# THE ABLE DIABETIC
# Able Guide No. 17

INNER CIRCLE RESOURCE

**The Mental Load of T1D: Understanding and Managing the Cognitive Weight**

*An honest account of what it actually costs to manage this condition, day after day, over many years*

## Why this guide exists

There is a version of Type 1 diabetes that is visible - the injections, the CGM sensor on the arm, the kit on the table. And then there is the version that is entirely invisible: the constant, low-level cognitive engagement that never fully switches off, which runs in the background of everything you do, and which nobody around you can see.

This guide is about that version. The mental load of t1d is one of the most significant aspects of living with this condition, and one of the least talked about. It does not appear in clinic summaries. It is not understood through HbA1c numbers. But it is real, it is cumulative, and over three decades I have come to understand it in ways I wish I had been helped to understand much earlier.

## 1. What the mental load actually is

The simplest way I can describe it is this: approximately five percent of my brain is permanently assigned to my type 1 diabetes. Not the same five percent doing the same thing all day. It shifts in and out of focus, sometimes quietly ticking in the background, sometimes demanding full attention. But it is never entirely off.

A non-t1d reading this might wonder what that actually means in practice. Here is what it means.

On waking, the first conscious thought is often a blood glucose check, or the anticipation of one. Before every meal there is a period of calculation: what am I eating, roughly how many carbohydrates, what have I already taken, how active have I been, how do I feel, what is the trend on my sensor? Two hours after taking mealtime insulin, there is a check point - am I going too low, am I running too high, does anything need adjusting? Before any kind of physical activity, there is a separate set of considerations. In the hour or two before bed, there is a settling process: is everything in a stable enough place to sleep without incident?

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None of this takes a long time. Most of it happens in parallel with everything else. But it requires focused thought. It is not automatic. And it happens multiple times every single day, without exception.

Between those peaks of engagement, the monitoring continues at a lower level. I will think about my glucose level and glance at my sensor most hours. Nobody around me knows when those thoughts arrive. They arrive constantly.

The emotional texture of the mental load is worth naming too, because it is not neutral. It is tedious. It is repetitive. It is relentless in the most literal sense - it does not relent. And it is guilt-inducing, because there is always a gap between the management you are delivering and the management you know is theoretically possible.

## 2. When the load is heavier

The mental load is not constant. It has varied considerably across my thirty plus years, and understanding what drives that variation is useful.

The hardest periods for me have been:

- **The first year after diagnosis**. The learning period is exhausting in a specific way, because you are building knowledge from scratch while also managing the condition with that incomplete knowledge. After a few months, the realisation of what "relentless" actually means: that this will never be over and that there is no endpoint, hit me hard.

- **Periods of demanding work**. I have spent significant stretches of my career in high-intensity environments: final stages of audits, major client events, critical management periods, roles with extensive organisational responsibility. During those periods I would be spinning plates from early morning until evening, then continuing at home. My t1d was always a lower priority than was ideal. The load did not reduce; it simply had to compete with more.

- **Pregnancy**. The need to maintain very tight glucose control, combined with the fear and guilt when that control was imperfect, made my pregnancies some of the most mentally demanding periods of my life with the condition.

- **Difficult personal circumstances**. Periods of family stress, or when a partner or family was not a stabilising presence, added to the load considerably. The mental overhead of t1d does not exist in isolation from the rest of life. When everything else is harder, the condition becomes harder to carry.

I have to say that the load has never been light. There have been periods that were manageable, periods that were genuinely very difficult, and periods where I made a clear-eyed decision that perfect control was simply not possible and I would have to live with the consequences of that. That doesn't amount to failure. It was a realistic response to a finite amount of cognitive and emotional resource.

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## 3. Burnout as something distinct

I only encountered the term “t1d burnout” in recent years, but I recognised it immediately, because it described something I had experienced without having a name for it.

Burnout is not depression, though it can accompany it. It is a specific state of being “done”. Of being unable to summon the focused effort that good management requires. Of going through the motions: taking the insulin, looking at the numbers, without genuinely engaging with what the numbers mean or what you should do about them. Of knowing that your glucose is probably running high and choosing, consciously or unconsciously, not to look.

I have been in that state. Looking back, I can identify the periods when I was not really managing so much as functioning. The condition continued to demand attention; I simply stopped giving it full attention. That was burnout.

Understanding that this is a recognised phenomenon, and not a personal moral failure, matters. Your HbA1c might be the evidence of it, but nobody will necessarily ask why. Naming it, to yourself, and if possible to someone who can support you, is the first step toward coming out of it.

## 4. What actually helps

I do not have a clean solution to the mental load. It is not something that can be solved. But I have developed, over many years, a set of principles that have helped me manage it more effectively, and I recognise that they come partly from my professional background in business performance management.

- **Ruthless prioritisation**. Not every number requires action. Not every deviation demands a response. Learning to identify what genuinely matters and what can be tolerated takes time, but it reduces the cognitive overhead considerably.

- **The sunk cost principle**. The past is the past. Fixating on yesterday’s poor numbers serves no useful purpose. The only question that matters is what the next decision should be. This sounds obvious. It is surprisingly hard to internalise.

- **Everything is learning**. A difficult stretch of management, a period of instability, a transition that does not go smoothly - these are data points. They tell you something. Approaching setbacks as information rather than failures changes the emotional texture of the experience.

- **Relying on others where possible**. The mental load is lighter when it is shared. This might mean a partner who genuinely understands your regime. It might mean a diabetes team you trust enough to be honest with. It might mean a community of people who know, without explanation, exactly what you are carrying. Finding those people matters.

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- **Accepting that change is constant**. Technology changes, life changes, your body changes, your regime changes. Treating each change as a crisis adds to the load. Treating it as the normal texture of a long-term condition reduces it.

One final thought I want to offer: the maths involved in managing t1d is non-trivial. Carbohydrate calculations, dose adjustments, understanding trends and percentages - all these require numerical fluency. I am professionally numerate, and I believe this has given me an advantage. For people for whom maths is not a strength, the cognitive load of t1d carries an additional layer. That is not sufficiently recognised, and it means that some people need more support than they are offered or ask for.

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*Based on Sarah's lived experience of over 30 years managing Type 1 diabetes. Not medical advice. If the mental load is affecting your wellbeing significantly, please speak to your diabetes team or a healthcare professional.*

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**Want to understand more?**

Read Sarah's blog which often discusses aspect of the psychological and emotional aspects of having type 1 on the website: theablediabetic.com

Contact Sarah at sarah@theablediabetic.com

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