

# Taking care of the mind

Shane O'Donnell went through a hard time dealing with diabetes, but mindfulness and new technology were of huge help, writes **Deborah Condon**



When Shane O'Donnell was diagnosed with Type 1 diabetes 20 years ago, he struggled with many aspects of the diagnosis, particularly a fear of hypos. However getting help for this proved to be a complicated journey.

Now in his mid-30s, Shane, who lives in Milltown in Dublin, was diagnosed with Type 1 diabetes when he was 16. He had been displaying some of the classic symptoms – thirst, losing a lot of weight and lethargy.

"I remember once walking to my friend's house which was only around 100 metres away and I had to rest under a tree for half an hour. There was no family history of diabetes so it went unrecognised and I ended up in hospital with diabetic ketoacidosis (DKA)," he explains.

DKA is a potentially life-threatening complication of diabetes. While in hospital, Shane was put into an adult ward and the patient in the bed next to him was a blind double amputee with kidney failure, all related to diabetes.

"It was quite a shock to the system to see that. I was confronted head-on with the potential consequences of diabetes," he says.

Initially, he adapted well and even the injections didn't really bother him. However, things took a turn when he

went to college in UCD.

"I was mindful of what I had seen in the hospital and I was trying to keep my blood glucose levels as tight as possible, but I didn't have that much education. I remember clearly where it all began."

One day, Shane was sitting in a lecture theatre when he started feeling a "hypo-like sensation".

Hypoglycaemia, often referred to as a 'hypo', occurs when blood glucose levels go too low. Symptoms include feeling sweaty, weak, irritable and/or drowsy. Immediate treatment is required.

"I was at the back of the theatre. I was sweating profusely and felt like I was going to pass out. I bolted out of there and checked my blood glucose levels, but they were actually high so I thought 'what the hell was that?'. I really had no idea what had happened but it kept happening. I'd be sitting in the theatre and maybe 10 or 15 minutes in, I'd get the same sensation and have to run out. It got to the point where I was avoiding lectures and seminars. It was very disruptive to my college life," he recalls.

## Panic attacks

He decided to go and see a student counsellor where he learned that what he was experiencing was actually panic attacks. However, while he finally had some explanation for what

was happening to him, he believes that it then became a vicious circle of constantly wondering if his feelings were related to a hypo or a panic attack. As a result, he was constantly checking his blood glucose levels and this went on for around three years.

"I didn't do as well in college as I would have liked and the issue progressed when I finished college. I was almost afraid to leave the house and I worried about getting a job. I did manage to get a job but found it hard to concentrate. I just didn't know where I was going and had a fairly bleak outlook at that stage," he says.

He spoke to his diabetes team at the time, who he notes were all very supportive "in as much as they could be".

"My impression is that they didn't know what to do with me. This was 15 years ago and I am not sure how much training in this area they had. Basically, there were no psychological services available to me," he recalls.

The counsellor in UCD had given him some breathing exercises that had worked well at taking the edge off the panic attacks, but it got to the stage where Shane was really struggling. The counsellor had suggested that he see a mindfulness practitioner, so he decided to look into this.

## Mindfulness

He undertook an eight-week mindfulness-based stress reduction programme run by a certified mindfulness counsellor in Wicklow and it was then that things took a positive turn.

“She was absolutely brilliant. Other than the counsellor in UCD, she would have been the first person I would have spoken to in great detail about the underlying symptoms. There were lots of other things going on – my dad had passed away around the same time I had been diagnosed with Type 1, so the panic attacks weren’t just about diabetes. There were lots of compounding factors,” he explains.

Another positive thing that happened around this time was related to diabetes technology. Shane was very concerned about double dosing on insulin and had previously asked a consultant whether there was a way of tracking the amount of insulin that has been delivered.

“The consultant was a bit dismissive at the time and told me to ‘just write it down’, but I might have been taking insulin seven or eight times a day so I wanted an actual record,” he notes.

## CGM and pumps

Around the time of the mindfulness course, continuous glucose monitors (CGMs) were not widely available, but St Vincent’s University Hospital where Shane attended had CGMs that you could take home for a week.

“The CGM would give you an idea of the trends in your blood glucose levels, so I was able to combine the mindfulness with this data. I could see my blood glucose levels in real time and this really helped me because I was checking 13 or 14 times a day,” he notes

He had also heard about insulin pumps online, so he went to his consultant and said he thought it would benefit him both from a diabetes management side and a psychological side. His consultant agreed and six months later, Shane had an insulin pump.

“This made another huge difference because I now had a record of the insulin I was taking so I didn’t have that fear

of double dosing. These all added up to really improve my psychological outlook and help me get over the worst excesses of the panic,” he says.

## Cognitive behavioural therapy

He also did cognitive behavioural therapy (CBT), which he says was “really instrumental” in helping him to get over his fear of hypos by teaching him to differentiate between a hypo and a panic attack.

However, Shane emphasises that he was lucky he could afford all these psychological services, as the services attached to diabetes clinics are underfunded and under-resourced in many parts of the country.

“The psychological aspect of diabetes is so important and it should be put front and centre. A lot of these fears can be dealt with,” he insists.

Since then, Shane’s life has been very different and his diabetes has actually led to exciting new opportunities. Having originally studied social science in UCD, he returned to UCD to do a masters in sociology of health and illness.

“I was looking for a topic to research and was quite interested in stigma around diabetes, particularly Type 2 and this idea that it is a self-inflicted illness. So I did my thesis on that. I then did a PhD on a similar topic,” he explains.

As part of the field work for his PhD, he went to the World Diabetes Congress in Dubai, where he met people involved with a young leaders’ training and advocacy programme run by the International Diabetes Federation. It brings together young people with diabetes from all over the world.

## World stage

“I met the president elect of the young leaders in Dubai and he said that the next young leaders’ programme was in Australia and he asked if I’d be interested in going,” Shane recalls.

In order to take part in the young leaders’ programme, you must be nominated by your local diabetes association. Shane was nominated by Diabetes Ireland and he went to Australia for a few weeks in 2013. He says this trip played a big part

in helping him to get over the mental health aspects of panic. There, he was trained on different aspects of advocacy and while it was intensive with long hours, it was worth it for what he gained out of the experience.

“It is hard to put into words the impact that trip had because I hadn’t met people with diabetes until that point and I got a sense that they had gone through some of the same difficulties as me. It gave me a sense that there are positive aspects of living with diabetes or I can turn it into something positive. I was very privileged to have this experience and to have the education which led to it.”

His research is now focused on building an evidence base around the effectiveness of Do-It-Yourself artificial pancreas systems, collecting data and experiences of people with diabetes who are building their own artificial pancreas through open source technology.

“I co-founded the research consortium that is looking at this and almost everyone involved has Type 1 diabetes. I feel like I am doing something worthwhile and if I hadn’t had all these experiences with diabetes, I wouldn’t be involved with this international research group that is hopefully making a difference,” he says.

Looking back, Shane points out that he didn’t want diabetes “to be a part of my identity”.

“I didn’t want to be talking about it the whole time and for it to be all-encompassing and all-consuming, but the reality was it was being all-encompassing and all-consuming anyway in a very traumatic way.”

## Peer support

He believes peer support is vital and he encourages anyone who is struggling to reach out and talk to their diabetes team.

“When I was going through it, the worst part was feeling alone in it. Our mental and physical wellbeing go hand in hand and when one is not well, the other is not well. All people with diabetes who experience psychological distress should have access to psychological support based on need and not the ability to pay,” he adds.