

Stories of Type 1

Type 1 diabetes can be diagnosed at any age. Four people share their experiences of diagnosis and living with Type 1 diabetes, with both ups and downs, writes **Deborah Condon**



Interview with Ciara Tuke, mom of Lucas

Around 25 children are diagnosed with Type 1 diabetes every month in Ireland. In 2020, over 40% of new hospital admissions with diabetes had diabetic ketoacidosis (DKA), a potentially life-threatening complication of the condition.

Ciara Tuke's son, Lucas, ended up seriously ill in hospital with DKA in 2019 at the age of just three. She had noticed that he was thirsty "all the time" and had started wetting the bed. However, she was unaware that these were signs of Type 1 diabetes.

"He had always been a big drinker but it got to the stage that he was thirsty all the time and he couldn't get enough. Even when he was brushing his teeth, he would try to suck the water off the toothbrush," she recalls.

She brought him to her GP one Friday after he started complaining about a sore mouth and throat. He was found to have thrush and was prescribed medication for that.

"On the Saturday, he was very lethargic and then on the Sunday, things took a turn for the worse. He wasn't eating and he wasn't really drinking. Then he started vomiting and his breathing seemed laboured. He was awake but seemed spaced out.

"We live in Dublin so went to CHI in Tallaght University Hospital where he ended up in a high dependency unit because he was in full DKA," Ciara explains.

With DKA, as the body starts to run



Above, Lucas, who ended up seriously ill in hospital with DKA at age three, right with mom Eimear Tuke



out of insulin, harmful substances called ketones start to build up. If the condition is not detected and treated quickly, it is life-threatening.

Healthy ketone levels are considered lower than 0.6mmol/L. Lucas's levels were at 6.6mmol/L.

"On the Monday morning, we met with the diabetes team and one of the nurses explained that Lucas was lucky to be alive. That's when it hit us how sick he really was and how close we had been to actually losing him," she notes.

Ciara did not know anything about diabetes, but she says the diabetes nurse took a lot of time to explain that what had happened to Lucas was not anyone's fault. There was nothing she could have done to stop Lucas developing the condition.

Lucas slept for 24 hours straight and

he remained in hospital until the following Thursday.

"Those 24 hours were very scary, waiting for him to wake up. I don't want to experience DKA again, but I can test for it now and try to make sure it doesn't happen again," Ciara points out.

Over those next few days in hospital,

Ciara was taught how to care for Lucas's diabetes.

"We were taught how to finger prick and how to inject. We learned about low bloods, high bloods, when to check for ketones, how to know how much insulin to give, carb counting. It

was an awful lot to learn. There was so much information and we even got homework!

"But the nurses were amazing. They let you do it at your own pace and they would come back to things if you didn't understand. They did injections for the first two days and then I did it and they would make sure I was doing it right," she explains.

Lucas hated the injections and he would get very upset when given them.

"When we went home, he would hide under the table when it was time to inject and not want to come out. You feel terrible because you know it's hurting him in that moment, but you have to do it. The first few weeks were very rough.

Lucas now uses the Dexcom G6 CGM and a pump, which Ciara describes as a "game changer".

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"The Dexcom updates every five minutes onto my phone so even when he is in school, I can see how his blood glucose levels are doing. We still might finger prick the odd time, for example, if the Dexcom says he is low, I'll finger prick to confirm.

"And Lucas will tell you he loves his pump because there are no injections," she says.

Having been so seriously ill with DKA and learning to live with Type 1 diabetes, Lucas is now doing great and is due to start primary school in September.

"He doesn't really understand diabetes completely. He knows he has it and he

knows he has a pump and there is insulin in it. If the Dexcom alarm goes off, he'll say 'my blood sugars are low'. But, he misses out on nothing. He is so active and he loves running around and going on his scooter and bike," she notes.

Ciara encourages everybody to be aware of the symptoms of Type 1 diabetes and if you are concerned about your child, to bring them to the GP and ask for a finger prick or urine test.

"If you feel in your gut something is wrong, get it checked. If it is diabetes, it will take a while to get used to. I'm over a year into it now and there are still good

and bad days, but there are more good now than bad. It does take a while to adjust to, but you will adjust," she insists.

Ciara tries to highlight Type 1 diabetes on her social media because she feels there is a lack of knowledge about it.

"People often confuse it with Type 2 diabetes and think it only affects older people and is associated with being unhealthy. It's so important to remind people that Type 1 and Type 2 diabetes are completely different," she says.

Ciara adds that if she can help even one person to avoid having their child as sick as Lucas was, "that would be great".



Interview with Leah Chung

When Leah Chung from Wexford was around five years old, she watched her grandmother, who had Type 1 diabetes, test her blood glucose levels by finger pricking. She told her grandmother she would "hate to have to do that". However, at the age of 12, she too was diagnosed with the condition.

