clearly. Both from an average standpoint and from a day-to-day standpoint in terms of what blood sugar levels are doing. And so, it just enables me to fine-tune insulin dosages and make recommendations for things such as exercise and stress and surgery. It's just that much easier.

We've covered a lot of bases today. If you met somebody who was newly diagnosed with Type 1 diabetes, what recommendations might you provide?

J: Knowledge is power. And so, when I meet with students today who are just becoming diabetics, generally in their early teens, I do stress for them to find out as much as they can about the technology that's available to them because that technology creates excellent control and makes you feel that you're in charge of a disease that quite often can overcome and take over much of your life. And I do believe that the more excellent control that you can achieve results in a better quality of life. When I say better quality of life: if you're a teenager, you want to be able to get in play sports and not be called out in the middle of a football or soccer game because of a blood sugar low. If you're a college student and you're about to take some important tests, you want to be able to have your concentration focus on what it is you have to do, not where your body is in terms of highs or lows. If you're an adult, I think that you want to be able to lead

a normal life and be able to do what you do and not have to worry about what is your blood sugar and how that's having a detrimental effect on your overall system.

TD: Great recommendations. And that's our goal and I think should be everybody's goal who has type 1 diabetes, is to manage the disease but live as normal a life as possible in a healthy way. Joe, I want to thank you so much for joining us today. You have shared some very useful information hopefully to our listeners.

RK: Thank you.

J: Thank you so much for allowing me to be a part of this.

RK: Thank you so much, Joe and Dr. Donner, for that engaging and insightful conversation. It was really, really illuminating. And we really appreciate having you both here today so thank you. I'm Dr. Rita Kalyani, and you've been listening to *Diabetes Deconstructed*. We developed this podcast as a companion to our *Patient Guide to Diabetes* website. Our vision is to provide a trusted and reliable resource based on the latest evidence that people affected by diabetes can use to live healthier lives. For more information, visit Hopkinsdiabetesinfo.org.

We'd love to hear from our listeners. The email address is Hopkinsdiabetesinfo@jhmi.edu. Thanks for listening. Be well and see you next time.