

EPISODE 7: A Real Patient Story - Alan

Dr. 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. 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*.

We are thrilled to welcome Alan today for the podcast, who has graciously agreed to share some of his experiences living with diabetes. Welcome, Alan.

Alan: Well, thank you for having me.

RK: Thanks so much, Alan. It's such a pleasure to have been a part of your journey with diabetes and for you to be willing to share that with our listeners today. I wonder if we could just start off from the beginning. If you could tell us how you were diagnosed and at what age were diagnosed with diabetes.

Alan: I have kind of a unique experience for being diagnosed in that I was in my late 30s and I have Crohn's Colitis. Anyway, I was on a heavy dosage of a drug called prednisone. And I went into what they call a steroid crisis. During that process, I went diabetic for whatever reason. It was a total shock to me. I had to get on insulin with the syringe and all that. It was totally devastating but as they reduced my prednisone dosage down, I converted back to normal. As I got into my late 40s and 50s, I had adult onset diabetes.

RK: Yes, steroids such as prednisone or hydrocortisone can increase blood glucose levels, and particularly when people have risk factors for diabetes already, such as a family history, or high blood pressure, high cholesterol, may be what causes people to have levels that go over the edge and then go into full-blown diabetes. Did you have any risk factors for diabetes, such as having any family members with the disease?

Alan: Yes. My grandmother, she had diabetes from the time she was in her 50s until her death.

RK: Given the family history and seeing her journey with diabetes, were you surprised at your diagnosis? Or how did you feel? Were you scared or angry or surprised?

Alan: Having dealt with it in my late 30s, I was shocked at that time, but I became accustomed to dealing with giving myself a shot. So as I got into my 50s, initially, they were able to control it with oral medication. And then as I age more and more and the situation got worse, we had to go to the syringe. I guess I had time to adjust. <chuckles>

RK: And that's always great to have both the background where you saw a family member with the disease so it wasn't a surprise about what it was, but to be able to adjust to having it yourself as well. Now it sounds like you were on the pills for some time. Did you tell people you had diabetes at that time? Or how do people react when you shared that news with them?

Alan: I wasn't really open about telling people of course, my close family members and all that. My wife is a nurse and she's a nursing professor so that made it a lot easier. She, you know, ... I had somebody here in the house with me to guide me through the process. Other folks, I didn't hide the fact that I had it. I wasn't ashamed that I had.

RK: Did you ever have any surprising reactions when you did share it with people? Or where people mostly understanding and curious?

Alan: For the most part, they were understanding and curious. I was 50 years old by the time that I got the adult onset. So I had a lot of friends that were probably diabetic, too.

RK: So this gave something that might have a community, perhaps.

Alan: Yes, yes.

RK: And where did you find that you learned about managing your diabetes day-to-day? Was it from those friends? Or how did you figure that out?

Alan: When I had the steroid crisis, they gave me the full-blown training, you know: how to give myself injections and all that. It was a crash course. You know, you start out giving the injections to the orange and then you switch to your body and that kind of thing. So I went through the process because I had had the surgery from the steroid crisis. It was kinda like an out-of-body experience. But I knew I had to deal with it. So I did.

RK: And sometimes it's the necessity of having to deal with things that really accelerates the learning curve and adjusting well. What were some of the challenges that you faced in managing your diabetes?

Alan: When I was on the pill, there really weren't that many challenges. When you move from the pill to the syringe, that's when it gets complicated. Because with the syringe, you know, you have to make sure that you've got everything with you at all times- your medications, and all that kind of thing. And at night, you got to keep the bottle refrigerated once you open it- that kind of thing. If you're pricking your finger to measure your glucose blood level, first of all, you can only do it three or four times a day because your drug company is not going to allow you to prick your finger 10-15 times a day and use the... you know... I mean, it's just too expensive.

