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He couldn’t want so much water

In May 1975 my younger brother and I caught measles. I was four years old, Peter was three. We were put into bed – the same bed – until we recovered. Eventually, our spots disappeared, but even after they had gone I did not make the expected recovery. I was always thirsty and constantly asked my mum and dad for glasses of water. One night, when my grandparents were staying with us, I went downstairs for a glass of water to quench my raging thirst. Ten minutes later, I went down again. And then again. And again.

Finally, one of the grown-ups said, in a mixture of exasperation and concern: ‘He couldn’t possibly want so much water!’ But I did need to drink a lot, and it was decided that I should be taken to the local GP. He simply bent down, smelled my breath, and pronounced: ‘Diabetes!’ We were then sent to the Harcourt Street Hospital in Dublin.

I can still recall the corridor of the hospital on that night – 15 May 1975. It must have been quite late, as it was dark. I remember sitting on a chair, apart and away from the doctors, nurses and my parents, who were all on the other side of the corridor, huddled in what seemed to me to be a conspiratorial manner. The medical staff were informing my parents about the need to admit me to hospital to investigate

Figure 1 John – two years before diagnosis, July 1973.

this *diabetes* thing – or at least what they knew about it then – and about how long I would have to stay.

From where I was sitting, though, it all looked rather sinister. Being only four years old and being told that I would have to stay in hospital while my parents went home only confirmed my suspicions that they were all out to get me!

I spent six long weeks in hospital, such was the lack of knowledge and information about the condition at the time. Sometimes, I was allowed out for the day, but, when I thought I had finally escaped, I soon discovered that I was expected to return the very same night. One morning, as I was dressing myself in anticipation of being collected, a nurse asked me why I was getting dressed. When I said that I was going home, she answered: ‘No, you’re not.’ This completely terrified me – I honestly thought I would have to spend the rest of my life in that hospital.

It was decided that I should be getting more exercise, so I was told to run up and down the stairs. This confused me – why couldn’t I use the lift like everyone else? And what was I going up and down the stairs for anyway? My dad also took me out to St Stephen’s Green, in Dublin city centre, on occasions. There he would time me as I ran round the park.

Figure 2 John – two months after diagnosis, July 1975.

After I had left the hospital, I recall one of the nurses who had cared for me there coming to our house to pay me a visit. I still have a vivid image of a bright, sunny day and that nurse – whose name and face I can sadly no longer remember – playing football with us in our back garden. This was a very generous and selfless thing to do, I now realise, but I am glad I still remember that special day. This sort of gesture, by a member of the medical profession, can really make a difference. The personal touch, the aftercare, for which overtime is neither sought nor paid, is very valuable.

I am from a fairly Catholic family background and I believe very much in God. It is something I have inherited from my parents, to my delight. A couple of years after I was diagnosed, it was suggested that I was taken to Lourdes in the south of France. In fact, I remember my grandfather saying to my parents: 'Send him to Lourdes.' I was horrified. At seven years of age, this sounded as though I was being banished. I had still not come to terms with being taken into hospital, away from my parents, when I was four – now this!

Lourdes is a town in the French Pyrenees which is visited by millions of people because of its reputation for healing people through their faith. In February 1858 Our Lady appeared to Bernadette Soubirous, a young peasant girl, on several occasions and told the young girl to search in a nearby grotto, where she would find a spring.

News quickly spread that drinking water from this spring would provide a miracle cure for a variety of illnesses. Since then, the grotto has been visited by people from every walk of life, who come in search of a cure. Parish pilgrimages from Ireland have been regular events, and my dad and I went on one of these in October 1978.

While we were there I bathed three times in the freezing cold waters. After five days we returned home. The visit to Lourdes made a lasting impression on me, and it definitely brought me closer to God, which has made my life much more complete. I was not, however, cured.

I had a problem with bedwetting as a child, which I now know to be the result of having raised blood sugars at bedtime. I had no glucometer (see Glossary) to check my levels – this was in the 1970s – so a great deal of my lifestyle and treatment was down to guesswork. I now know that one of the side effects of raised blood sugar is an increase in the amount of urine to be passed. But back then I simply thought I was weird. My younger brothers had well grown out of the stage of wetting the bed, while I seemed to be getting left behind. I carried a lot of needless guilt and shame about this, negative emotions caused by diabetes. These were to influence my life as a teenager, and, even now as an adult, some of those feelings still persist.

When I returned to school in September 1975, I explained to a classmate that I had been in hospital for six weeks during the holidays. Naturally, he asked what was wrong with me. 'I am a diabetic,' I told him. 'Oh,' was his response, 'so you're allergic to sugar.' I suppose that this other boy, who was only the same age as me and I am aware I should make allowances for five-year-olds, must have heard this response from someone older. Obviously, his informant did not have much of an idea about diabetes. This was my first encounter with some of the myths and misconceptions about diabetes, which I would have to challenge throughout my life.

