



Living with Type 2 Diabetes: Podcast of a Patient–Physician Discussion

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ABSTRACT

For patients with type 2 diabetes (T2D), the journey to diagnosis may not be straightforward. Patients can present with one of many diabetic complications before a diagnosis of T2D is made. These include heart disease and chronic kidney disease, in addition to cerebrovascular disease, peripheral vascular disease, retinopathy, and neuropathies, all of which can be asymptomatic in the early stages. In their clinical guidelines on standards of care in diabetes, the American Diabetes Association recommends regular screening for conditions such as kidney disease in patients with T2D. Furthermore, the frequent coexistence of diabetes and cardiorenal and/or metabolic conditions often requires a holistic approach to patient management, with specialists from multiple

disciplines, including cardiologists, nephrologists, endocrinologists, and primary care physicians, working together. In addition to the use of pharmacological therapies, which can improve prognosis, the management of T2D should include attention to patient self-care, including appropriate dietary changes, consideration of continuous glucose monitoring, and advice on physical exercise. In this podcast, a patient and a clinician discuss a lived experience of the diagnosis of T2D, and the importance of patient education for understanding and managing T2D and its complications. The discussion highlights the central role of the Certified Diabetes Care and Education Specialist, and the role of ongoing emotional support in managing life with T2D, including patient education through reputable online resources and peer support groups.

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DIGITAL FEATURES

This article is a transcript of a discussion between a patient with type 2 diabetes and a physician. To access the podcast please go to <https://doi.org/10.6084/m9.figshare.21995090>.

TRANSCRIPT

PK: Hi there. I'm Dr Pamela Kushner, a clinical professor at the University of California Irvine Medical Centre in Orange, California. I want to introduce Anne Dalin. Anne, introduce yourself.

AD: Thank you. I'm really happy to be here. I am a co-leader of DiabetesSisters [1], a group that's a peer support group for women, and I'm a patient advocate for the National Kidney Foundation [2]. I've had diabetes for approximately 22 years and that's type 2.

PK: Please tell me a little bit, Anne, about your journey so far with type 2 diabetes. I think the audience would enjoy hearing that.

AD: Well, my journey started, as I said, about 22 years ago, and it goes back before the type 2 diabetes diagnosis. I had heart issues, which is what my father had, and I felt fine. I didn't think there was anything wrong. I was in denial because I felt great, and it wasn't until after I had a heart attack that my type 2 diabetes was diagnosed then, and I didn't realize at that time that heart disease and type 2 diabetes were connected. So it all fit together afterwards, but it was through a long journey of finding this out, and after my heart attack, I had stents inserted, and that caused other issues. And so it went from the heart disease to diabetes, and then to kidney issues because I was allergic to the dye, and I also had type 2 diabetes, which was part of the issue as well.

PK: That's a rocky road you had. So you had those four stents placed, and that's consistent with triple-vessel heart disease, which is very common in people with diabetes [3]. So two questions for you: how old was your father when he had heart disease?

AD: Oh my gosh. I think it was probably his later 40s as well.

PK: Okay, that's very young. And did you have any symptoms during the time that you had that heart attack?

AD: Not really any that I connected to a heart attack. I was tired, but I was busy, and then, in the middle of the night, I couldn't sleep, and then my breathing was a little bit harder, but I couldn't understand why. And the

next day, I did have some typical symptoms, which was the pain in the arm, the tightness in the chest, and that's when I realized, 'I know these symptoms,' and that's when I called 911.

PK: This is very typical, Anne. You're basically well until you're not, and a lot of people think they're fine until it's almost too late. Sometimes clinicians are very busy, and in that way asymptomatic conditions could be diagnosed later, and if the patient doesn't bring it to the physician's attention, the early stages of type 2 diabetes and chronic kidney disease might be missed. We need to remember that kidney disease is commonly seen in patients who have diabetes, so we want to make sure to screen patients regularly for this [4].

Also, we want to remind clinicians to be aware of the cardiorenal metabolic risks that are an important part of type 2 diabetes. What this means in English is that the heart, kidneys, pancreas, liver, and brain all work together, which is why clinicians call it the name 'cardiorenal metabolic disease' [5]. How did you feel emotionally about this whole process?

