- Diabetes

When Billy Mills was diagnosed with type 1 diabetes as a 32-year-old, he was surprised but not shocked. Billy had a family history of diabetes, but for many adults diagnosed later in life, a type 1 diagnosis comes as a huge shock and everyday life drastically changes. Maggie Stewart, a diabetes educator from the Baker Heart and Diabetes Institute, explains what a type 1 diabetes diagnosis in adulthood means.



getting a LATE T1 DIAGNOSIS

type 1

A cup of coffee, an early morning walk, a weekend away, or even a work presentation – each of these previously regular activities, plus many, many others, suddenly have to be looked at in a completely different way once a type 1 diabetes diagnosis in adulthood is made.

Carbohydrate consumption, activity, routines and stress levels are just a few of the many considerations you now have to factor more carefully into your lives.

So, what should you do once you're diagnosed as an adult with type 1 diabetes (T1D), and how do you get your head around this life-changing event?

WHY WOULD SOMEONE BE DIAGNOSED WITH TYPE 1 DIABETES AS AN ADULT?

We don't know the exact cause of T1D, but we do know that genetics play a large part and that it can't be prevented. People who develop diabetes have certain genes that make T1D more likely, and then an environmental trigger occurs which kickstarts the autoimmune reaction that destroys your insulin-producing cells.

It's difficult to pinpoint what those triggers are, but we do know that certain viruses have been associated with triggering T1D. We also know that the cause of T1D is not lifestyle-related but that a healthy lifestyle does help with management.

HOW IS TYPE 1 DIABETES DIAGNOSED IN ADULTS?

The journey towards arriving at a T1D diagnosis can take a number of paths. For many, the diagnosis comes during childhood, with two noticeable peak periods for diagnosis occurring between the ages of 4 to 7 and 10 to 14. This is childhood-onset diabetes.

However, recent research has found that more than half of all new cases of type 1 diabetes occurs in adults – adult-onset diabetes. How they arrive at that diabetes destination varies.

For adults diagnosed with T1D, we frequently see that a type 2 diabetes (T2D) diagnosis comes before a T1 diagnosis. A significant proportion of these people have originally been misclassified with T2D as there are many overlapping symptoms between T1 and T2 and no definitive diagnostic tool.

It's estimated that about 10 per cent of adults diagnosed with T2D actually have T1, and that more than a third of adults with T1 were initially treated for T2.

Latent Autoimmune Diabetes in Adults, or LADA, shares features of both T1D and T2D. It begins in adulthood but does not initially require insulin for



glucose control. It slowly gets worse over time, and because the pancreas is still making some insulin, many with LADA are first misclassified with T2D. This is a journey frequently seen in adults diagnosed with T1D.

Following a period of not needing any insulin support, those with LADA may then need basal insulin – the background insulin that keeps blood glucose levels consistent during fasting periods. Then as the disease progresses, they may need to introduce the fast-acting bolus insulin at mealtimes to keep levels consistent following a meal. The deterioration may be slow and last years, but for others, the deterioration can be rapid.

Adults diagnosed with classical type 1 diabetes are usually very unwell at time of diagnosis and require insulin for survival.

WHAT SHOULD I DO IF DIAGNOSED WITH TYPE 1 DIABETES AS AN ADULT?

T1 and T2 diabetes are two very distinct diseases that have different management strategies, and LADA adds another dimension, so a new classification or a new diagnosis can come with lots of confusion, anxiety, and significant re-learning.

For example, if you've previously been diagnosed with T2 and now have T1, a brisk walk to lower high glucose levels is no longer the approach you should take to manage it. You now need insulin. These differences in strategies take significant re-adjustment and can be dangerous if not applied.

No matter how or when you are diagnosed with T1D, you need the support of a diabetes management team. The first step is to see a diabetes educator and a dietitian because anyone newly diagnosed with T1D needs to understand how to manage their diabetes and how food, and specifically carbohydrates, impacts blood glucose levels.

But it's not as simple as just food and insulin. Throughout a diabetes journey, there will need to be a diabetes team, which can include a GP, a diabetes educator, a dietitian, an endocrinologist, a podiatrist, a dentist and an ophthalmologist. Getting the right counsel is imperative.

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UNDERSTANDING THE FACTORS THAT AFFECT GLUCOSE LEVELS

There are 42 different factors that affect your glucose levels. So, if you eat the same thing every morning, your body's not going to respond in the same way every time, and you may need differing amounts of insulin.

Similarly, you would likely need a different amount of insulin at basketball training compared to playing a basketball game because the competition of a game comes with increased stress hormones; and grabbing a takeaway latte could have a very different response to grabbing a long black. Being unwell, altitude and even the weather can have an impact.

You have to know what those other factors are that are impacting your glucose levels and factor them into your decisions. That comes with educational support.

ACCEPTING YOUR DIAGNOSIS

Billy Mills works as a carpenter on large construction projects. Despite having some knowledge of T1D following his brother's childhood diagnosis, he found his own diagnosis as a 32-year-old difficult to accept, particularly as he didn't have any symptoms.

"I had to have a health examination and they found I had high glucose levels," he says. "I had tests and was originally diagnosed with type 2 diabetes, so I was put on metformin (T2D medication). Everything was fine to start with but then I took three months off work and I think because I was less active during that time, I got worse."

Billy was referred to the Baker Heart and Diabetes Institute where he was diagnosed with LADA but he now requires both slow-release and rapid-release insulin.

"There was a lot to learn in a short period of time. I have to be careful around decisions I make, like when I have a takeaway meal or consume alcohol, and around my football training," Billy says. "I now have a continuous glucose monitor, which helps, but I also listen to my body.

"When I was first diagnosed, mentally, it got to me a lot, but my advice would be to lean on your diabetes management team; they are there to support you. And whatever you do, don't let a diagnosis eat away at you. You can continue to live a full life."

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