



Darling Daniella

When Donna Meads-Barlow's five-year-old daughter, Daniella was diagnosed with Type 1 diabetes, she had no real understanding either of the disease or of the potentially fatal risks associated with this incurable condition.

AS TOLD TO CATHERINE MARSHALL

Daniella was diagnosed at the age of five, on 6 October, 1999. My husband Brian and I had just touched down in London. We had a nanny, Robbie who had Type 2 diabetes and she'd taken Daniella and her little brother, Josh to a party that afternoon back home in Sydney. They'd had a lot of chocolate cake to eat at the party.

When she was sitting on the couch watching TV with the kids that night, Robbie was doing a finger prick to test her blood glucose levels or BGLs and Daniella said, "What are you doing?" Robbie told her, "I'm checking my sugars." Daniella asked, "Can you try it on me?"

And that's how we found out. Robbie knew that when Daniella's BGL was 15 (the normal range is between four and eight), that something was wrong. She rang the endocrinology section at the hospital. The hospital told her to put her to bed, not to give her any food and do another test in the morning. I think her BGL was about 19 the following morning. The doctor sent her straight to hospital.

We spent the next two days trying to get on a flight and to understand what was diabetes, why did Daniella have it and who was responsible?

We spent the next year trying to get our head around it and to understand it was for life and it was never going to go away.

LIVING WITH DIABETES

Over the years, Daniella got used to living with type 1 diabetes. We were always actively involved in awareness campaigns and fundraisers. We'd go out with buckets to collect donations and she would talk to people face to face about her condition.

Daniella managed her diabetes well. On 8 November 2011, she had been on a Year 12 school excursion the day before. She loved to sing, so we sat and watched *The X Factor* that night. She had a massive bowl of custard and a banana and went to bed with a BGL of 12.2. When I went to wake her up for school at 6.30 the next morning, she was face down. I thought she was having a hypoglycaemic attack (when blood sugar levels drop too low and diabetics can fall into a coma).

I screamed and, because she was down stairs, I ran upstairs to get Brian. While he ran downstairs, I ran to the fridge to get the **Glucagon** (an emergency medication that releases sugar stored in the liver, increasing BGLs). I turned up with the needle and by that stage he'd turned her over

and he knew something was very wrong. She was blue and had blotches throughout her body, through her legs. Your brain just scrambles – there was a phone in the room, but I didn't think to use it. I ran upstairs again and rang 000; they said we needed to do CPR. I reckon I did CPR for at least 25 minutes while my husband and my stepson, Chris disappeared upstairs to wait for the ambulance.

I was screaming and shouting, "Come around!" But she was gone. I didn't know that, and I couldn't have comprehended it anyway. When the ambulance arrived they took her off the bed, onto the floor and within minutes they said, "Look, I'm really sorry, she's been gone for hours".

A CANDLE IN THE DARK

When Daniella died, someone from the Juvenile Diabetes Research Foundation (JDRF) put a blue candle up in memory of her online and it went around the world. After that, I had all these parents contacting me. It was all very raw at the time but when I had an opportunity to take a breath, I realised they were parents of kids who had also gone.

I started to count them and I was shocked. They'd died not just from hypoglycaemia, but also from hyperglycaemia, which can result in coma and death. I realised there were

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DONNA MEADS-BARLOW

so many kids and adults out there suffering from these (particularly nocturnal) unaware hypoglycaemic attacks. I was told three kids including Daniella had died in Australia within a period of six weeks.

When Daniella's endocrinologist, Dr Neville Howard arrived at the house after her death, I asked him, "How could this have happened?"

He said, "You know, Donna, there are technologies in other parts of the world that **could** have saved your daughter's life."

Dr Howard was on the board of Diabetes Australia, so he put me in contact with some people there who knew Daniella and they set up a trust (this was later changed to the DANII

AU only

FIGHTING FOR THE FUTURE

In the eight years since its inception, the DANII Foundation has been instrumental in lobbying government to subsidise continuous glucose monitors, which can both alert diabetics to BGL emergencies and make the management of diabetes more effective, thereby reducing complications and preventing fatalities. In 2017, the federal government introduced stage 1 of the Continuous Glucose Monitoring (CGM) Initiative, providing fully subsidised CGM products to children and young people under 21 with type 1 diabetes. In November 2018, the Minister for Health, Greg Hunt announced the Australian Government would commit more than \$100 million in additional funding to expand the CGM Initiative. Although potentially life-saving, these device subsidies are currently not extended to all Type 1 diabetics. The foundation provides grants for such equipment, raises funds and awareness with its annual Jelly Bean Ball and convenes an annual Jelly Bean Educational Cruise supporting people living with Type 1 diabetes and their carers and extended families.

Foundation). The aim was all about getting technology into Australia that would alert parents and carers when their loved one is approaching a diabetic emergency. That's been the goal right from the day she died.

WHAT IS TYPE 1 DIABETES?

Unlike the more prevalent and potentially preventable and reversible Type 2 diabetes, Type 1 diabetes is caused by an autoimmune response in which the pancreas' insulin-producing cells are destroyed. Onset most commonly occurs in childhood, and there is no known prevention or cure. Type 1 diabetics must inject insulin every time they consume carbohydrates.

Both hypoglycaemia (low blood sugar) and hyperglycaemia (high blood sugar) are life-threatening in all diabetics.

Anybody who knew Daniella loved her. She lived to try and make a difference in the world of diabetes. I know she would want me to make sure we were doing all we can to make sure what happened to her doesn't happen to anyone else.

Today, I get thousands of emails through the DANII Foundation, people telling me their stories, saying their child is unstable, that they're frightened they're going to die. You never actually really think there's a chance they're going to die but when they do ... I mean, we've lived every parent's worst nightmare.

It's more prevalent than we know but it's not discussed. I feel so much for the parents, I really get where they're at. 

• World Diabetes Day, 14 November annually, is a special day for the Meads-Barlow family in memory of Daniella and acknowledging those who live with this life-long disease. danii.org.au

VISIT MINDFOOD.COM

Unlike type 1 diabetes, type 2 diabetes is largely lifestyle-driven. There is much you can do to reduce your risk of developing type 2 diabetes and these seven suggestions are a great start. mindfood.com/reduce-risk-diabetes



TEARS TELL A STORY

Tear-testing may be the future of screening for diabetic peripheral neuropathy, a debilitating condition that affects people with diabetes, new research from UNSW Sydney suggests. The study, recently published in *The Ocular Surface*, is the first to show that peripheral nerve damage – often the earliest sign of the condition – can be traced in tear film. "We found that people with type 1 diabetic peripheral neuropathy – which can result in recurring ulcers of the feet and in severe cases require amputation – have reduced levels of a protein known as 'substance P' in their tear film," says Dr Maria Markoulli, senior author of the study.

"In the future, people with Type 1 diabetes may be able to have a quick tear sample collected either at their optometrist, the chemist, GP or endocrinologist, and be told whether they are at risk."

Peripheral neuropathy is the most common complication of diabetes and affects almost 50 per cent of diabetics. It occurs when chronically high blood sugar damages the nerves connecting the brain and spinal cord to the rest of the body. Symptoms include pain, numbness, imbalance, weakness, pins and needles, and recurring foot ulcers. While nerve damage cannot be reversed, early detection can help patients better manage the condition and prevent further complications. However, current early testing options are limited to invasive examinations such as skin biopsies.