

# Type 2 Voices Survey

After joining an online support group for people with Type 2 diabetes, Valerie Humphries felt it would be a good idea to further explore people's experiences. Interview by: **Deborah Condon**

Despite a family history of Type 2 diabetes, Valerie Humphries was still shocked to develop the condition in her mid-60s. She was further shocked about the lack of information available to her when she was diagnosed, prompting her to carry out a survey to try to find out more about other people's experiences.

Prior to her diagnosis almost five years ago, the retired special needs teacher, who lives in Dublin, recalls that she would fall asleep very easily.

"It was actually quite embarrassing if it happened in the cinema or concerts or plays – things I really wanted to stay awake for," she says.

One day, while bringing her husband to a hospital appointment, she fainted and ended up in the emergency department. As her blood glucose level was quite high, she was advised to go to her GP and get checked for diabetes.

"It should have been no surprise – my dad was diagnosed at 45 and my mam was diagnosed in her mid-70s. But at the same time, it was still a shock that your body, which has worked in a particular way for years and years, is suddenly not doing what you expect it to do. So even though I always knew Type 2 diabetes was possible, it was still a surprise," she admits.

While the development of Type 2 diabetes is often associated with excess weight and a sedentary lifestyle, Valerie points out that this did not apply to her.

"I was always very aware that before my dad was diagnosed, he had put on a large amount of weight, so I always tended to watch my weight and not get too heavy," she explains.

She also notes that when her father was diagnosed in the 1960s, he was given a diet sheet to follow. The whole family ended up following that, so her diet was always relatively healthy, "but I still developed diabetes".

When she was diagnosed by her GP, she was put on medication and was referred to hospital.

"What I needed medically was done, but the hospital appointment wasn't going to be for another six months. The biggest challenge was that gap between seeing the doctor and being told I had diabetes and the hospital appointment – there was no roadmap," she notes.

She says she looked on the internet and found out things like she could get her eyes checked and she was eligible for a Long-Term Illness book.

"Also, because I had been a special needs teacher and had sat in on many home economics classes, I understood about carbs and protein, but it got me thinking, what do you do if you don't have that knowledge, or if you don't have access to the internet or aren't very good on it? I was aware that I could understand it, but it occurred to me that a lot of people could be left high and dry," she says.

While her diabetes is very well controlled now, she believes this is easier because she is very active in her retirement.

"It would be much more difficult if I was working or if I became more sedentary or sick – it's not plain sailing," she insists.

Valerie joined a private Facebook group for people with diabetes. She noticed that people who joined after a Type 2 diagnosis often said they did not know what to do, "or they asked questions that showed they did not know what to do".

She expressed concern about this and Grainne Flynn, who had been running the group for some time, got in touch with her to say this was something she was worried about as well.

"If you have Type 1 diabetes, you go to hospital fairly quickly and you get the supports that you need, whereas if you have Type 2, you may only or mostly be seeing your GP and you can feel quite isolated.

"I felt I had little idea about the lived experience of other people with Type 2, so myself and Grainne decided to undertake a survey to find out more. We were trying to see whether people's responses bore out what we thought was happening," she explains.

Valerie acknowledges that this was not an official survey and those who took part "are probably people who wanted

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to get something off their chest”. However, the results certainly reflected her experience of dealing with a Type 2 diagnosis.

### Survey

With promotional support from Diabetes Ireland, the survey was completed by participants between autumn 2020 and summer 2021. An analysis of the replies from 89 respondents nationwide revealed that 54% were from Leinster, 26% from Munster, 12% from Connacht and 8% from Ulster. Overall, 72% of respondents were aged 46 or older and just over half had been diagnosed since 2016.

Some 70% of respondents said they were on oral medication for their diabetes, 16% were using insulin, while 14% controlled the condition with diet and exercise.

The survey revealed that over half of respondents were originally diagnosed by their GP after attending because they felt unwell or had a different condition that required attention. A significant number noted that their diabetes was discovered as a result of routine blood tests or medical assessments for work/insurance.

Valerie says this finding really stood out to her and highlights the value of regular blood tests by your GP or testing in the community by organisations such as Diabetes Ireland.

When asked how they felt about the diagnosis, many reported a negative reaction. The most common reactions were shock, horror and fear. A small number admitted they were angry with themselves and their bodies.

Just 7% said they were not surprised about the diagnosis.

When asked about their family's reaction, the response was varied, ranging from helpful and understanding to worried, shocked and upset.

When it came to the information the respondents were provided with at the time of diagnosis, there appeared to be major gaps. Some 32% said they received no information at the time of diagnosis on ways to manage their

diabetes, while this figure rose to 40% among those diagnosed between 2016 and 2021.

When asked if they were told about the Long-Term Illness Scheme, which allows people to obtain diabetes-related medicines for free, 62% said they were not, although this fell to 40% among those diagnosed between 2016 and 2021.



Participants were also asked if they had received any information on managing their blood pressure at the time of their diagnosis, however, 73% had not. When asked if they were given any information about caring for their feet or told about the importance of having their feet examined annually, 53% said they were not.

The results were better when it came to the eye screening programme, Diabetic RetinaScreen, with 63% of respondents stating that they were given information about this at the time of diagnosis. This increased to 70% for those diagnosed between 2016 and 2021.

“Going back to this idea of a roadmap, I think people should be leaving the doctor's surgery or their pharmacy with something in their hand, like an information leaflet, telling them what supports they can get and what things they should be trying to do,” Valerie noted.

### Personal experiences

When asked if they speak about their diabetes with their family or friends, while 40% of respondents said yes, 30% said they did not and 30% said they did so only sometimes/rarely. Responses to this question included:

– “Sometimes I hate talking about it. I am still in denial”

– “I would but they never ask. They don't understand it”

– “I only talk to immediate family. I don't talk to others. I feel they are judging me”.

Valerie says there appears to be a stigma attached to Type 2 diabetes, with some people choosing not to talk about the condition for fear of being blamed or judged.

“People will say to me, ‘but you are slim, how can you be diabetic?’ During the last election campaign, I was speaking to one of the election candidates about diabetes services and mentioned I had Type 2 diabetes. He said to me, ‘you can't be diabetic, you are slim’ and then he followed that up with ‘well you don't have to be diabetic’. I asked what he meant and he told me I can ‘cure it by eating in the right way’.

“This idea permeates that if you are diabetic, you are overweight and you haven't eaten very well,” she notes.

She emphasises that there is so much more to it, with issues such as lack of education about food and eating on a limited budget also playing a big role.

“That blame game becomes doubly worrying if you are somebody who is trying to manage your diabetes on a limited income - it may actually be incredibly difficult,” she points out.

Not surprisingly, the survey also found that people with Type 2 diabetes have many concerns about potential complications. Going blind or other eye problems appeared to be the most common concern, with other worries including heart problems, amputation and kidney damage.

Comments about this included:

– “I worry about losing my sight or having an amputation like my nan”

– “I worry about not seeing my children grow up”

– “I worry about having a heart attack”.

Valerie says she would like the Type 2 diabetes community to have a greater voice and says people are welcome to share their comments, stories or experiences at [type2voices@gmail.com](mailto:type2voices@gmail.com)

“The Type 1 community seems to be quite cohesive and united, whereas the Type 2 community is quite different. It would be really good to continue the dialogue on this topic,” she adds.