

# Don't let diabetes go "off the rails"

For Eimear Gilroy, neglecting diabetes management in her 20s has had huge consequences. **Deborah Condon** talks to her about important life lessons and future plans

At just 35, Eimear Gilroy already lives with a range of diabetes-related complications. However despite this, she remains positive and wants to emphasise to people the importance of maintaining good diabetes control.

Eimear, who lives in Athboy in Meath, developed Type 1 diabetes 20 years ago, shortly before her 16th birthday.

She believes that the way information is provided to young people and the type of language that is used is key.

"With teenagers, I don't think reading a leaflet about future complications is going to work. I think if I had met someone like me back when I was diagnosed, that would have had a bigger impact. I would love to educate young people about what not to do.

"I would love to go into schools and tell people that diabetes doesn't mean that you have to be totally different from your peers. It is a serious condition, but I would be more inclined to promote the fact that you can live a normal life and do what your peers are doing as long as you do certain things, such as eat



healthily and manage your insulin and other meds," she explains.

Eimear says that at the time of her diagnosis, she had "no understanding" of the condition, because she did not know anybody else who had it. Her symptoms included major weight loss, excessive thirst, going to the toilet a lot and fatigue.

Her diabetes was diagnosed when she underwent a blood test for another health issue. While it was a shock, she says she doesn't recall being upset about the diagnosis itself, but she did worry

about some of the consequences, particularly putting on weight.

## Diabulimia

"Before I started my insulin, I was scarily thin and I had that mindset then that that was the way I wanted to look. One healthcare professional said to me 'you'll pile on the pounds once you start taking insulin', and that was the worst thing anyone could have possibly said to me at that time. I later used my diabetes to fuel an eating disorder. Language is so important – you must tailor your language to suit your audience," she insists.

Eimear subsequently developed diabulimia, an eating disorder which sees people with Type 1 diabetes deliberately restricting the amount of insulin they take in order to lose weight. If left untreated, it can result in serious complications such as diabetic ketoacidosis (DKA), and if insulin omission and lack of diabetes control lasts for a long time, it can lead to complications such as neuropathy, retinopathy and nephropathy.

## Off the rails

Eimear says that initially, she managed

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her diabetes well, but she went “completely off the rails” in college.

“It really started in my second year of college, when I was 21, and it went on for a decade. At that time, I wasn’t experiencing any of the complications they warn you about and I just didn’t realise the implications it would have later in life,” she explains.

She recalls that she had lost a lot of sensitivity in her toes and she went through a phase of chronic insomnia.

“For months, if I got an hour’s sleep at night, that was good. In the end, that turned out to be neuropathy, which caused a burning feeling in my toes and feet. I used to get up at night just to stick my toes into cold water and my feet were very jumpy. I was put on medication and within two months, there was a big improvement, including with my sleep,” she says.

However, she then developed a blister on the big toe of her right foot, which then became infected. She says she tried to look after it herself, but eventually ended up in hospital, by which time the infection had “gone too far”.

“They had no choice but to amputate the toe. After about six months, the second toe also had to go, which can happen because all of the pressure is going onto that second toe.

“I have three toes left on my right foot, however, I get ulcers regularly and that foot is always changing shape. It is a constant battle to try and keep it well,” she points out.

Eimear then had to undergo a below-the-knee amputation on her left leg after developing Charcot foot, a rare but serious complication that can affect people with neuropathy, especially those with diabetes. Charcot foot causes a gradual weakening of the bones, joints and soft tissues of the foot or ankle.

“I was sitting in my kitchen watching TV one day and when I stood up, I had a dead leg and I just twisted over on my ankle. Two weeks after it happened, my leg was entirely swollen. I couldn’t stand on the leg for ages and I ended up being in an air boot for two years. My ankle



*Eimear Gilroy on prosthetic legs: “You can literally get any design you want, which makes it easier to go through the process”.*

was deformed - it was like an elephant ankle on one side and a gazelle ankle on the other – there was a total lack of symmetry,” she recalls.

After two years in the boot, Eimear and her orthopaedic surgeon agreed that amputation was the best option. She had her leg amputated in July 2020 after two years in a boot, and had an artificial leg fitted that September.

“All I wanted was to be able to go for a walk like a normal person and I couldn’t do that with the boot because I would be in so much pain, or if I put a runner on, the swelling would become too much. At least now with my artificial leg, I can walk more and do more of the normal things that I want to,” she explains.

### **Kidney disease**

During her 20s, Eimear was also getting a lot of kidney infections. Around the time her second toe was taken, blood tests revealed that she had kidney disease (nephropathy). This progressed to the point that she only had 40% function left in her kidneys. She notes that by the time she found this out, her diabetes control was excellent, but unfortunately, the earlier years of long-term poor control and her eating disorder had already had an impact.

She now has to undergo dialysis in hospital three times a week, for four

hours each time.

She also has gastroparesis, a condition which means that food passes through her stomach slower than usual. This can have a big impact on her blood glucose levels and when she needs to take insulin.

“I could eat something at 1pm and I wouldn’t need anything insulin-wise until maybe 6 or 7pm, but that can mess up your diabetic control. And if I experience a low and eat something to correct that low, it won’t work quick enough, so you have to be very careful,” she notes.

Now, to help manage her diabetes, she uses continuous glucose monitoring. She describes Dexcom as a “total game changer” because she can now see when her blood glucose levels are going too low or too high.

Eimear was a primary school teacher for 10 years, but she stopped working almost four years ago as a result of her health problems. She hopes to work again, but admits that teaching is no longer an option.

“I am always conscious that if there was an emergency, would I be someone who would be able to care for others or would I need to be cared for? And I also know that if I get sick, it doesn’t tend to be something small. It usually involves a hospital admission, so I would be missing a lot of school. So I will go back to work at some stage, but not teaching,” she says.

However, her interest in educating young people about diabetes is clear. She says she is happy to see that there is a better understanding of diabetes now compared to 20 years ago, and there have been so many advances in medication and technology, but she again emphasises that the “language used around diabetes is so important”.

Diabetes Ireland reminds people that if they see their diabetes team, check their eyes (RetinaScreen) and HbA1c levels regularly, are aware what their blood glucose levels are and react appropriately and quickly to hyperglycaemia with insulin, their risk of developing complications is significantly reduced.