

# Security is the opposite of fear: Our family story with diabetes

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Mrs Elisabet Norin is a Swedish mother of a son with Type 1 diabetes. Her son was diagnosed in the early 1990s, aged of six, and here she tells the story of the family's meeting with the paediatric medical system in her country. Focus is around trials and treatment, especially the supportive work made by the diabetic nurse and the paediatric staff. Their work made it possible for the family of a divorced mom and four kids to learn how to successfully handle the new situation in several aspects.

**Keywords:** Diabetes Type 1, Family story, Sweden, Multidisciplinary medical team, Treatment, Strategies, Methods, Child–parent

I was born a privileged citizen in one of the richest and most democratic nations in the world. Little did I understand – or appreciate – what it meant when I was young and first met relatives who had diabetes. My nan was the first one, half-blind, with lozenges in her apron pocket she died when I was around six. Later on, I met my father-in-law, blind since long, sitting in the darkness of his workshop, making brushes of different shapes and sizes. Also his daughter, my husband's sister, had diabetes. They all belonged to a mysterious tribe of people who were to be handed glasses of milk in bed early mornings, and who had to have their meal long before the rest of us during holiday dinners and who put tiny white pills in their coffees. I tried those and found the chemical taste unbearable. Once or twice every year, they went to hospital or the village doctor to give blood samples. They never talked about results or changed anything in their diet. I can't remember seeing any medication during these years, no pills or needles, no injections, and definitely no checking up on blood sugar levels at home. That was the situation when my youngest son, six years old, fell ill in 1991. First he became extremely tired. We went to the doctor's but nothing was wrong, so we kept on trucking for a couple of months. The situation was difficult in many ways due to other changes: after years in a destructive marriage with the father of my kids, I had managed to pull myself together and ask for a divorce. There had been enough abuse, I had lost enough, and wanted to show the children a better way of life. With a new job in hand, I could provide for myself and my children – life was definitely shifting to the better. But of course: times had been tough for years and also during this period. Of course it would affect the children, of course little J was tired. However, J became exhausted, he often woke up and ran for the bathroom in the

middle of the night and then to the fridge for a litre of juice, but also for breakfast and after school ... I understood better and took him to the health centre again. We were immediately ordered to go to the hospital, J's blood sugar level indicated 'HI', meaning it was not possible to measure. A friend passing by at the right moment drove us to the hospital: little J, his older sister C and me. A new part of life started, indeed. I spent three weeks with J at the paediatric inpatient ward at the regional hospital. Meanwhile, I was paid a certain amount by the state for being off my new work. It was a time of confusion and information. We learnt a lot, J and I. We had one special mentor among the nurses as well as the nurse that would be our contact later on as outpatients. Everyday brought new knowledge, for example, in meetings with the dietician, as well as doing some cooking in her kitchen, the doctor, the therapist and the social worker. It was all about foods, carbohydrates, shots and taking blood tests with gear that would be part of life for now on. New to me was that no one talked to me, they all directed the information to J as a method to make clear his life was his responsibility, not mine. At a certain moment during these weeks, J suddenly understood that he wouldn't get fixed by the doctors – a true sorrow that made him cry for a long while, absolutely heart-breaking for me to watch and not being able to give consolation by saying otherwise, just hold him. His teachers were soon involved in his treatment and stood up for him in every aspect. They met 'our' staff at the hospital together with us. The method: they all went together with us – actually, the day care centre closed during the occasion – was great. Everybody would see and hear the same information, and J and I would know what they had been informed about. They could ask us as well, and we could relate to the same

discussions. There was no hesitation at all from their side. If they had any doubts about the situation, they did not show – it was all professional behaviour through and through. This was followed up later on when J started elementary school with new teachers. Friendly and experienced attitudes all along, no need to pursue anything. This was the bottom security in our everyday life. His father, who saw the opportunity to move back into the house I had bought, during the weeks when I was with J at the hospital, refused to take part in any information or treatment. He was finally summoned to the hospital to see the social worker in a separate meeting – this was the only occasion he turned up at the hospital. Afterwards she told me she had made a note for him with our house sketched out as a box and ink strokes that indicated him walking back to his own place. He was clearly supposed to leave and so he did, to my great surprise. My mother, who had been too scared to go inside, came back with a locksmith; J and I could finally go home from the hospital. After some months, I could go back to my new job on a part-time deal, still some salary paid by the social insurance system. As a family, we adjusted to new thinking about meals and lifestyle. Things slowly changed to openness, we were not isolated from relatives and friends anymore and little J learnt to handle his situation even if he hated it and let us know. But he also learnt how to cook his own meals when coming home from school and sometimes got accompanied by a friend or two who cared for a burger cooked by J after school. What really mattered during these chaotic months and years was the multidisciplinary medical team. They were the bottom to me, my stable ground. They were our resources, medically of course, but also supporting us in other ways and as good listeners when I was to bits, or when J was angry with his situation. The encounters with J's father went on; he still refused to have anything to do with J and/or his diabetes. My frustration was tremendous when he could not overcome his fear of needles or his fear of diabetes, I'm still not sure about the main reason. J's father never attended any

diabetes education or took part in his care during these years, and at 18 J became an ordinary adult outpatient. We saw the social worker now and then – and I could always call her in between – and also our doctor as well as our paediatric diabetes nurse Britt-Marie quite frequently, first once a month, then once every third month, for blood tests and discussions about the overall life situation. After a year, we saw Britt-Marie once or twice a year, and our doctor in between once or twice a year. They helped us when we were in emotional turmoil by being very pragmatic. I also think the medical check-ups were quite frequent in order to see to our social situation as well. We first met Britt-Marie during our three weeks in the hospital ward, so we were well acquainted when J started to see her as an outpatient. Among other things, she saw to that J got a blood tester for free – it was paid for by Sweden's biggest children's charity, called Majblomman. Our doctor until J turned 18 was also part of life from start, even if we met only once a year. We also had contact during the first years with the dietician, the therapist and the social worker. They also tried to make our small local municipality social service to give support when I had to divide my time between J's three older siblings and my new job as well. The idea was that J would get a social support family one weekend every month. It didn't work out, since J's dad intervened: he neither wanted J to be at some other family's, nor take care of him at his place for a weekend. I had to go on a part-time sick leave for a while. A couple of years after J's debut I got Diabetes type 2. Actually no problem at all, drama was elsewhere. We had a special social situation and the medical team was willing to offer time, creativity and empathy to give support. I will be thankful forever for their dedicated job. I trusted them and felt secure – therefore feeling confidence and faith: the future would be bright. No fear, even if the situation was troubled on a daily basis. This was of course an outcome of a society with a well built up health care system and wise and intelligent people who understood that we all needed to stand on our feet in every aspect.