While many people with Type 1 diabetes do not know many or any other people with the condition, Leah was in the unusual position of having a number of relatives with it.

"My granny, granddad, three great uncles, uncle, aunty and cousin all have it. In fact, my cousin was diagnosed the same week I was," she explains.

Now aged 21, Leah recalls some of the telltale symptoms she had around the time of her diagnosis.

"I was really exhausted and I was drinking so much milk because of the thirst. I was also losing so much weight," she says.

Because of the strong family history of Type 1 diabetes, her mother had a 'fair idea' of what was wrong. Leah was brought to the GP, who sent her straight to hospital, where she stayed for the next week. She remembers feeling "overwhelmed" in hospital.

"I had to have my blood glucose



Leah Chung during a gym session

levels checked regularly, even when I was sleeping, so I would wake up to them checking my bloods. I didn't like injections, and still don't, so I remember injecting and crying. I also remember being told I couldn't eat too many grapes and I loved grapes!"

Luckily her mother had some experience with diabetes as she would have dealt with Leah's grandmother having hypos over the years. Leah says that it was also nice to have relatives who knew what it was like to have diabetes. However, despite this, she didn't always find it easy to talk about.

"Even though when I was young I had

a lot of family members with Type 1, I felt shy talking about it and was very aware of myself. I think people with no family members must also feel shy talking about it. They may want to hide certain things, like they may not want to take their insulin in public. But you have to realise it's normal and you have to do it," she insists.

She also believes young people might keep it to themselves if there is something wrong.

"Pay attention to the condition and tell some-

one if something is not right. It's not always just your hormones. It could be something else," she notes.

In her teens, she experienced high ketones and was at risk of DKA.

"I remember being told about DKA in the hospital, but thinking that would never happen to me. I remember being in my early teens and I was still getting to grips with everything. My ketones got really high and I felt numb and just awful, like I wasn't there. I didn't pass out, but I had that 'almost there' moment. I checked my ketones and they weren't good," she recalls.

Since then, she has had many other

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things to figure out. She embraced technology early on and has been on a pump “for years”. She has used the Freestyle Libre and is currently changing over to the Dexcom.

Socialising is obviously a major part of a teenager and young adult’s life and this

has brought new challenges.

“Alcohol was a tricky one to learn about. And even clothes came into it. Sometimes if I was wearing a dress, there was nowhere for my pump to go, so I would take the pump off and bring my injection with me,” she explains.

While there is a lot to learn when it comes to diabetes, Leah reminds people that they are “not alone”.

“More people are starting to slowly understand the condition. Don’t keep your voice in the dark. If there is a problem, tell someone,” she adds.



Interview with Ruth O’Mahony, mom of Robyn

Just before Covid-19 hit in February 2020, Ruth O’Mahony’s five-year-old daughter Robyn was diagnosed with Type 1 diabetes.

Ruth, a primary school teacher from Wicklow, had noticed that her daughter was very thirsty and was going to the toilet a lot. However, the reason she booked an appointment with a GP was because one day, she picked Robyn up and realised she was lighter than expected, which “set off alarm bells”.

When she looked up the symptoms on the internet, diabetes was repeatedly suggested, but she admits she did not want to believe that’s what it could be. She checked with her daughter’s play-school and childminder and they all said that Robyn was in great form, running around and playing. But Ruth still felt something was wrong.

She told some co-workers her suspicions, but they thought she was being “a bit dramatic”. She went ahead and brought Robyn to the GP. A urine test confirmed diabetes and Ruth was told to bring Robyn straight to CHI at Tallaght University Hospital, where she remained for the next week.

“At the time, it felt life-shattering, but the team in Tallaght was fantastic. They took such good care of us. And Robyn was entirely herself throughout, she just rolled with it. One day, we were allowed out of the hospital for a while so we visited my parents. They found it difficult to understand because she was running around and looked so healthy,” Ruth recalls.

On the day Robyn was scheduled to



Ruth O’Mahony with daughter Robyn

leave the hospital, she experienced a hypo, so she was kept in for one more day.

“The hypo was so scary. It reminded me of when we brought her home from the hospital for the first time as a newborn. You wonder ‘how can I protect her?’ But the team at Tallaght made it very clear that they would always be at the end of the phone,” Ruth notes.

Ruth and her husband, Simon, found finger pricking and injecting Robyn stressful initially and Ruth warns the parents of newly diagnosed children to be careful if using the internet for information.

“You have to be really careful and not go online too much during that time, particularly the American websites. They scared me so much. I’d find myself completely overwhelmed by what those sites were saying. They sent me to such a place of anxiety and made the whole thing seem unmanageable,” she says.

Ruth acknowledges that Robyn’s diagnosis coming at the time that it did, just as the Covid pandemic was starting, has led to a “very disjointed, strange year”.

