

## DIABETIC RETINOPATHY

# 'I was pregnant and they said I had changes in my eye. I was scared'

Vicky Williams always knew that having type 1 diabetes would make any pregnancies harder, but she always wanted to be a mum. She shares her story with *Liadán Hynes* of being diagnosed at 11 and how she coped

**T**heir doctor probably isn't top of most women's list of the first person they will call when they learn they're pregnant. But for Vicky Williams, her doctors had been warning her throughout her twenties that if she ever became pregnant, she was to ring them immediately.

"They always used to joke, when you do find out you're pregnant, the first person you tell is a diabetes nurse. And not your husband or your partner or whatever. The first thing you do, you ring the hospital, and we'll get you in straight away, and start working on your blood sugars," she says with a smile.

Williams (34, who works for the HSE and is the mother of two daughters — Chloe (3) and one-year-old Ellie — was first diagnosed with type 1 diabetes at the age of 11.

"I always knew it was going to be harder," she says of pregnancy. "Not in terms of conceiving; well, it can be in terms of conceiving if your blood glucose levels aren't controlled, it can inhibit conception too. But I knew the risk and, I suppose, the dangers.

"It's never going to be like somebody who doesn't have diabetes. What they recommend is to make sure your blood glucose levels — it's called a HbA1c [the blood test that reveals your glucose level] is as tight as possible before you even start trying for a baby.

"They try and encourage you not to have unplanned pregnancies, because once conception happens, within the first few weeks if you have blood sugars that are quite high, that can cause lots of issues and complications. I knew this. All the way up through my twenties, they were always making sure, 'have you got contraception, when you are starting to plan please tell us, and we'll be part of it'."

Williams was diagnosed in 2000, at the age of 11, with type 1 diabetes, which causes the level of glucose in your blood to become too high. An autoimmune condition, insulin keeps blood glucose within the correct range.

She lists her symptoms before diagnosis. "Nothing could quench my thirst, I was drinking gallons and gallons of water. I lost a lot of weight quite quickly, about two stone in a matter of about eight weeks, and I was quite sporty, I didn't actually have much weight to lose anyway, so it was quite noticeable. A couple of days

before I was diagnosed, I got quite tired and lethargic. Pale and grey looking."

Her mother booked an appointment with their GP, where a urine sample revealed high glucose levels and a diagnosis of type 1 diabetes. Williams was sent straight to hospital.

"I remember it really well, it's one of those big things. I suppose it was shock, really. Me and my mum, we cried the whole way over to the hospital. The two of us bawled our eyes out. It was just really daunting, we didn't understand what it was, what it meant. I was in the hospital for a week. Straight away I was put on insulin."

She speaks in glowing terms of the treatment she received in the paediatric ward.

"Straight away you get all the diabetes education from the diabetes team, you get to see a psychologist in the hospital. Just to process what's going on. My mum got to see them as well. They explained how our life was going to change. The thing that really stuck out for us from the beginning was this is not going to stop you doing anything. If you're proactive with it from the very beginning, you don't have to stop playing sport, you just have to mind yourself a little bit more."

## Determined

From the outset, Williams was determined to take as much charge as possible over her treatment. "The nurse gave me the insulin once, injected me, and after that I said 'no, no, no, I'll do it myself'. I was an age where I was old enough to understand, but not old enough to rebel against it.

"I took on the management myself. Obviously, my mum helped me, of course. I wanted to make sure that it didn't stop me doing anything I want. Not to be different from anybody else. I was big into tennis, and athletics. I competed highly in both. It never stopped me. Now, I had

to mind myself."

Going to birthday parties of friends, her mum would pack her a separate lunch, with a bag of popcorn as she was not allowed the treats the other children would have. "Routine was really important. Monitoring the blood sugars, pricking my blood sugar before mealtimes. And in school my teacher had to be taught how to manage it as well. I had my own little press in the classroom with Lucozade and biscuits and stuff like that, which my classmates used to rob all the time," Williams laughs.

As Williams got older, a different attitude did set in. "Going into your late teens early twenties, you kind of get this thing called diabetes burn out. They say on average a type 1 diabetic makes 500 more decisions than the average person.

