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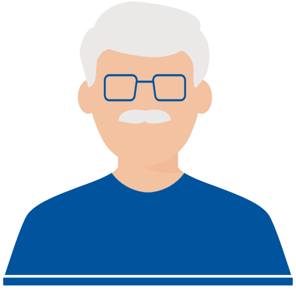
LIVING WITH DIABETES

INTERVIEW

How long ago and how did you find out you had diabetes?

Type 1 | 30+ | Cyprus

It was the beginning of May 2001, when I was 11. My mom had taken me to the doctor's office because she had noticed that I had lost a lot of weight in a very short time and was feeling extremely fatigued. The moment the doctor saw me, without even testing, he said that I either had a thyroid problem or diabetes. He immediately took my blood and sent it for testing. The results came back a few days later; I remember when I came back from school my dad was already home with my grandmother and he told me that the doctor called. I had diabetes and had to be taken to Makario children's hospital immediately. My mom was already in my room packing a small bag for me. I still remember her coming down the stairs with the bag in hand, crying. My grandmother was also crying.



Type 2 | 70+ | UK

I long suspected I was at risk, and was formally diagnosed in September 2009. Various skin issues finally prompted testing, which included fasting blood sugar testing and a glucose tolerance test.

Type 2/3c | 50+ | UK

Around 12 years ago now, I think. My doctor suggested the test because of repeated yeast infections. The test was the standard blood test following a sugary drink (glucose tolerance test). I had to wait in the surgery for a few hours but otherwise it was straightforward, and the results were back within a week. I was diagnosed with type 2, but I actually suspect it is *3c*, which is a direct result of having had pancreatitis in the past and responds slightly differently to treatment. I had an appointment with the doctor who also referred me to a diabetic specialist nurse in the practice.

What was your reaction to your diagnosis? How did your family and friends react?

When my dad told me I had diabetes I didn't react at first. I even asked my mom and grandmother "Why are you crying? We don't even know what it is." I didn't react badly when the doctors told me that I would have to take injections daily; I think my parents helped a lot with that, because they tried to make it seem as normal as possible. My friends were too young so they didn't really understand the condition. I remember one friend asked me if it's contagious!

I was not really surprised as I had suspected it. My family and friends didn't have any reaction either. There is no family history.

I was quite upset, and I remember that I had nightmares for a few weeks, specifically around blood. I was frightened. I spent quite a lot of time researching diabetes online, which on reflection was probably not helpful because I ended up being more worried than I needed to be. I don't remember any particular reaction from friends. My mother, in particular, was and continues to be very worried. She was very worried indeed during the Covid pandemic. Nobody else in my family has diabetes, although my father, who is now 80, has recently been told he is pre-diabetic.

When you found out you had diabetes, did your doctor give you immediate guidance and treatment?

Yes. Type 1 diabetes usually manifests in people under the age of 18 and the children's hospital in Cyprus has a great support system. When I got diagnosed, I spent 3-4 days in the hospital where the doctors regulated my insulin and brought it down to normal levels, and they also taught me and my parents how to inject insulin.

Yes, I was started on the oral medication metformin.

Yes, I was referred for an information programme on diet and lifestyle as well as being put on the list for annual check-ups and for eye and foot testing. I also had further blood tests.

Did you look elsewhere for information?

Other than the information we got from the hospital, which included a very thick booklet about diabetes, my dad, an ex-army officer, did meticulous research, mostly online. He also found out about the available support groups in Cyprus.

I looked up a few references and searched on the internet.

I did quite a bit of research online, and joined Diabetes UK, which provides a quarterly magazine that includes updates on the latest research.

Did you receive any support when you were diagnosed? Are there any support groups or communities that help one another?

Yes, the Cyprus Diabetic Association for people with type 1 and type 2 diabetes are dealing a lot with children that need support. They organize annual camping trips, meetings and events. In the beginning, I was a bit reluctant to go on the camping trips, but a high school classmate who was also diabetic suggested I should join. From then on, I met a lot of people and made friends for life as my main group of friends are people I met in such events. I think it's a very strong community in Cyprus.

There are support groups – I joined Diabetes UK which is both a patient facing and a research organisation.

I was invited onto an information programme for people who had been recently diagnosed. Other than that, I have not received, or, to be honest, sought any further support. I have never felt that it was necessary.

How has your treatment changed over the years?

Since I was diagnosed, I go to the doctor once every three months to check my HbA1c. That's the average percentage of glucose levels in your blood for about a period of three months. It is supposed to be under 7% and for healthy people I think it should be under 6%. There are different types of insulin: fast-acting insulin, medium-acting insulin, and slow-acting insulin. The slow-acting insulin is a shot you usually take once a day to keep your insulin levels steady and it lasts for about 24 hours. The medium and fast-acting are the ones you inject right before or after a meal. When I first started injecting insulin, I was using the medium-acting insulin, which I think was the only one available in Cyprus. Through the years my doctor suggested switching to fast-acting, which even though requires more daily injections is more flexible regarding the time I have to inject it and when I could have a meal.

When I was first diagnosed, I started metformin. My HbA1c failed to come under control and various medications were tried, including two of the injectibles: exenatide and liraglutide. I was eventually given dapagliflozin, which at the time was relatively new and not available on the UK's National Health Service, although it subsequently became so. My current anti-diabetic medication consists of three different medications: six tablets overall on a daily basis. My treatment is reviewed regularly. I also have reqular eye screening for retinopathy.

Initially, and for a number of years, I was treated with diet alone. The first medication I received was metformin, which has since been supplemented with empagliflozin and semaglutide. My treatment is reviewed every six months, and I have eye and foot tests annually.

"After more than 20 years of having diabetes, it's part of everyday life, it's like waking up and brushing your teeth."