AD: Well, I kept it a secret. I felt I was responsible for what was happening to me. So everyone knew about the heart attack, but when I was diagnosed with type 2 diabetes, I didn't mention it to anybody, and I had no idea that any of this was connected. So it wasn't until many years later that I learned—and I was lucky to be part of an organization called DiabetesSisters [1], which I'm still part of, and co-lead a group—that there are so many things that come into play when you have type 2 diabetes, and that these things are all interconnected in your body. The inflammation doesn't choose one organ or the other; it affects everything, and so it was a big learning situation for me to find out what was going on.

PK: This is a very important point because I think it's important for patients to recognize that they have a role in their healthcare [6]. They need to share responsibility and decision-making with their clinicians, which means that they need to understand the link between heart disease, kidney disease, and type 2 diabetes. And I'm glad you had some support because many patients feel shame when they get sick. It's kind of crazy, but they feel like they're solely

responsible for their gene pool and their poor diet, but it's not just only about that. So what treatment were you on, Anne?

AD: In the beginning, I was on metformin, and I dealt well with that. It helped but unfortunately I didn't change my diet enough. And so, as much as I was taking the metformin, things were still happening that caused my health issues to worsen. So it was one of these situations that even though it was up to me to learn more about it—this was 22 years ago, almost—at that point I didn't really have any information and didn't know where to look and my doctors weren't suggesting anything.

I stumbled upon DiabetesSisters from somebody else that I knew. So I was very, very lucky, and it wasn't until later, when I was having my kidney issues and my diabetes wasn't improving, that I realized, 'I need to go out and find out more information and learn what will help improve my life, rather than just dealing with the symptoms of these health issues.'

PK: So, basically, you recognized that the kidney disease was progressive, and you were very close to dialysis, right, when you had your kidney transplant?

AD: I'd say it was within a couple of weeks. My son was being tested to see if he would be a match, and thankfully, he was a perfect match; the screening process that he went through came through with a positive and he could be my donor. So the hospital called me and said, 'You're ready. You're coming in next week,' and my kidney function was incredibly low. The GFR (glomerular filtration rate), which is the filtration rate, was under 15, which is not really very good, and so I was, like I said, about 2 'weeks' away from going on dialysis, and that's what they had said to me.

PK: Right, and then the reduction in insulin requirement can increase the risk for hypoglycemia when you have a much lower blood sugar [7]. And were you symptomatic from that?

AD: Well, I didn't realize why my numbers were not crazy. I didn't know that that's what happens when the chronic kidney disease is progressing. I thought, 'Oh, look, my blood sugars are doing really well,' and so everything was being masked by what the kidney disease was doing to my body. And actually, after I had

the transplant, my blood sugar numbers soared. They went up to maybe 400 [mg/dL] while I was in the hospital, so they put me on insulin, and that was –

PK: Yes, that makes sense.

AD: Yes, I had never taken insulin before, so that was a big adjustment for me.

PK: Yes, well, after the kidney transplant, there's a risk of worsening glycemic control because you take immunosuppressive medications [8]. Now you have a functioning kidney, and this can affect how your glucose metabolism goes on. So we have to remind ourselves and patients that kidney disease increases the risk for low blood sugar as it progresses [7], and some medicines stay in the body longer, so we want to do everything we can to prevent the need for kidney transplantation and dialysis and preserve the kidney function we have [4].

But all clinicians and all patients have to recognize the potential risk for cardiorenal metabolic disease. Even if that patient appears well and the glucose is well controlled, like you had, there still could be damage occurring under the surface in the myocytes, the heart cells, and kidney cells [5], and so it's really challenging. You were lucky enough; you had some symptoms with shortness of breath. Some people have swelling, and some people have severe fatigue; but that's why we have to spend some time looking at the risk factors for declining kidney function, heart function and pancreatic function. So tell me what advice you were given, other than 'Eat better.'

AD: Yes, that that was one of the things I was told initially—to eat better. So I went to a dietician who I think specialized in type 2 diabetes and renal issues, but what she was suggesting as a diet for me didn't really work as well as I hoped—it was too many carbohydrates I guess for me—and so my numbers kept going up, even though I was doing what she said for each meal, what to eat. And so, again, I had to go do some other research to try to figure out what to do, and –

PK: But let me—I'm sorry to interrupt you, but you made a very important point. Hopefully, all patients and clinicians who listen to this will make sure that they have a Certified Diabetes Education Specialist [9] giving them

nutrition advice because it's almost impossible for you to figure this out on your own, and a person who's not educated specifically in this area and certified would have difficulty figuring out the best diet for somebody with heart disease, kidney disease, and diabetes. So this is really a very good point, and I want everybody to leave this podcast getting a specific plan for themselves to make sure that they see somebody who's a specialist like this; they're available, and insurance should cover it in most cases.