“We really wanted to teach Robyn

how to live with her diabetes and show her how to do all the things that she wants to do, but we haven’t been able to do much because of the Covid restrictions. And we have great family and friends, but they haven’t really seen much yet. They haven’t seen the rollercoaster diabetes can be,” she explains.

Ruth and Simon have also had to figure out how to ensure that Robyn’s eight-year-old brother, Oisín, does not feel left out either. She notes that it is a “big balancing act”.

However, despite the rollercoaster year the family has experienced, Robyn is doing very well.

“Robyn has been a rock star throughout. Of course she has bad days, but she has never been scared of the condition. Maybe that’s because she was never really sick with her diabetes. If she had developed DKA, things might be different,” she notes.

Robyn now uses a pump, which has given her “better control”. However, Ruth says she is glad she learned how to deal with diabetes without technology first.

“The technology is amazing, but I’m glad I don’t have to panic if, for example, the sensor doesn’t work. I know we can take care of Robyn either way,” she points out.

Ruth encourages anyone who thinks there may be something wrong with their child to check with their GP.

“At the moment, people are even more hesitant to make contact with their doctors because of Covid, but you know your child. My GP said to me, ‘if you come in with something and it turns out to be nothing, that is a good result for the GP’. Trust your gut, especially during Covid,” she adds.

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Interview with Catherine Brady

When a person is diagnosed with Type 1 diabetes, one of the fears they may have is that they will not be able to do the things they did before, especially if they are involved with sport. However, world champion kickboxer, Catherine Brady from Dundalk, has proven that diabetes does not have to hold you back.

Now aged 38, she has won five World Championships, four of which she won after being diagnosed with Type 1 diabetes at the age of 20.

"I was diagnosed just after my 20th birthday. I had been waking a lot at night to go to the toilet and had an intense thirst. I was also tired constantly, had no appetite and had lost a lot of weight quickly," she recalls.

One evening, she came home from college and was so tired, she lay down on the sofa and fell asleep. Her mother woke her up to ask her if she was going training that evening.

"I was so tired, I said no. Kickboxing was my life so I never missed training. My mam had noticed that I had been very lethargic, but when I said I wasn't going training, she knew something was wrong. She suggested I go to my GP," Catherine says.

Her GP gave her a blood test and a few days later, she got the results and was sent straight to hospital.

She admits that during that first year, she knew very little about the condition and there wasn't as much education about it as there is now.

"I knew I had no insulin so I had to replace that by injecting it, but I didn't know much else. I didn't really know about carb counting and the insulin doses I took would have been advised by my consultant, so there wasn't much flexibility," she notes.

However, she never let the condition hold her back when it came to the sport that she loved. Catherine started kickboxing at the age of eight and was competing for Ireland by the age of 13.



Catherine Brady up the hills

She won her first World Championship at the age of 18, going on to win four more in the years after her diagnosis.

"The summer after I won my first World Championship, I was beaten in the finals of it, and that December, I was diagnosed. Looking back, the signs were there. The girl I shared a room with at the finals I was beaten in said 'why are you so tired all the time, you are sleeping constantly?' But I didn't know why," she recalls.

At the end of that October, she went on a trip to Paris with her boyfriend, who is now her husband. She says she was exhausted throughout the trip and he couldn't understand why she was so tired. They came home in early November and the following month, she was diagnosed.

Catherine believes that Type 1 diabetes is "very individual" and what works for one person may not work for another. Even people with good control can have off days due to things like hormones and stress.

"A lot of my routine is the same. I work from home, I train most days, I walk a lot, I eat similar foods, and I track

carbs, proteins, and fat, but it still doesn't mean that my blood glucose levels are going to be on the money.

"I train a lot so I would have very fluctuating levels in and around my training. For me, it is about seeing a pattern and seeing what works," she points out.

Catherine admits that in the early years, she probably didn't test her blood glucose levels as much as she should have.

"I was probably in denial about having diabetes, but I use a CGM now so it is a lot easier for me to see what is happening and work out my patterns," she explains.

Her overall diabetes control is aided by exercise – the more she moves, the better her control is.

She does three 20-minute walks a day, in the morning, afternoon and evening, and she lifts weights five or six days per week. While she doesn't compete anymore, she still does kickboxing training, and she also works as an online fitness coach.

"Previous to Covid, I would have met people face-to-face, but I was already moving online as Covid was starting, so once the pandemic hit, I transferred all my clients online and officially registered my business at end of the summer of 2020. I have a bigger reach online," she says.

Catherine is delighted that there is more awareness of diabetes now and there is much more information out there. She adds that Type 1 is a "very livable and manageable condition, but you have to put the time into it to find out what works for you".

You can contact Catherine about online training on Instagram at @bradycatherinex or by emailing info@catherinebrady.ie