RK: I did just want to touch upon what you were saying about being on the pills for diabetes and how when you made that transition to the syringes for insulin, now we have pen devices. But at the time that you were initially put on insulin. It was probably just syringes that the storage and the drying up the insulin that those extra steps certainly added to your daily routine. But in general, how did the injections work for you after a while? Did you feel like you got used to them? Was it uncomfortable in any way? Or did it smoothen out and and just a part of your daily life?

Alan: I'm one of those people who prior to diabetes, hated needles. When I go to the dentist, I go to a dentist that medicates the area before he gives me the shot. I mean... I'm what I had to do and what I had to go through, it was a challenge. But it's like when I wore contact lens. I was one of those people that when I got a hair in my eye, it was an ordeal. But once I started wearing contact lenses, I could touch my eye, anything. I adjusted really quickly. What are you going to do? You either you adjust or you live in terror or you rest of your life.

RK: And what would you say to someone who is newly diagnosed with diabetes and is prescribed insulin? What would you say to them about having to go through that process, if they're afraid of needles?

Alan: It's a choice. You know, either you want to get better, and you do what you need to do, or life is not going to be the way... your life is going to be challenging if you don't grab the bull by the horns and adjust to the situation. You have to do it.

RK: I really liked the way that you described that about taking the bull by the horns and having to adjust which is really what it's about, isn't it? Being open and adjusting to what happens along the way. Diabetes is a progressive disease and with time, many people will need to be on insulin. But, once you learn how to do it, it isn't so bad.

Alan: Every night I give myself a shot. I keep my insulin pen in my pocket. You have to carry that stuff with you.

RK: And you've had diabetes now for a while and over 25 years and you've seen changes. Right? Now you're using the insulin pen device, which is a prefilled device that has insulin. Can you talk about how that's made things easier?

Alan: Yes, prior to my meals, I take my measurement. I measure my glucose level and then based on what that is, I have to give myself the shot from my pen. It does not have to be refrigerated or anything once you get it out.

RK: Well, I'm so glad to hear about how the pen device has made it easier, also not having to worry about refrigeration of the vial all the time as you would when using the syringe. You can carry it in your pocket, you know. It's easy to turn the knob to the dose you require and just to clarify you choose the dose based on the glucose reading, right? ... based on the fraction scale that we that we've talked about, in addition to the fixed doses of insulin that you would take irrespective of the glucose. And then the FreeStyle Libre which is a continuous glucose monitor... there are a few on the market. We have the Dexcom versions also the Medtronic insulin pumps have continuous glucose monitors. The Guardian integrated as well. These are devices that sense glucose every few minutes or on demand when you wave the scanner on

top of the sensor but they do allow you to check your glucose without pricking your fingers which is pretty remarkable after years and years of pricking your fingers. How does it feel now not to have to do that?

Alan: I love it. The only thing is every two weeks, you have to change the monitor that's on your body. But that's not really an ordeal compared to pricking your finger is... first of all, your finger becomes raw. You switch fingers, and this device has really allowed me freedom.

RK: And there are a lot of technological devices. These were just a few that we mentioned. But there are others as well. And it's really about what works best for you, as the person living with the disease. For some people, the finger sticks... it's just something you're used to. People get used to a certain routine. It might work out better. For others, the technologies can be really helpful. So it's really a personal decision about what works best for you. So I'm glad that we were able to find kind of that regimen that really works best for you.

Alan: I have a good friend who... he's a golfer. He switched to the FreeStyle Libre. And then he went back to pricking his finger because when he swung, you know, the golf club, he would pull the monitor out of his arm. Go playing golf was more important to him than having that monitor. You didn't want to give up his golf game.

RK: That sounds interesting. <chuckles> That's yeah. And that's a perfect example of how it really needs to be individualized to the person living with disease. Now, in terms of physical activity, could you tell us a little bit about what adjustments you had to make to your diet? What kind of physical activities you've enjoyed?

Alan: Prior to COVID, I was... we call the hand dancing in the African American community, which is a form of ballroom dancing. Since the COVID thing has hit, I've kind of gone underground. I'm hoping to get back into it but I'm not there yet. I just don't want the contact and people in your face breathing... that kind of thing. And if you've got students, you're introducing yourself to a lot of people that aren't familiar with you. COVID has just changed my life. I don't know how else to say.

