

Daily jabs keep balance between life and death

Rebecca Johnson

Type 1 diabetes is the other diabetes — the one you don't hear about much.

Unlike type 2, which is related to lifestyle choices, type 1 is an autoimmune condition.

This means my immune system destroyed my pancreatic cells that make insulin, the critical hormone for metabolising carbohydrates.

Without insulin, my body cannot use the glucose in carbohydrates for energy and the sugar in my blood becomes unregulated. Scientists don't know what causes type 1 diabetes.

It could not have been prevented and there is no cure. The only treatment is to replace the insulin my body no longer makes.

So every day, in order to stay alive, I must do a number of things. I inject insulin six times a day. In fact, I've had nearly 31,000 insulin injections since I was diagnosed 14 years ago at age 17. I prick my finger for a drop of blood to test my sugar level between five and 10 times a day.

I've had more than 40,000 blood tests so far. I get up early every morning to exercise hard for an hour.

Sleeping in and slacking off isn't really an option, because if I don't exercise, my blood sugar levels rocket as my body becomes less sensitive to the insulin I take. And I have counted every single gram of carbohydrate in every meal and snack I've eaten in the past 14 years.

I must pay around-the-clock attention to my type 1. No matter what I am doing or where I am — at work, playing sport, seeing friends, even going to sleep — I am continuously making life-preserving management decisions to keep my blood sugar level in the safe range.

I do this because if I allow my sugar level to go too high, I cause lasting damage to every system and tissue in my body. The tissues in my eyes,



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kidneys and feet are particularly vulnerable and I live with the real risk of going blind, suffering kidney failure or requiring a lower leg amputation in the future. If I allow my blood sugar level to go too low, I am in immediate and serious danger. My brain powers down without enough glucose to fuel it. I become disoriented and confused, which can be quickly followed by seizures, coma and death.

Maintaining safe blood sugar levels is not easy. The human metabolism is finely tuned and despite my discipline, factors outside my control can shift me into the danger zone within minutes.

Not knowing the carbohydrate content in sauces in a restaurant meal, the effect of exercise in a dash to shelter in the rain, and stress or anxiety which release hormones like adrenalin can all mess up my levels.

I am lucky. I am an adult who can compute complex dose calculations, with the dexterity to test my blood and draw up a syringe, and with language to communicate when I am in trouble.

Try being a five-year-old with type 1. Kids with type 1 do not have the tools to do the complicated diabetes maths or give themselves an insulin dose, and they can't always communicate that they need help.

It's a difficult world for a kid with type 1. The routine cramps their spontaneity, the constant attention makes them feel different from their friends, and the blood sugar rollercoaster can stop them from hurling themselves joyfully at childhood, which is what kids should

do. Parents of a child with type 1 have the job of being their child's substitute pancreas. Being a parent is hard enough, but being a bodily organ is staggeringly difficult.

Parents inject their children with insulin, wake up multiple times a night to test their child's blood, count the carbohydrates in meals and snacks and ensure their child eats enough to balance an insulin dose. With type 1, the daily dinner battle can have life-threatening consequences.

It is no surprise that the daily burden of managing type 1 can wear families down. However, with empathy, education and support, families cannot only survive but thrive.

At the Telethon Juvenile Diabetes Family Centre, which is under construction in Stirling, we acknowledge that managing type 1 is a team effort, and that each member of a child's family copes differently with type 1. We will help children develop the emotional resilience to face type 1 every day and understand that until a cure is found, they will never get a day off. We will support families to manage type 1 confidently and teenagers to deal with the condition positively.

The centre will be the vanguard in Australia for supporting emotional and mental wellness in kids with type 1 and their families. I remember what it was like to eat, play sport, socialise, sleep, travel, work and study without type 1. World Diabetes Day reminds me just how much my life has changed.

It took time to make peace with it, but type 1 has brought some surprising positives — the focus, discipline and resilience, and the drive to get the most out of every day.

The Telethon diabetes centre is the first of its kind in Australia. It opens next year and is supported by Telethon, Lotterywest and the State Government.

Rebecca Johnson is general manager of the Telethon Juvenile Diabetes Family Centre. Tomorrow is World Diabetes Day