

EPISODE 3: A REAL PATIENT STORY - LEON

Rita Kalyani: Welcome to *Diabetes Deconstructed*, a podcast for people interested in learning more about diabetes. I'm your host, Dr. Rita Kalyani, at Johns Hopkins University School of Medicine. 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 *Hopkins Diabetes Info dot org*. That's all one word.

For today's podcast, it is my pleasure to introduce a patient with diabetes, Leon, who will be sharing his journey living with the disease particularly focused on self-management of diabetes.

He will be joined by his diabetes educator, Gene Arnold, who has worked with him very closely and will also be enlightening us on how they have worked together to improve the diabetes self-management over time.

Gene Arnold is a registered dietitian and nutritionist and certified diabetes educator in the Johns Hopkins Diabetes Center since January of 2019.

Welcome Gene & Leon.

Leon: Thank you

Gene Arnold: Thank you very much. Very excited to be here.

RK: We're very excited to have you both here too. I wonder if I could ask Eugene to start the conversation and perhaps kick it off with a question that you think would help us understand at Leon's Journey with diabetes.

GA: Ok, perfect. So Leon and I, we've been working together for over a year now, and fun fact... interestingly, we've never actually met in person, right? So we've made a whole lot of progress, all virtually. So this podcast can be a great example for patients, you know, who might be hesitant about virtual care, that they can make some serious changes and improvements without having to go anywhere. So there are a lot of things that we could discuss. What I think for the listeners I think we'll be helpful, Leon, if you were able to share a short background as to let, you know, when you were diagnosed with diabetes how you felt, etcetera...What's kind of led you to this podcast today being a chosen patient to meet with us. If you wouldn't mind sharing your story.

Leon: It's a pleasure really to be here and to have the chance to speak. A little bit of my background as far as my diabetes is concerned. I've been a diabetic over 48 years - 1973 - and I became a diabetic, Johns Hopkins used to have classes for new patients, and going to those classes I found out that diabetes was very important. I learned to manage my diabetes from that class. And one thing I learned... other diabetics I meet I try to let them know what I've learned from those classes, as well as from Gene right now. When I first went into those classes, I learned the fact that managing your diabetes far as diet exercise a combination of both will help you with diabetes. We also have to look at the fact that diabetes can harm you. Diabetes can harm you to the extent that if you are not doing what is required as far as managing diabetes you could go blind. And you could also lose limbs. So that right there made me want to be a stickler to paying attention to my endocrinologist, and dietitians at the same time.

GA: Awesome. Appreciate you sharing that you would have been to the classes previously, probably a long while ago, you know. I've.. I think I'm very familiar with what might have been covered during that sort of program. And I'm sure you might agree that it's sort of things that you and I have been working together on might be a little different than what you talked about in the class. Wouldn't you say?

Leon: Yes. *[chuckles]*

GA: Yes, a lot different, right? So... Maybe you could clue the listeners in to how your diabetes has changed, you know, over the last 40 years. What's different now than what you were doing, you know, even ten, twenty years ago?

Leon: When I became a diabetic, and going to the classes and taking the information in, I don't think that I was taking it that serious. I think some of us do that some of us being diabetics, we can listen and sometimes don't take heed. and when I said don't take heed to the extent that I wasn't following what I was supposed to do. I wasn't really following my diet like I should. I was doing the exercises because that's what I do. [chuckles] You know. So occasionally I'd would maybe want to have a taste. You know. On a weekend I might want to take a taste. But I'm saying that so you can understand the fact that doing those things at that particular time wasn't beneficial to me. So now today meeting Gene, and Gene having patience with me because of where my diabetes...it was like it was out of control almost, and it was out of control. Gene had to have patience and I had to have patience with Gene. How do we get this together? How do we get you blood sugars down? Your A1C down? And listening to Gene in reference to different ways of eating and dieting [chuckles] and carb counting, you know, so all that's a combination of trying to have control. When we had these first classes at Johns Hopkins they were very interesting, but at the time, mentally, I didn't really take heed to it. And then once I start listening and taking heed to it to the extent of what the ramifications of diabetes could be... not only to myself but it observing other diabetics that I've met over a period of time, coming in with diabetes to the extent some of them in the period of time that I've known them have lost their leg. That right there is enough, I would think, for anybody to take heed, you know to manage your diabetes. Not only that, listening to your endocrinologist and what he or she has to say, and also you know sometimes you have to pick up and read a little bit. [chuckles]

RK: Leon, I think you have hit the nail on the target when you talk about all the different resources that you've had and that you found beneficial to you over the years. I'm glad to hear that you listen to your endocrinologist, and that you've worked so closely with Gene. You know, often is hard to come and have multiple visits for your diabetes. For those people who may not be as familiar with why you need to see a clinical educator such as Gene, can you share what you would recommend about why it was beneficial to you.?