RK: And physical activity... it's so important, has so many benefits in general, but living with diabetes, have you noticed that at times when you were more physically active? How did that impact your blood glucose levels?

Alan: When I'm more physically active, my glucose levels are lower, I think. You need to to exercise. Exercise helps keep your glucose levels lower.

RK: Yes. And, you know, we emphasize weight loss so much. But irrespective even of losing weight, just exercising and having that increase in muscle, perhaps some decrease in fat, can improve insulin's action. It can make your body more sensitive to the effects of insulin. So you really get the best value for the medication you're taking. And physical activity really helps make sure that you optimize the benefits of the medications you're on. So I really hope you can get back to doing that dancing that so important to you.

Alan: Yes, I do, too.

RK: And what about your diet? Can you talk a little bit about are there foods that you've noticed that impact your blood glucose levels, or how has diet impacted your diabetes management?

Alan: But turkey really... in the last 5 to 10 years, I used to be a big red meat eater, salt in my food, a lot of fried stuff. I've had to change my diet. Now I eat a lot of broiled fish, I eat sliced turkey, and it helps. As I age, it does become more difficult to control my diabetes. But my problem is, although I've got a very good endocrinologist, sometimes I'm a bad boy. And I get off my diet. I love candy. I love all the things that have sugar in them. I wish I had better control that way. I'm 79 years old, and I'm still functional. So I must be doing something right.

RK: You most definitely are. And you know it happens to everyone at times. We're all human. And this is part of the reason that we really don't restrict overtly; 'you can't eat this' 'you can eat that' but it's really about choosing healthier foods and really making wise and healthy choices. And particularly around the holidays it can be difficult. Especially if you're eating in group settings or if there are tempting choices to choose from. How have you managed in those situations? What tips might you have for those who are also struggling during those times?

Alan: I've got an advantage. I am a lifetime member of Weight Watchers. So Weight Watchers taught me you can eat anything you want. It just depends on the quantity, how much. In some cases it might be one bite. That's it. I used to love apple pie. I used to love pound cake. I basically had to give those things up. As my diabetes got worse, I just had to give them off. Sometimes I can't... I still sneak and do.

RK: Well, a bite here and there from time to time... Even your endocrinologist may be fine with that. But it can be hard. I think that what you mentioned about quantity is really important. That sometimes it's the quantity that's the problem, in addition to, you know, the healthier food choices. So that's so great to hear about what has worked for you. What about the role of your family members? You mentioned that your wife is a nurse. How have they had a role in helping you with your diabetes?

Alan: She's the consummate nursing professional. She's always on me. You're doing this wrong, you're doing that. I don't like it. But she's right. I don't have any children. It's just the two of us. But boy... she does stay on my case.

RK: I think you're particularly lucky or perhaps at times, maybe. It may not seem so but to have a wife who's also a health care professional who can support you. But I think in general, having a supportive family who is attentive to what you're doing and holding you accountable and supporting you and your choices is important. So it's so great to hear about how much she's been a partner for you, in also managing your diabetes effectively. I wonder if you could talk now a little bit about any complications from the diabetes that you feel comfortable sharing.

Alan: I had a mild stroke maybe 10 years ago, but I'm not sure that it was from diabetes. I think I do have some forms of neuropathy, in the webbing of my hands, and in the webbing of my feet. Even though when they tested when I come in to prick it with something, I passed the test. But there is some numbness there that is there permanently. It's not debilitating, but it's there.

RK: Having diabetes for as long as you've had, for more than 25 years, you know, with time it is more common to develop complications. But we hope by keeping the glucose levels at target for most people with A1C less than 7% that we can reduce those complications from occurring. And the neuropathy in particular, it can kind of come about very gradually. You may not have symptoms initially and then the symptoms can kind of evolve over time. But in general, as you've mentioned, you're very functional, you're able to do the things that you want to do, and have been in good health with this disease. So having the understanding and the motivation to take care of yourself, as you've mentioned, is very important. I wonder if you could talk a little bit about having diabetes on the work at the workplace. You know, how did having diabetes impact your ability to work if at all? And did you feel comfortable sharing your disease? And what was needed with your supervisor and colleagues?