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How do you feel about the treatment you've had, and do you know whether the treatment options differ among countries?

I know for sure that the US and other European countries are further developed in the diabetes sector although, in recent years, most of the treatments and devices available in other countries are also available in Cyprus with a small delay. For example, the insulin pump was available in other countries earlier than in Cyprus. I know they have been experimenting with pancreatic cell transplants that produce insulin but that is still in the trial phase. Because diabetes is an autoimmune disease, there is an expiration date on the transplant as your body is still going to attack the healthy cells.

There is a very wide range of anti-diabetic medications available, and I am sure there will be differences around the world. I have no doubt there is constant research and new therapies being developed. I am happy with the regime I am on.

I feel that I have been taken care of very well. I have a good relationship with my diabetic nurse and have always had access to annual and semi-annual tests.

Are there any difficulties, limitations, or side effects concerning treatment?

If you inject too much insulin, you might get hypoglycemia, so you have to check your blood glucose to know how much insulin to inject. These are things you learn either through the doctor or through trial and error. There are some limitations in things you should eat. In theory, you can eat whatever you want as long as you inject the correct amount of insulin, but since insulin stops the breakdown of fats, the more you use the greater the risk of becoming obese. I feel like I have the same dietary limitations as a healthy person; I can still eat a piece of chocolate or a piece of cake when I feel like it, but not daily. When I was younger, myself and my parents were a lot stricter on my diet, thinking that if I had a small piece of chocolate it would be the end of the world. As I grew, I realized that with balance, I can continue to enjoy foods I like. As for difficulties, I would say fear of needles. I've heard stories of children who had to go to psychotherapy to overcome their fear of needles to be able to receive insulin injections. Even though I did not have that fear, it still took me some time to gain the confidence to comfortably inject myself.

None other than number of tablets I need to take per day.

Not really. The empagliflozin gives me very regular yeast infections which can be quite painful, and is managed with a regular prescription for external thrush cream. The metformin also means that I can have diarrhea with very little warning, usually shortly after the first time I eat in a day. Obviously, I am being affected by the current shortage of semaglutide, and I am currently trying to arrange an appointment with my doctor to discuss possible alternatives.

> **"Talk to your healthcare team. They are your new best friends."**

Are there any specific precautions you need to be taking for specific events, such as traveling?

Yes, I should always have something sugary with me in case of hypoglycemia, preferably something with fast-acting sugar such as chocolate, candy, or juice. For me, I find it the easiest to always carry a juice box with me. Of course, I always have my insulin and glucose meter with me.

I make sure to eat regularly during the day. When traveling, I ensure that I carry an adequate stock of medication.

Not really. If I am going to be away from a toilet for more than 2 hours, I wear incontinence pads. That is really about all.

Do you feel like things are changing and there are improvements in how diabetics are being treated?

I don't think this was ever an issue, but I did hear stories of parents asking their diabetic children not to tell someone they have diabetes because of what people would say. Most people are okay with this, there is no difference in how we are being treated. At different jobs though, they have asked me to give them instructions on what they may have to do in case something happens, which is not a bad thing. It's good for people to know what to do if I faint and not to freak out.

Without doubt.

I have not noticed any particular changes since I was diagnosed, but I am lucky in that I think the care I have received locally has always been excellent. The one issue I have is not currently being able to get semaglutide, which is used as a weight loss drug, meaning that demand is exceeding supply.

How does having diabetes affect your everyday life?

If you have asked me this question 15 years ago I might have had more things to tell you. Now, after more than 20 years of having diabetes, it's part of everyday life, it's like waking up and brushing your teeth. It's a mechanical thing I know I have to do. In the beginning, there was an adjustment period, especially with the injection of insulin. With time it becomes a routine, I estimate how much carbohydrates I will eat to know how much insulin I will use.

It doesn't really other than controlling sugar intake and eating sensibly.

Not very much at all other than planning around being close to toilets. My close friends are aware of toilet issues and there really isn't anything that affects me.

Is there any advice you would offer to someone newly diagnosed with diabetes or anything you would like to share?

Diabetes is probably one of the best things that happened to me. I have an awesome group of friends who also have diabetes and they have been my friends for more than 15 years. Out of every condition and disease in the world, I would say that diabetes is the least painful to have and most manageable if you do the things you are supposed to do. I am lucky that it is diabetes and not something unpredictable. It is nothing to be scared about! Don't be afraid to tell your friends, don't be embarrassed about it. Inject your insulin when you are supposed to, it's ok if you have hypoglycemia, it's ok to ask your friends for a 5 minute break. And don't let diabetes dictate your life, if you do the things you are supposed to do, you will be fine.

Follow the guidance and advice. To me the most difficult thing is the diet. Trying to eat sensibly for the diabetes but also considering other nutritional issues is not always easy. As a self-confessed 'chocoholic' for many years, controlling this aspect has been diffcult but achievable.

Don't panic. It is not necessarily a huge problem, and all of the worst case scenarios you read about online are unlikely to happen to you. It does not automatically mean insulin injections and all of the issues that go along with that. For me, it has had very little effect on my day-to-day living so far. Talk to your healthcare team. They are your new best friends! Most of all, remember that you can still do all of the things you enjoy. You may have to think about diet and life-style more than you did, but that is a good opportunity to get healthier!!

> ***"Trying to eat sensibly for the diabetes but also consider other nutritional issues is not always easy."***

Disclaimers:

- *Names have been omitted to protect the privacy of the individuals taking part in the interview.*
- *The content of this interview is intended for informational purposes only, and should not be perceived as medical advice. Diabetes is a complex condition with different treatment plans. Alaways seek advice from your healthcare providers if you have questions or concerns about diabetes or treatment.*