My school bag was always packed with sandwiches and a plastic container of milk, which I had to drink at breaktimes. But, many times, I would open my bag to find that the milk had spilt from the container and soaked my books and papers, all dripping wet with stale, smelly milk. This was a nightmare then, though I can laugh about it now. Another memory that springs to mind is of realising, one day, that I had forgotten my 'life-saving' sandwiches. I was a very timid child, and, when I began to appreciate the enormity of the problem, I began to cry so much I could not stop.

One of my classmates went to get my brother, to see whether he would be able to stop me crying, and I vividly recall Peter galloping toward me, all the time stuffing his own sandwiches into his mouth. This memory now prompts a wry smile. It reminds me of the terror, the absolute dread that I felt so often during my childhood. When I knew that someone had gone to get Peter, I felt relieved. I knew that he would give me his sandwiches. But when I saw him actually eating those sandwiches, I was paralysed with fear. I really thought that I might die. I would never, ever, want anyone to experience the feelings I had that day. Even as I write this, I am reliving that fear, all because I had done something as trivial as forgetting my sandwiches.

Eventually, a teacher saw me and asked what was going on. I sniffled my way through an explanation and was then given some of the milk and sandwiches supplied to the school each day. I was saved. But I never again want to experience the fear I felt that day. As a child it affected me greatly. It helped to sap my self-confidence for years. The feelings of dread also really knocked the stuffing out of me for a long time. That was something I feel I did not deserve.

Sometimes, my usual class teacher was absent. I hated this happening as it involved the class being broken up into groups and sent into different classes until it was time to go home. I had to try to explain to the new teacher that I had to eat at certain times, even sometimes during lessons, which was usually frowned on. Every time this situation arose, my heart thumped as I tried to convince the teacher that I was not an attention seeker; it was just the safest way for me to get through the day.

In the 1970s the world seemed to be mystified by diabetes and so was I. At the end of a whining and invariably unsuccessful attempt at explaining my predicament, I usually ended up blurting out: 'Diabetic!' It almost always ended with me in tears, which shocked the teacher and amused my classmates. I hated those times.

One day, I was walking to school with my precious container of milk in my bag. Slightly late, I was running across the road and, as I ran, the container of milk fell out and rolled into the road. Having had it drilled into me how important to my well-being drinking milk was, I turned, ran into the road and grabbed it. It never entered my mind to look left and right. My only thought was 'I have to get my milk. It is vital to my health.' As I was bending down in the middle of the road, I was almost knocked down by a van coming round the corner. He hit the brakes just in time and I grabbed the milk container, turned and ran away. Ironically, it was a milk delivery van that had almost hit me!

For the first few years, the way I knew whether my sugars were up or down was through urine testing. This required me to wee in a pot, in order for me to extract five drops of urine, which I would add to a test tube along with ten drops of water, then put in an acidic tablet, which would dissolve in a fizz. There was a scale to measure how much sugar was in my urine: navy blue meant there was none; dark green meant there was a 'trace' of sugar; three progressively lighter shades of green indicated more sugar was present; and bright orange meant there was a lot of sugar present.

Every day I would come home from school and do one of these tests, and every time I would eagerly anticipate the concoction in the test tube turning navy blue. I was usually disappointed, as it often went bright orange. Sometimes, however, it was a shade of green and, very occasionally, it did go navy. I loved this. It could mean an ice cream or a bar of chocolate for me – heaven!

Because I was diagnosed at a time when knowledge of diabetes was not as advanced as it is nowadays and information was not as readily available, I was encouraged to try the 'diabetic foods' of the time. Diabetic jam, diabetic

Figure 3 John – first Holy Communion, May 1978.

biscuits and diabetic chocolate were great ideas, except for one thing – they tasted awful, except perhaps for the biscuits, as they seemed to have been made without any taste whatsoever!

When a pot of diabetic jam was brought home I would eagerly anticipate a major treat – bread and jam. I would butter the bread, open the pot, scoop out as much jam as I could get onto the knife, spread it richly all over the bread, drop the knife and hungrily take a bite. All the time I would be thinking about how good this was going to be. I am having bread and JAM! I would begin to chew, my taste buds tingling in anticipation of the treat to come. Then the 'flavour' would hit – and it was indescribable. Argghh!! Take it away! The lid would be firmly replaced on the pot and it would be hidden at the very back of the kitchen cupboard.

Ages later, this experience having been long forgotten, something in the cupboard would be moved, revealing the hidden pot of jam and I would decide to try it again. The lid was opened and then I would need to step back, holding it at arm's length and trying to decide whether it was worth scraping the old man's beard off the top of the remains of the jam. It was truly gruesome.

Not only were the diabetic jams devoid of flavour, they were also a waste of money, as they never were finished and were always thrown out. Nowadays, with our knowledge, we can eat ordinary jam on bread, without it causing too many problems. There is also a much better quality of sugar-free foods now available. But, a few years ago people with diabetes were stuck with largely tasteless foods. How times have changed.