

The importance of early support

Reaching out for support can be difficult but is essential says Jean Langford. **Deborah Condon** reports



Jean Langford was diagnosed with Type 1 diabetes at the age of 11. "Peer support and a good supportive medical team are key", she says.

Jean Langford from Limerick was diagnosed with Type 1 diabetes 16 years ago at the age of 11. During that time, she has experienced the impact that both an under-resourced health service, and a properly-resourced service, can have.

Now aged 27, Jean recently moved to Edinburgh where she is studying to be a dietitian. Her aim is to return to Ireland when she is finished so that she can try to make a difference for people with diabetes here.

Jean remembers the time around her diagnosis well. She had lost lots of weight to the extent that she could not find any clothes in her age group to fit for her upcoming confirmation.

"I was really thirsty all the time and just felt so unwell for a good few weeks. I was also constantly eating sugar looking for energy sources. Type 1 diabetes is prevalent in my family on my dad's side. My grandad, uncle and two second cousins had it, but it still wasn't at the forefront of my parents' mind even with the family history," she explains.

A urine sample taken by her GP led to an immediate trip to University Hospital Limerick where Type 1 was confirmed.

She then spent the next two weeks in hospital.

Dealing with the diagnosis

"We were all shocked and quite upset driving to the hospital. Going in, I was upset because my parents were upset but I thought I was going in just to get checked and that this was a scary thing that would pass. Then I got told what it actually was and I had to start using insulin," she recalls.

She describes the team in paediatrics as "phenomenal", particularly as she is naturally a "very squeamish person", which made injections even more challenging.

Following her hospital stay, she says her parents "did a lot of the leg work" around diabetes so she ended up being

quite sheltered from it all.

"There was talk of complications but I never really knew what they were. I never really understood the importance of eating certain foods and avoiding other foods. As a young person, it didn't feel like anything to do with my health, it just felt like more rules. I didn't fully accept diabetes for all it was and everything that is involved until I was in my 20s and going to college," she explains.

School was a very supportive environment where she was "constantly surrounded by good friends and good teachers".

"I missed a lot of school because my diabetes was brittle and so my blood glucose levels were chaotic. However, the teachers never made me feel shame or

INTERVIEW

bad for missing school and despite being absent a lot, I did very well because when I did show up, I was fully present,” she notes.

After school, she opted to study international business in the University of Limerick and she says that it was while she was in college that she first started asking ‘why me?’

“I loved the course but it was very competitive and I could see the difference between me and my peers. In school, people are generally all moving at the same pace - everyone is moving through the same thing at the same time. In college, I saw people going off travelling or just doing certain activities with such ease. And of course, these were all optional activities so you could opt out. There was no structure like school,” she recalls.

She points out that if she was sick in school, “there was a sick bay and you could bring a buddy with you, but in college, if I was sick, it was just me on my own unless I actively asked someone to get involved”.

Disability services

While there are disability services in college and diabetes is legally viewed as a disability, “you feel a bit weird using these services because diabetes is invisible” so some people don’t view it as a disability.

Despite these challenges, Jean achieved first class honours in her four-year degree and also managed to fit in lots of travelling during this time – spending four months in Lille in France as part of her Erasmus studies and completing work placements in Nice in France for eight months.

While she loved living in France, she admits that this was the first time she was “really alone” with her diabetes.

“In college, because I’m from Limerick, I still had the same doctor and pharmacist, so going abroad was overwhelming, having to pack all the supplies and make sure everything was ok. However, I learned real life skills doing it and I think it’s something people with diabetes should do from a young age – travel

abroad – to remove that fear and teach people how to orientate themselves, for example, how to find pharmacies in a new area,” she suggests.

In 2017, Jean finished college but she also made a change that had a massive impact on her life – she changed hospitals for her diabetes care. She had been attending the UHL adult diabetes clinic since the age of 16, however she did not feel like she was getting adequate support there. In Limerick at that time, there were no dietitians for the adult clinic and only a part-time consultant endocrinologist “so you’d never even get to meet the endocrinologist”.

There was also no access to insulin pumps in the adult clinic. In fact, there was no access to any technology in this clinic.

However after college, at the age of 21, Jean moved to Cork for a new job and decided to also change hospitals.

“When I moved to Cork, my health was crap. My diabetes was awful from college, it had been completely neglected and I had completely lost track of it all and didn’t have support in hospital. When I went to hospital, I wouldn’t actually meet with the specialist. I’d meet different staff every time so there was no consistency and that was for all of my young adult life. These are pivotal years.

“So when I went to Cork, I went to a GP and asked for a referral to Cork University Hospital and the care was so different, I finally figured out how to manage my diabetes as a young adult,” she explains.

Such was the impact of this change on her, Jean found herself “drawn to dietetics” and she decided to return to education to become a dietitian. She started the MSc in Food Nutrition and Health in UCD in September 2020.

However, while she loved the content, she found online learning during the pandemic was not for her, so she withdrew from the course in late 2021 and then enrolled for the MSc in Dietetics in Queen Margaret University in Edinburgh in January 2022. She was accepted for the course in June and moved to Edinburgh in July.

Her intention is to return to Limerick and work in the area of diabetes, as she has experienced firsthand how badly dietetic services in that region are required.

Instagram and advocacy

She started an Instagram account at the end of 2020 where she often talks about her journey with diabetes and she joined the Midwest Diabetes Advocacy Group in August 2021, which works to improve services for people in the Midwest.

She says if she could go back in time and change anything, “it would be getting peer support earlier” as she believes her college experience would have been different if she had that support in place. However, she admits that reaching out for support can be difficult.

“I met someone in first year on a random night out. A friend introduced us and mentioned that we both had diabetes, but we didn’t connect again after that because at the time I had stigmatised it so much in my head. I thought ‘why would I reach out, she’s probably doing fine, I’m not’. It’s hard to take that step and reach out to someone with diabetes. But now we are amazing friends and she actually lives in Edinburgh too,” Jean notes.

She emphasises that you don’t even have to talk about diabetes when you are with someone with the condition.

“Sometimes, just being around someone who gets it is enough,” she believes.

She also emphasises the importance of a supportive medical team.

“The way I think about it is, to be an endocrinologist, you’ve to study for a minimum of five years, to be a diabetes nurse specialist, it’s a minimum of four years study and yet people with diabetes are just sent out the door and told to take insulin every day and they are expected all of a sudden to be an expert in physiology, anatomy, chemistry and that is aside from what is going on in their personal lives! This is why peer support and a good supportive medical team are key.”

You can follow Jean on Instagram or Twitter using the handle @The_Dia_Being_Mindset