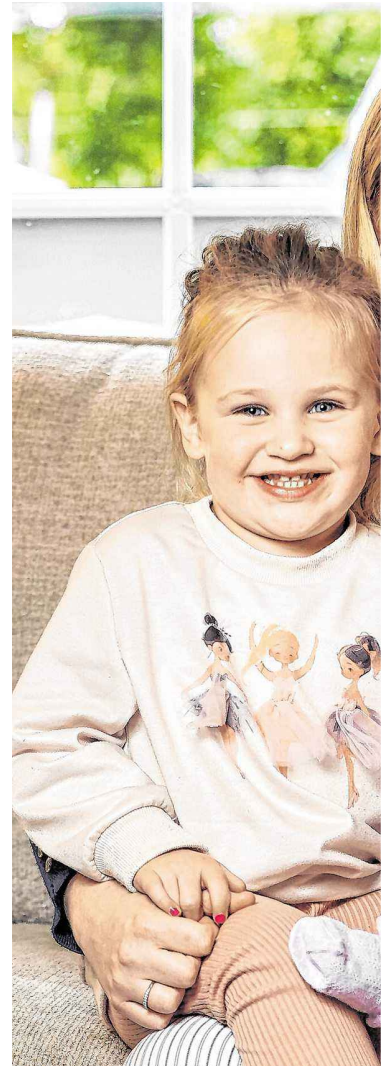
"Because you're constantly thinking. So if you're sitting down having lunch with somebody, and they just order whatever meal they want, I'm constantly thinking what are my blood sugars now, carbohydrate counting, how much insulin I need to match that, do I need to take extra in two hours' time, what am I going to be doing later on, am I going to be doing any exercise, am I going to have dinner later on and what's that going to look like. So it's constantly in the background — of course it's going to cause a bit of fatigue.

"I wouldn't say I was excellent at it during college, because you know, you're drinking, you're not sleeping well, and you're doing exams. You do have peaks and troughs throughout your life. But unfortunately, it doesn't go away. It's just how you cope with that, and how you manage that throughout the life cycle, you know?"

Williams met her husband, Alan, on Tinder. She was single for a time after the break-up of a long-term relationship, and her friends suggested she join the dating app. "I was like, absolutely not, I couldn't think of anything worse," she laughs. "One day one of my friends set me up. We went on a date and that was it. We're very lucky. We're married five years, together nine all together."

Williams had always wanted children. Alan said he could take it or leave it, "so long as he was with me. But that would have been a bit of a dealbreaker for me. He wanted one, I wanted three, so our compromise was two," she laughs.

She knew that as a diabetic, pregnancy would be "a lot of work".



"I was so nervous, and I'm a bit of a perfectionist, so I was very anxious going into it and how hard is this going to be in terms of managing. You're looked after so well. You've to document your blood sugars 10 times a day. You've to write them down. Say how much insulin you're taking, what you're eating, weekly food diaries, in hospital every two weeks for check-ups. You do it because you want to make sure your baby's OK. You get on with it."

The intensity required in monitoring what she was eating was a mindset she found hard to shake off even after her two pregnancies.

"That pressure, even when you've had the baby. I had my two kids within two years, so I never got out of the mind frame, because I knew, as soon as I had my first child, I wanted another, so I had to keep really tight until I had the second one. I've had a good three years where it was tight control."



Vicky Williams at home in Celbridge, Co Kildare with her daughters — Chloe (3) and one-year-old Ellie. Photo: Steve Humphreys

"I got pregnant on Ellie quite quickly," Williams says of her second daughter. "This pregnancy went well but I did find it a little bit harder to manage. I suppose you're a little bit older, hormones again. It was just a little bit harder this time, and then I had the screening around the eyes."

In 2023 Diabetic RetinaScreen (DRS), the national diabetic retinopathy screening programme, began offering convenient additional screening for mums-to-be living with types 1 and 2 diabetes.

Diabetic retinopathy is a complication of diabetes that happens when high blood glucose levels damage the back of the eye, and the risk of it happening may be higher for diabetic women who are pregnant.

DRS offers free regular eye screening to everyone aged 12 and over in Ireland with types 1 and 2 diabetes, with tests every two years.

The additional screening offered to mums-to-be checks their eyes at two points in their pregnancies for any early signs of changes which, if left untreated, can affect sight. The earlier retinopathy is caught, the easier it is to treat and the higher the chance that sight can be preserved.

For Williams, the new initiative meant instead of extensive travel from her home in Celbridge to the centre of Dublin for her eye screening appointment, as in her first pregnancy, she could now visit her local clinic.

The additional screening initiative is one of several layers of care offered to women with type 1 and 2 diabetes while pregnant, which also include access to a dietitian, diabetes nurse and diabetes team.

