

Loes Heijmans-Beek

# My Diabetes Diary

The naked truth about living with type 1 diabetes

**b:k light**

## *Foreword*

On 28 January 2004, I was diagnosed with type 1 diabetes. My world simply turned upside down. The next day, my mother gave me a diary so I could write down my experiences, sorrows and frustrations. During the years that followed, I kept on writing. Not daily or on a daily basis – only important, memorable days got a place in my diary, whether they were sad or incredibly happy.

To share my stories with the world, I started writing a blog in 2010. Not only did it help me cope, it also gave others a helping hand. It turned out to be something many people could identify with. With this, a new dream arose: writing my own book.

In 2015, the first Dutch Diabetes Diaries came out, followed by Diabetes Diaries – Oh Baby in 2018.

This renewed version brings about my new dream: a book translation. Both books have been bundled and complemented with my most recent diabetes adventures.

Enjoy the read!

Loes Heijmans-Beek

## *The day after*

28 January, 2004: a day I will never forget. And if I do forget, I will always have this journal to remind me. When my mom gave it to me as a gift today, I immediately begin to write; there is so much going through my head right now.

It has only been a week since I was in Valencia, enjoying my last glass of sangria, tapas, and everything else that Spanish life has to offer- the life I have been able to enjoy for half a year. The past six months have truly been 'the time of my life'. I completed an internship in a beautiful five-star hotel, made new Spanish friends who showed me around this beautiful country, learned the Spanish language, worked, and partied hard. And obviously, I enjoyed all the delicious local drinks and meals. 'Living the good life' was almost an understatement.

It was about three weeks ago that I became extremely tired. "Oh well," I thought, "I'll be home soon, I will catch up on my sleep." I was also incredibly thirsty; at one point I drank so many glasses of soda in a row that my roommate said: "why don't you just drink from the bottle itself?" I emptied the bottle within no time. Just a little thirsty ... or so I thought.

I dragged myself through those last few weeks before flying home on Saturday. When the flight attendant came by with her drinks cart, I could have kissed her! On Sunday, my dear friends surprised me with a welcome home party. Great to see everyone again!

Finally, I can drink sweet white wine again; apparently that is not a thing in Spain. I had to miss my favourite drink for half a year! My parents bought in bulk, but I cannot be bothered. The only thing I want to drink is water to quench my thirst, but even after fifteen glasses it does not go away. Gosh, how thirsty can a person be?! I even get up in the middle of the night to get some water. When I also start to get splitting headaches, I decide to go to the doctor. "As long as

it's not diabetes", says my dad. Sure dad ... I just got home, and he is already overprotective.

My mom goes with me. It only takes one blood test to diagnose the obvious. A fasting blood glucose level of 16.1. Boom! Diabetes!\* I used to know a girl next door who had diabetes, so I am well aware that my carefree life is over. Just like that.

I am so stunned that I can't even cry yet. Mom, on the other hand, is in tears so I put an arm around her. In the waiting room we come across one of her acquaintances who, coincidentally, happens to have a daughter with diabetes as well.

"Loes has diabetes," I hear mom say. The two mothers fall into each other's arms, crying. I just stand there and look at them. This is about me.

Half an hour after the diagnosis I find myself at the hospital. After having a lot of blood drawn, I speak to an intern and diabetes nurse. The nurse immediately helps me with putting a syringe containing clear fluid instead of insulin in my own abdomen, for practise. It almost comes naturally; it doesn't hurt and I don't even think about it. Apparently, I entered a 'do-what-needs-to-be-done' state of mind that I did not know I had in me.

A few hours later I can go home, with a set of detailed instructions and information. There you have it. Me, always the healthy one in the family. The one who has only seen the inside of a hospital during visiting hours. Unbelievable. Armed with an injection kit, insulin and insulin pens, an injection schedule, a diary to keep track of my blood glucose values and a bag full of information sheets. One moment you believe you are fit as a fiddle and, just half a day later, you discover you are chronically ill, and you need to put a syringe in your stomach four times a day just to stay alive ...

*\* For an explanation of diabetes and other unfamiliar terms that you come across in this book, you will find a list with an explanation starting from page 212. On page 217 you can find a conversion table mmol/l to mg/dl.*

12 February 2004

## *Fear of needles*

I have filled buckets with tears and still they keep on flowing. How can a perfectly healthy, sporty 20-year-old girl who enjoys life and only takes an occasional paracetamol after a night out, suddenly be chronically ill? It's mainly the powerlessness that drives me to despair sometimes. The thing is, I don't feel much different than I did a month ago. The only difference is that I have found a way to quench my thirst, and that I never leave home without a suitcase full of diabetes materials.