Leon: Like I say you know for the period of time that I have been a diabetic coming back and forth to Hopkins, for different appointments and for the endocrinologist, for my dietitian... that's kind of like what you would say repetition, [chuckles] you know...with all that it was important to be able to do those things and be acquainted or introduce to those educators. This what we have to think as far as being a diabetic is also think of the time and patience that our endocrinologist has to put in to try and keep us on the straight line.

GA: Are you going to share what your daily life is like in terms of diabetes self-management? We've implemented a number of new technology, right, and you're doing great. It might be helpful for the listeners to hear what your day to day is like and what your routine in terms of diabetes self-management is.

Leon: My day-to-day management has changed somewhat from the beginning to where it is at now. In the early stages they didn't have an InPen. I have an InPen now. They didn't have G6, where you can monitor your diabetes by a phone. Before all this technology came in you had to really pay attention to what you was doing as far as you diet was concerned. And then you test differently. You know, you had to prick your fingers all the time, you know, and sometimes it can be a little like "hey wait I don't want to do this today" or "my fingers are sore" or something like that. But we're here now, I'm working with my dietitian and my endocrinologist introducing this technology really makes it a lot easier. I want go back to something that Gene said. Some patients are maybe kinda leery coming into the hospital but now you don't have to come into the hospital. You can do this virtually like we're doing now. You can control yourself if you want you just as well as coming into a hospital to see your endocrinologist or dietitian.

GA: Just to clarify for everyone listening, Leon had mentioned the InPen; it's a smart insulin pen. Essentially what is done is the user will enter their blood sugar and they will also enter, you know, whether they're eating or not, and it comes with a smartphone app that can help the patient have a more accurate insulin dose. Somebody might not be totally sure how much to take, when to take it, etcetera. It can help somebody remember to take a dose maybe you don't remember if you took it, you can look back at either app and it will tell you. The Dexcom G6 - that's the continuous glucose monitor for anybody who doesn't know. And we're actually able to look at Leon's glucose readings in almost real time. You know, these are reports that him and I will go over at every visit and find out, you know, what's working, what's not. You know, Leon, we'd like your comments on this, but I think, you know, having a deep dive hour to hour, you know, what happened at 6 o'clock yesterday... I think that that's been a critical part of our success. What do you think?

Leon: That 6 o'clock hour. I'm gonna use the word critical, but it's not really critical. I just want to use that to extent that what we had to go through in order to be on track where I should be... where Gene would like for me to be. So that meant do I eat bacon and eggs for dinner, or do I constantly add a little bit more... let's say starches, which I didn't pay too much attention to but it's starches in the bread that I was eating... threw me out of control. The starches raise your blood sugar. Talking to Gene, discussing it with him, I keep eating, but my blood sugars keep going up. Gene says, well maybe we need to eliminate two slices of bread, or three...I'm a bread eater. Really, I'm really a bread eater. Speaking on those terms and listening to him and following his advice, I noticed that there was a difference. Another thing that I was doing, this is at night before I go to bed, that's with the G6 and my InPen, I would eat a little bit before going to bed. I would eat peanuts, Gene, sometimes because they're peanuts, they would be a little bit longer, a little bit slower, in raising your blood sugar. I was eating peanut butter crackers thinking that I needed to eat that, but I found out again, with Gene, that eating a peanut butter cracker, it would raise my blood sugar. I used to eat 3 or something like that before I go to bed. Then I found out (Gene and I discussed this) maybe we need to just eat one. One thing I think a lot of us being diabetics should also have that emergency kit with us right at hand, you know, that you can reach just in case that blood sugar drops down low...you know, have a piece of candy, Starburst, something like that and maybe a peanut butter cracker which maybe take your blood sugar up slow and not fast because if you eat more than three it will raise your blood sugar up. You know discussing that, what to eat at dinner and then also what to do at night at bedtime. What I'm saying is because of Gene as well as myself, it's a team. It's a team effort. You may be the star of the show but I'm just a participant, then I have to follow the instructions that is necessary for me to be a better patient. And that's what I'm trying to do - be a better patient, follow instructions. And I hope some of this discussion we're having, I'm hoping that other diabetics, they will understand the importance of their diabetes. I've been a diabetic for 48 years and have no complications. Other doctors when I tell them that I've been a diabetic for that period of time and no complications they've really been amazed. You been doing good and that's what I want other our patients - when I say our patients because we are family, we are family, we all are one; we're diabetics. No getting around it; we're diabetics. And being diabetics, and because of the team that we have at Johns Hopkins Hospital, and the concern, the interest that you have in us, can't put it in the dollar and cents form, no more than you can.