When Williams was in her second trimester of her second pregnancy, the screening found

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## Stay Well: My eyes are dry, scratchy and inflamed. How can I fix them?

The experts will discuss the symptoms for  
cases of dryness, irritation and  
itchiness in this article.

**Y**ou wake up in the morning and your eyes are dry, scratchy and inflamed. You blink a few times and the irritation persists. You reach for your eye drops, but they don't seem to help. You're not alone. Dry eyes are a common condition, and there are several ways to manage them. In this article, we'll explore the symptoms, causes, and treatments for dry eyes, and how you can keep your eyes healthy and comfortable.

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**Vicky Williams: 'After having kids my diabetes went down the list of priorities.'** Photo: Steve Humphreys

changes to her left eye and she was referred to the Royal Victoria Eye and Ear Hospital, to be monitored for background **retinopathy**, an eye disease linked to diabetes.

"I had my second screening done, and I got a letter saying 'you've changes at the back of your eye'. I nearly died. It's probably my worst fear of everything with the diabetes; blindness would be my biggest fear.

"You're pregnant, you're growing a baby, and you get a letter saying that you have changes in your eye. I was quite scared."

The change was unrelated to diabetes, but Williams was monitored closely for the rest of her **pregnancy**. At her most recent screening, she was told her eye had gone back to normal.

Since becoming a mother of two, alongside her busy job in the addiction services, she has also reconsidered how she manages her diabetes in the future.

### Control freak

"I've always been a bit of a control freak with my diabetes, it always comes first, it's a priority. Then as soon as I had the two kids, not that it's half as important, but it's down my priority list." She plans to change from insulin injections to an insulin pump.

"Now I know my family life, my work life, is too busy. I need that extra help. It's taking that decision away from me so I can concentrate on family.

"What made the decision for me was, I was on maternity leave, we had the two kids, and we went for a walk. I was coming in the door, my blood sugars were dropping. I knew I was going low, I was having a hypo [hypoglycaemia, meaning blood glucose is low], and I needed sugar. My baby was crying for food, and my other little kid wanted to go to the toilet.

"When you're having a hypo, you feel kind of disorientated, you're not fully with it. I'd describe it as you kind of look drunk. Who do I prioritise, what do I do first? That's when I decided I need the pump. That will be able to predict that my blood sugars are going low, and it will shut off my insulin, and it will stop me going low. I just need that extra help with that technology."

*Women who have an existing diagnosis of type 1 or type 2 diabetes and who want to find out more about **diabetic retina screening** can talk to their midwife, diabetes nurse or GP or call 1800 45 43 53. There's also information at [hse.ie/diabeticretinascreen](http://hse.ie/diabeticretinascreen). For information on managing type 1 and 2*

*diabetes in **pregnancy**, see [www2.hse.ie/conditions/diabetes-and-pregnancy](http://www2.hse.ie/conditions/diabetes-and-pregnancy)*

### Diabetic retinopathy

● **Diabetic retinopathy** is a complication of type 1 and type 2 diabetes that affects the small blood vessels at the back of the eye, in an area called the retina. It can cause the blood vessels in the retina to leak or become blocked, which impacts sight.

● **The risk of **diabetic** retinopathy** may increase during **pregnancy**. Screening looks for early changes, before symptoms start. When **retinopathy** is caught early, treatment is effective at reducing or preventing damage to the sight.

● **Women who develop gestational diabetes** do not need to attend **diabetic** eye screening as the condition usually resolves after their baby is born. People do not usually notice **diabetic retinopathy** in its early stages.

● **Contact your GP or diabetes care team** immediately if you have:  
– gradually worsening vision  
– sudden vision loss  
– shapes floating in your field of vision (floaters)  
– blurred or patchy vision  
– eye pain or redness

● **Most pregnant women** with diabetes will go on to have a healthy baby, but there are some possible complications.

● **Risks to the baby** can include:  
– having low blood glucose levels, low calcium or jaundice after delivery; this is common  
– having a larger baby, which can cause problems during labour  
– having a smaller baby than expected who might need care in a neonatal unit  
– malformation – incorrect development of the baby (this is rare)  
– Being stillborn – the baby dies before it is delivered (this is also rare)

● **Risks to the mother** can include:  
– More frequent low blood glucose (hypos)  
– Poor hypo awareness of a low glucose  
– High blood glucose levels  
– **Diabetic** ketoacidosis  
– Miscarriage  
– Needing an early birth  
– Developing a blood pressure problem  
– Worsening of existing diabetes kidney or eye problems

