# THE ABLE DIABETIC
# Able Guide No. 11

INNER CIRCLE RESOURCE

**The Misdiagnosis Problem: Why Adult T1Ds Are Missed**
*What the data shows, why it happens, and what to do if you suspect your diagnosis is wrong*

## Why this guide exists

I was diagnosed with type 1 diabetes at 21, at university, in the summer of 1993. In that respect I was fortunate - the diagnosis was suggested as a possibility immediately by my GP, I was tested immediately when results proved she was correct, I was treated quickly. That is not everyone's experience.

The evidence is clear that misdiagnosis of adult-onset t1d is widespread, consequential, and still largely unaddressed. This guide is about why it happens, what the data shows, and what to do if you think it may have happened to you.

## 1. The scale of the problem

Type 1 diabetes is not a childhood condition. Over 50% of all new cases of type 1 diabetes occur in adults. That figure consistently surprises people, including many in the medical profession.

It is estimated that up to 40% of adults older than 30 with t1d may have been misdiagnosed with type 2 diabetes, and the risk of error increases with age.

The consequences are serious. A person with t1d who is being treated for t2d is not getting insulin. Without insulin, a t1d will not be managing their condition - they will be deteriorating. Under-diagnosis of type 1 diabetes can lead to recurrence of life-threatening episodes of diabetic ketoacidosis.

## 2. Why it happens

The assumption that type 1 is a childhood condition runs deep - in public perception, in medical training, and in clinical decision-making. When an adult presents with diabetes symptoms, the default assumption is type 2. Statistically, that assumption is usually correct - less than 5% of new diabetes cases in adulthood are type 1. But when it is wrong, it matters enormously.

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There are also clinical reasons the distinction is genuinely difficult. Some adults with t1d - particularly those with LADA (Latent Autoimmune Diabetes in Adults) which is slow-progressing - do not need insulin immediately at diagnosis. Their condition progresses more slowly and the presentation can look very similar to type 2. Additionally, obesity and metabolic syndrome, once considered hallmarks of type 2, are now far more common in the general population and cannot be used to rule out type 1.

## 3. What misdiagnosis actually looks like

It does not always announce itself dramatically. Someone is told they have type 2 diabetes. They are given oral medication and dietary advice. Things improve slightly, or plateau, or gradually worsen. Insulin is not prescribed because the working assumption is that it is not needed.

Over months or years the picture deteriorates. Blood glucose becomes harder to control. Episodes of DKA may occur - sometimes more than once - before the question of correct diagnosis is raised. Meanwhile, the damage of uncontrolled blood glucose is accumulating.

I have written previously about my own MP responding to a letter about t1d misdiagnosis with a reply framed entirely around type 2 considerations. The confusion exists at every level - and it has real consequences for real people.

## 4. LADA: the specific adult diagnosis most often missed

LADA deserves particular attention. It is an autoimmune form of diabetes - the same underlying mechanism as t1d - but it develops slowly in adulthood, often over years. During the early stages, oral diabetes medication may appear to work, which delays the point at which it becomes obvious that insulin is needed.

LADA accounts for a significant proportion of adult diabetes diagnoses initially classified as type 2. Suspicion should be heightened in patients with coexisting autoimmune conditions, who are not excessively overweight, and who have deteriorating blood glucose control despite intensification of oral therapies. If that description fits your situation, it is worth raising directly with your doctor.

## 5. The tests exist - but are not always ordered

The diagnostic tools to distinguish t1d from t2d in adults are well established. Close to diagnosis, islet autoantibody tests are the most appropriate biomarker for diagnosing diabetes subtypes. In longer-duration diabetes, C-peptide testing is most appropriate, as it is the loss of insulin secretion that defines the treatment requirements.

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The problem is not that these tests are unavailable. It is that they are not automatically triggered for adults presenting with new diabetes, because the clinical assumption runs the other way.

It is also worth being clear about who this is relevant to. If you were diagnosed correctly as t1d in your twenties or earlier, these tests are not something you would have needed. The misdiagnosis risk applies specifically to adults presenting with new diabetes symptoms, particularly those over 30, where the clinical picture is less clear-cut.

If you were diagnosed as Type 2 as an adult and have found your condition progressively harder to control despite following the advice you were given, the question is worth asking directly: “Could this be Type 1 or LADA? Can we test for it?” GAD antibody testing and C-peptide measurement are the starting points. You are entitled to ask for them.

A correct diagnosis changes everything - the treatment, the technology you are offered, the monitoring, and the understanding of what your body actually needs.

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*Based on Sarah’s lived experience of t1d and research into adult misdiagnosis. Not medical advice. If you have concerns about your diagnosis, please raise them with your GP or specialist diabetes team.*

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**Want to understand more?**

Sarah's memoir **Invisible Impacts** covers her first decade living with type 1 diabetes.

Visit www.theablediabetic.com or contact Sarah at sarah@theablediabetic.com

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