So the other point that you make is the latest clinical practice recommendations from the American Diabetes Association have a range of treatment options, other than metformin, that can improve the prognosis for patients and can help prevent the onset of end-stage kidney disease [10]. So we want to remind everybody that while diet and exercise are a very important part of managing hemoglobin A1c levels, make sure you see that Certified Diabetes Education Specialist. I feel like I'm doing a commercial for them, but the support that they give the clinician is invaluable. They can also help in terms of continuous glucose monitoring, which really helps people see which dietary changes have the most impact on their glucose; for some people it's corn, for others it's a potato, and for some people it's neither of these.

So it's important to have that self-education and have the collaboration of a team so that you have that Certified Diabetes Education Specialist [6]. You have a pharmacist you see regularly. You make sure your other specialists all communicate together, and that would be really helping people understand more about their disease and more about their condition because it's not a disease. It's really a long-term condition. You don't just get over this. So tell me what DiabetesSisters does for you.

AD: Well, DiabetesSisters is an amazing peer support group, and it doesn't cost anything for someone to decide to join. The only thing you need to do to join is show an interest, and you can then start attending meetings, either in your area or online. So if you don't live near where a meeting is held, you can still always attend. And specifically for women, a lot of the issues are different than they are for men, and

there are support groups that are general support groups for women with diabetes. So one group will focus on things like whether it's from, let's say, menopause or there's PCOS [polycystic ovarian syndrome], which is a metabolic state. All sorts of different things come into it that men don't have to deal with, and so being part of an online support group like this has been amazing, and they've become part of my family. I'm friends with so many people, and it's just made a big, big difference in my life.

PK: I like the fact that you had said that, for diabetes, they recommended going to the ADA—the American Diabetes Association—website [11] and the Joslin diabetes website [12]. So I have a question for you. I know you lost around 60 pounds after you had your first heart attack, and this is an important risk factor to mention. You did this because you knew that obesity is a risk factor for the cardiorenal metabolic process, and if we can prevent obesity, which we're not doing a great job of in the USA, then that would help prevent some of the complications of diabetes, not all of them. And we want to be able to help patients manage their weight with a diet that they can keep to, to help keep their glucose under control [13].

In terms of dietary interventions, of course, physical activity is very important in maintaining a healthy weight, not necessarily losing weight. And I love the fact, Anne, that you pointed out that people need support. They need information so that they can participate in the management of their care. They need to understand the link between diabetes and other comorbid conditions like heart disease, chronic kidney disease, and obesity, all of which you were unfortunately exposed to. And I like the fact that you mentioned non-pharmacologic options that include healthier behaviors that you changed, and I want to remind people of something that you didn't mention, but sleep and mindfulness are also important in glucose control and help people manage their diabetes [6]. So—education comments, Anne?

AD: Well, I agree with you 100% regarding everything you just said, but I need to go back a little bit. After my heart attack, I tried to make some changes, but I wasn't successful. I really