GA: You've had diabetes for over 40 years, longer than I've been alive. You still went and saw a diabetes educator, who is younger than you've had diabetes. So what about the visit with me or visits with me were different than prior visits you've had that helped you? Because you had been going to visits; you have been receiving care for years and years and years and years, and we started working together, and it wasn't always easy, but we've made some really, really solid progress. For people with diabetes who might be apprehensive about seeing a diabetes educator, what is your message to them, you know... Why should they see a diabetes educator?

L: It's just like going to school. I mean it like that. It's just like going to school. We're in a stage... becoming a diabetic, we're in a stage of learning. When we're introduced to an educator, previous educators, I think with Gene, the period of time that I've worked with him, you know, it's really been a close relationship, and like I say, you'll call me up and you'll check on me. We may make an appointment and we'll juggle it around to his schedule, my schedule and I think that's important. Gene is really close to me.. <chuckles> He's really really close to me. And he shows concern. See, that makes a difference too. As a patient you don't get that feeling from your doctor wherever that may be... I think that also has an effect on the response that one get in trying to be cured. If you don't have that feeling of trust of the person that you're working with. And I have that feeling with Gene. And I would think that he doesn't only work with me like that. I would think that he works and cares for all of his patients like that. I really do. I really appreciate him. I've told him this so many times. as many times. I appreciate you Gene.

EA: Thank you very much. We do our best

RK: Leon thank you so much for sharing your experience with diabetes self-management and how that's changed over the 40 plus years that you've had diabetes and especially benefited not only from your close relationship with Gene and the diabetes coaching you've received there, but also with the new technologies that it clearly have also helped as well to manage your diabetes at home. You talked about the emergency kit and I just wanted to elaborate on that. Being the glucagon emergency kit that we often recommend for people with insulin, just in case of low blood sugars at home. We do have a video on the website about that for anyone else that is interested in learning about that.. I did just want to ask you one last question. For those people who are newly diagnosed with diabetes, who are overwhelmed and concerned about what a life will be like living with diabetes: What advice or words do you have for them?

L: My advice to those that are just becoming aware of now being a diabetic is to pay attention, listen... because all this is a part: pay attention, listen, and understand the importance of following directions and understanding what diabetes can do to you to the extent of having problems. If you don't do what is required I would say to those that are diabetics now and may be apprehensive of working with the endocrinologist, educator, I would just say do the best you can. Listen and follow instructions. One thing that I learned a long time ago and I'm going to take you back a little bit. My mom used to say you have to be in a house at 9:00, or sometimes I was outside playing and I forget that it's 9:00. So when I go back home, my mom would say I told you to be in the house at 9:00. It's after 9; it's a minute after 9, so you are late. So you have to follow instructions. From what my mother told me about being on time - that stayed with me all of my life and even now. When I went to high school went to school you have to be at school at 8:00, not a minute after 8. When I joined the military, the Navy, you had to be on time. So I say all that to say to my new family members as diabetics: Pay attention, be on time, and follow instructions. I just hope that following what we gathered here will help other diabetics understand the importance of what we have to do as far as managing. This is what it is. It's managing our diabetes

RK: Thank you for those final, wise words, and your mom sounds like an amazing woman as well. I'd like to thank you, Leon, for sharing so candidly your patient journey. We truly appreciate it. And thank you, Gene, for your exceptional care of Leon, which he clearly appreciates, and for also sharing your insights as a diabetes educator. Thank you both for your time today.

L: It's a pleasure to be here and thank you.

RK: 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 ***Hopkins diabetes info dot org***.

We love to hear from our listeners. The email address to reach us is ***Hopkins Diabetes Info at JHMI dot edu***. Thank you for listening. Be well, and see you next time