If I count back, I have now injected myself sixty times and pricked my fingers even more. Once a day I inject slow-acting insulin. It ensures that I always have some active insulin in my blood during the day and works for at least fourteen hours. This should be able to compensate for, for example, snacks that I eat. Three times a day at mealtimes I inject fast-acting insulin to allow my body to use the carbohydrates in my food as quickly as possible.

The injections are going relatively well. At first, I didn't really realise what I was actually doing. Until about a week after the diagnosis.

There I was: sitting at the breakfast table, holding a syringe in front of my stomach. I burst into tears.

"I can't do it", I wail to my sister Inge. My hand starts to shake, a needle hovering wobbly over the area of skin that needs to be injected. 'Can't do' is not an option now. I need to do the injection. And again in a few hours. And not just today, but every day of my life. I try to pull myself together, but I can't. I freeze. Inge comes to my aid.

"Show me where it needs to go, and I will give it the final push." It works, we're in. Still sobbing, I start to eat my bowl of yoghurt.

Lots of crying and even more questions.

Why me?

What is happening to me?

Why is my body failing me?

I want to understand, but it's hard to grasp and at the same time I can't help but think about my illness twenty-four hours a day.

What happens if I eat a biscuit, right now? Or some candy?

I feel strange. Or might this be a hypo? Help!

Before dinner I take another blood sample, value: 29.7. Oh dear, that can't be good. An extra injection it is. But how much insulin do I need? And why are my values still through the roof half an hour later? Can that be right? I am faced with so much uncertainty that sometimes I just don't know what to do anymore.

Of course, daily life goes on as well. I happened to have a week off after my internship, but in that week, I still had to furnish my new room in Maastricht and last week I was expected to attend the lectures of the new block – just like any other student.

At the start of the term, I see my friends again. Everyone has the best stories from internships all over the world. I had a similar story. Until the diagnosis.

When I share my news, I get the most diverse reactions. While I still have to find my own way of dealing with my illness, my internship supervisor responds: "Oh dear, how terrible. Are you still allowed to drink milk? Because I drink a lot of milk, so I would hate it if I were to get that." Err ... OK.

Of course, many of my fellow students don't really know what it means, any more than I did until a fortnight ago. The only thing they notice about me is that I draw some blood from my finger and inject a syringe in my stomach. But they get used to that very quickly.

I don't mention it too much. It is something that happened to me, something I have to deal with. I pick up my student life again and carry on as if nothing has changed ... at least I try to.



31 March 2004

## *Goodbye life*

Something has definitely changed: how was I able to think that I could go back to my normal life - just like that!

My body doesn't function as it should anymore, so I have to adapt. Adapt to the good advice from the doctors and everything I read about diabetes on the internet. They say alcohol and diabetes are a bad combination. Bit of a shame when you are a student. To let the insulin do its job it's important to keep to rest and routines, to eat at the same times as much as possible and refrain from doing anything too crazy. Imagine combining all that with the busy life of a student!

I want to give it my best, like everything else in my life. But I just can't do it, no matter how hard I try. Besides, I don't feel like it either.

As soon as I can, I go home where I can be myself and cry my frustrations away. An emotional rollercoaster, as my mum puts it. As soon as there are other people around, I'm fine; I put on my big smile. But as soon as I am alone with my parents, Inge and my boyfriend Remco, my tears start to flow.

I have been diagnosed with an illness that I have to deal with. I have only been on this road for two months, and I wish I could say that it is easy for me. Unfortunately, it is not. My care team say that my blood glucose levels should be between four and eight. These are the values of a healthy person and this is what I aim for. But it seems that the more I try, the less I succeed.

Every time I take a blood sample, it feels like a test. If the value is too high or too low, it feels like I have failed again. No matter how hard I try, it doesn't work. It's never perfect, even though that's what I want it to be. This frustrates me immensely.

I have always learned that if I try really hard, it will eventually work out. Whether I was graduating in high school, training for a tennis match or mastering complex pieces of music when I still played the oboe. Do your best, and the result will come eventually. And if you don't succeed, try harder the next time.

It doesn't work like that with diabetes. At least, not for me. Yesterday I had another check-up with my diabetes nurse. I am happy that I can discuss my frustrations with her. She was able to help me out quickly: I walked out of the appointment with a referral for a psychologist. Much needed, I have to admit.