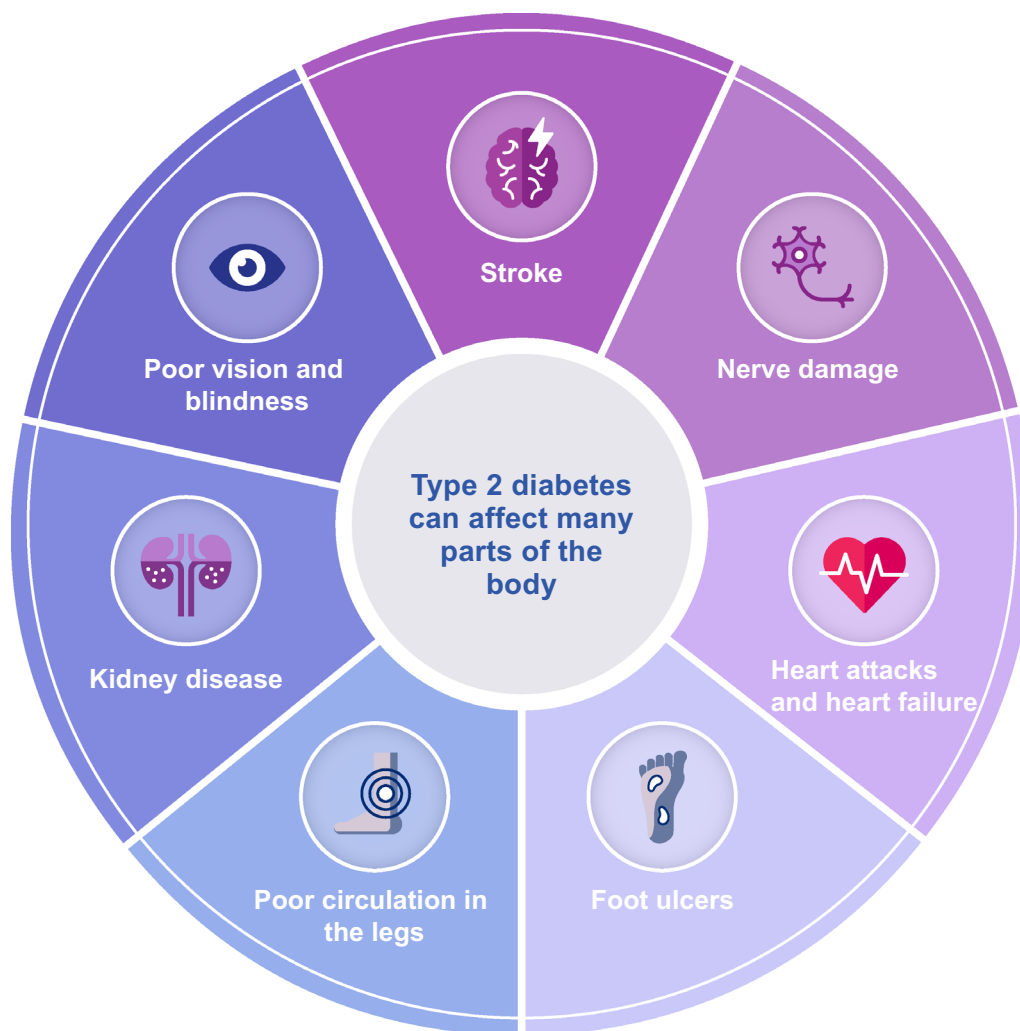


Fig. 1 How type 2 diabetes can affect the body

struggled, and so was having issues with food, which has been an issue for my entire life—that was hard to manage.

It wasn't until many, many years later that I learned what would work for me and what would be sustainable for me so I could manage all of these health issues. I wanted to improve my health as best I could, and I've been lucky in that the steps that I've taken have helped me either sometimes get off a medication or have it reduced by my physician, and I have to say that working with an endocrinologist was something that made a huge difference for me. My primary doctor was excellent, but he wasn't as well informed about different things regarding type 2 diabetes, so when somebody

recommended an endocrinologist, I was really very grateful because that made a difference in my care, and that's when all my health issues started to improve and I saw a big difference.

PK: I think that that's a point that you bring out which is very valuable—that it's involvement in your own care, recognizing that there may be therapies, both pharmacologic and non-pharmacologic, that could help you, and making sure you get that information are all very valuable [6]. Many patients don't recognize that type 2 diabetes affects many parts of the body, like you had the heart attack, heart failure, foot ulcers, circulation, kidney disease (Fig. 1) [3, 4, 14]. Blindness in diabetes is recognized by most people because diabetes is the most

common cause of blindness in the USA [14]—[also] of stroke and nerve damage. So I urge people to go to reliable sites that you had recommended here and that your organization recommends people to get more information. I want to urge people to go to reliable sites for information, and I want to thank you, Anne, for openly sharing your story with the group.

AD: It's my pleasure. It's part of my recovery, and that's why I am part of DiabetesSisters. I'm very active in that group. Like I said, I co-lead a group once a month, and so that's a major part of my life, and then I've become a member of the National Kidney Foundation advocacy group, of a committee. That's something that, again, because of the kidney transplant, being part of that organization and knowing that they are sharing very reliable, updated information, I need to have places to go to that I can trust, and so it makes a big difference for me to be able to know these are the organizations that I do trust.

PK: Thank you.

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