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...
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.

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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.

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