Alan: At the age of 65, I was able to retire. I was a senior patent attorney, Office of General Counsel, NASA Headquarters, Washington DC. So I had the kind of job that I kind of controlled my day. If there was stress, it was something that I allowed to stress me out. My boss and other folks like that... well, some of them had diabetes also. The bottom line is my job was the kind of job where I probably could still be working today, if I really wanted to, and I still do some practicing. There comes a time when that daily rat race of getting up, having to go you're gonna be on the road, 45 minutes each way. It's an hour and a half out of your day that if you have an opportunity to not have to do that, I took it. I didn't think I'd lived to be 79. But I have.

RK: You know, I think being able to retire when you did that that's really wonderful. How comfortable did you feel? I don't know if you were on insulin at the time that you were working but surely you were picking your fingers. How comfortable did you feel doing that on the workplace?

Alan: Well, I had my own office so I can shut my door. Nobody had to even see me. I really didn't have that much... at that time, 14-15 years ago, first of all, that's when I was in the finger pricking mode. Since then subsequently you've gotten me involved in the FreeStyle Libre. I guess it probably was a challenge. I'm one of those people that if I have to adjust to something, you know, you got to change your lifestyle. I've always had that kind of fortitude. If I gotta change my life, darn it, that's what you gotta do. <chuckles>

RK: And it really sounds like that's kind of been the theme, I think that you've had, is adjusting and doing what you need to do, and just recognizing that this is a part of living with diabetes, and the effectiveness of doing that has allowed you to reach 79. You've had a large role in reaching and living a healthy life with this disease. So I think that's really been remarkable.

Alan: I don't feel 79. What should 79 feel like? I don't know. But I don't feel like I'm 79 years old. I drive I do whatever I want to do. <chuckles>

RK: Well, you don't look it either and you're young at heart. And we're so glad to hear that you're able to still do all those things. And so that's really wonderful. I wonder if you might have some parting words for our listeners - those who either are just being diagnosed with diabetes and dealing with this for the first time or even those who've had the disease for a while. What advice might you give to them as they look forward to hopefully many years of living with this disease and having a long, healthy life?

Alan: I have friends that have a primary care doc, but they don't have a team. It's like, I'm on Jardiance. My primary care kind of pushed that towards me, and you worked with her to coordinate the process of taking Jardiance out. You know, it's like on Monday, I see my pharmacist. The pharmacist that's monitoring my Jardiance, I see him two or three times a month. I don't know that I'd have that if I wasn't in the Hopkins system. I just don't. That makes a difference. <chuckles>

RK: And it sounds like you've been a very effective patient navigator. Sometimes that can be really difficult to know who to go to, for what, and also a patient advocate, to be an advocate for yourself in coordinating all these different specialties and ensuring that they're all working together. So whether it's in an academic hospital or in a community practice, really having that network of health care team members on your side and working with them has sounded like it's been a really great solution for you, or a great combination, I should say, in terms of attaining good health in the long-term.

Alan: And it has. When I was in my late 30s, and I had Crohn's Colitis, and I had the steroid crisis, you know, I was in intensive care for five weeks. I had three major abdominal surgeries, and I survived all of it. But as a part of that process, I better learn what was going on with my health system. I'd better deal with my doctors and follow their advice. I've got a team and and I must I just commend you for what you've done for me.

RK: Well, thanks so much, Alan, for being here today and taking the time to share so candidly what it's been like to live with diabetes, some of the challenges and successes, for sure, that you've had over the more than 25 years of having diabetes. And it's been such an honor to be part of that healthcare journey with you and wishing you many more years of good health in the future.

Alan: Well, thank you, ma'am. You've been a godsend.

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***.

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