

From the other side of the desk: Patient perspective

Through diagnosis to pregnancy: My journey with diabetes

Karen Barrett

I was diagnosed with type 1 diabetes on Valentine's Day, 1983, a day meant for chocolates, roses and sweets. What an irony it turned out to be. Dressed in my school uniform and ready for school, my Mum, being a nurse, had known for some time that something wasn't right. I had lost a substantial amount of weight and the bathroom seemed to be my best friend, as did my unquenchable thirst. "Oh what a bombshell!" my Mum's colleague said that day after hearing my diagnosis. I never really comprehended the significance of the diagnosis at the time. I had felt fine.

In the early days after my diagnosis, to see my diabetes specialist meant a day off school and a trip to Canberra – that was the good part. The not-so-good part became the endless questions from the doctor – what was I putting in my mouth and at exactly what time of the day – measurements on the scales, numbers in books, pathology results and eye tests. On and on it went. Would I pass or fail? Had I been good or bad? I hated it.

There was never a time that I let my diabetes stand in the way. I was quite sporty growing up in a small country town, later trying triathlons and endurance sports. But in my school life, I was sometimes left out, missing the first school camp because everyone was so very nervous to have a person with diabetes at camp and friends' parents being reluctant to have me over, afraid of what or what not to feed me.

As an adolescent, I was studious and quite fit and healthy, with an obsessive personality. That was until my late teens, when I seemed to burn out with school, with life and with diabetes. Life became tricky. I found solace in food and subsequently paid the price, gaining weight.

My family, of course, was concerned, but the constant questions about how many blood sugar tests I was doing and whether I was looking after myself was a continuous reminder of my diabetes, something I wanted to forget. I ate in secret and lied to keep them satisfied while continuing to silently struggle. I was tired of all the rules, tired of all the questions and tired of being different and feeling restricted. As I entered adulthood, I thought I kept my struggles well hidden from others for many years. I went on to study nursing at university and the big wide world gave me even more freedom to hide from the reality of diabetes. Somehow, I stayed on the tightrope of avoiding routine doctor's appointments while also avoiding more serious hospital admissions. A visit to the doctor would mean tests, which I knew I would fail, and questions that I would be ashamed to answer – I wasn't up for the interrogations and judgements. But, I didn't *feel* like I was failing! I was eating what I wanted, when I wanted, and being like the rest of my friends and peers.

Time to get real

Then I found out I was pregnant...unplanned. For me, I realised it was not fair to have a child, with the high risk of complications to me and my baby as a result of me not looking after myself. A decision, that I feel to this day, even though I agreed, had already been made for me. Time to get real. If I was to ever create a family of my own, it meant facing the issues I had so long avoided – the medical world testing me on passing or failing at diabetes.

Unable, and not allowing myself, to be anything other than perfectly controlled, I became a

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About this series

The aim of the "From the other side of the desk" series is to provide a patient perspective on a topic within diabetes, to reflect on the doctor-patient relationship and to inform clinical care.

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champion of the tests. It was an intense time but my motivation to have healthy babies drove me to that perfection, and I went on to have three babies in 3 years. I told the medical team what they wanted to hear, but this time I wasn't lying.

It became my obsession to get the numbers right. Averaging about 12–14 blood sugars daily and the never-ending specialist appointments were vital to achieving the desired outcome. I was lucky that the care I received from my diabetes team during my pregnancies was excellent and well planned. I feel that it is vital to have a trusting relationship with an endocrinologist before, during and after pregnancies, and I was very fortunate to have that. But pregnancy with diabetes is not without its difficulties; the severe hypos during the first trimesters became frequent and increasingly exhausting, and with every pregnancy, I had another toddler to care for. My first-born was diagnosed with cerebral palsy (totally unrelated to my diabetes), and as if that was not sufficiently challenging, I became a single Mum when my youngest was 11 months old. Juggling three toddlers, a part-time job to survive financially and my diabetes became routine. The all-or-nothing personality has some advantages and in those 3 years, I was switched to “all”, determined to be a good Mum.

However, as the years went by, I let those numbers slip again. My three gorgeous children, my world, were growing up fast, and at aged 6, 7 and 8 years, they kept me busy. I kept the medical team at length – I knew I wasn't going to “pass the test”. My 7-year-old daughter, Presley, had spirit (sometimes too much!) and when she came down with a viral illness, as a mum with diabetes would, I checked her blood sugar. My Mum had suggested the “D” word as Presley kept sleeping through the day, which was very much unlike her. I still recall that moment, and I think I too knew something wasn't right. Weeks later, Presley mentioned to me that she was waking through the night to go to the bathroom. I knew. I waited.

My beautiful girl was dressed in her swimmers ready to go swimming. I did her blood sugar and there I was – the mother of a child with diabetes. Now it was me answering the questions not as a person with diabetes, but as a Mum. It was more than my own tests – I had to pass all of Presley's

tests as well.

I felt my skills as a parent were put under the microscope. I believed it was all my fault if her numbers weren't right. What was she eating when I wasn't there? Was she exerting too much energy during lunchtime at school? Could she recognise a hypo? I felt like I had to live in her head, and I became the “helicopter” Mum. Presley too hated the medical world, clamming up at all the questions and hating the scales and numbers. At home, she dealt with the never-ending motherly concerns and requests to check her blood sugar, blaming every ailment or headache on diabetes, whether or not it was.

Where I am now

Despite some complications of my own, at 44 years of age, I now take care of myself and feel as well as I can feel, given my past “bad behaviour”. I have a good relationship with my team and appreciate the rapport I have with them, which has taken many years to establish and develop. I now take charge of my appointments and we talk about the concerns I have. The first questions asked are not “shall we look at the numbers?” or “how many highs/lows are you having?”; rather, “how are you, and what's going on in your world?”

I have had a lovely relationship with my psychologist who somehow allows me to be proud of who I am and what I have achieved. I am now free of the judgement calls that I thought were placed on me as a person with diabetes and then as the mother of a child with diabetes. Mistakes are human. Rough patches enable us all to make better choices, and experience allows us to call the shots. It's OK not to be perfect. I truly hope that if anything, I can pass this on to my children and that they reach this point a whole lot sooner than I did.

As a person with diabetes, my advice to the medical world would be to consider the person in front of you without their diabetes diagnosis. Diabetes management is far more than looking at the numbers. Consider their state of mind and the unsaid pressures they may have put on themselves. The bravest thing one can do is to ask for help and say that we're not OK, and creating an environment where people with diabetes feel comfortable and safe to do so is vital. ■