

Jake's Progress

Bus pass, keys, iPod, NovoRapid insulin pen...

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In September 2006, something unusual started happening to my thirst. I was drinking more than I had ever done before, mostly water, and after one glass I wanted another. For a day or so I felt quite pleased; it was an involuntary detox, the sort of health regime I had always promised myself. But then the bathroom breaks became a bit of a drag, and I began to feel unwell. I felt lethargic, developed headaches, became hungry, started looking gaunt. Because I knew a little bit about these things, I thought I might have diabetes.

Things returned to normal after a few days and I put it to the back of my mind. In the next few weeks I felt healthy, but wondered about a health check. Like most men, I put this off. But then I had to have one for a new insurance policy, the usual half-hour in a private clinic near Harley Street, and I went in just as Russell Brand was coming out. I awaited the results with little anxiety - I had felt fine for months now - and when they came everything was fine. My blood sugar levels were within the normal range, as were my heart measurements and cholesterol.

A few weeks later, my 16-year-old son Jake began to fall ill. Initially I thought this might be stress from work - his AS Levels were approaching - but symptoms of tiredness were joined by other signs: thirst, frequent urination, increased appetite, weight loss, mood swings; again, the classic signs. He went to his GP, who took a urine sample and announced that everything looked normal. There was also a blood test, with results due in a week.

But during that week Jake's condition worsened. We went up the road for brunch one morning and he walked much more slowly than usual. We had to stop on the way for a rest, a worrying sign for my very active son who thrived on football, swimming and martial arts. When we sat down I noticed how pale he looked, and how the shape of his face had changed: his features were suddenly dramatically defined, and he told me that at school one friend had said to the whole class, 'Hey everybody, look at Jake's cheekbones.' We talked about what might be wrong. Both his mother and I had wondered whether he had taken any drugs, or whether he was depressed, and as Jake ordered two drinks with his food I mentioned the possibility of diabetes.

The following day he was due to take his first exam, but found it impossible to get out of bed. Our regular GP, not the one Jake had seen before, expressed concern over the phone, and requested the blood results from the lab. When she saw them, she suggested Jake go to hospital immediately. He was hyperglycaemic, his blood sugar levels excessively high. Within minutes of his arrival at A&E at the Royal Free in Hampstead he was diagnosed with Type 1 diabetes, the most common form among the young, and the most serious. It

was a shocking diagnosis, no matter how much we had anticipated it, but it brought a certain relief; at least it wasn't anything worse.

And so it began: my youngest son lying on a bed, drifting in and out of sleep, getting better all the time as the insulin dripped in and machines behind him gauged his statistics. And he was now a statistic himself, one of about 300,000 young people with Type 1 in this country, a steadily increasing figure with no certain cause.

I had never given diabetes much thought. I have written about cancer and Aids and depression, but diabetes - that was something manageable and unprofound, a disease where not much happens. About 130m people have it throughout the world. I had read that Type 2 diabetes, which accounts for about 85 per cent of the 2.24m cases in the UK, was on the rise due to increased levels of obesity, and part of me casually dismissed this as self-inflicted. I have a good friend who was diagnosed a few years ago and he looked great when I saw him recently. Occasionally, I read about famous diabetics overcoming their condition or failing through its complications. And I remember when John Peel announced his diagnosis on air, and then played another record at the wrong speed to show nothing would change.

As Jake spent the next few days hooked up in hospital I learnt a bit more, and even in a post-traumatic condition it made clear sense. Diabetes occurs when the body does not make enough or any insulin, the hormone that distributes blood sugar (glucose) through the body's cells. Glucose is our main supply of energy, supplied by the liver and through our intake of starchy and sugary food. Insulin is made in the pancreas, and when the cells producing it shut down, glucose fails to be absorbed and levels in the blood become excessive. To counteract this, the body attempts to pass the extra glucose through urine and our body will attempt to draw its energy supplies from fat stores instead, thus leading to weight loss. Many complications may follow.

Diabetes is the third most common chronic disease in people below 18 after cerebral palsy and asthma; 1-2 children in every 1,000 will have it. In Type 1, where no insulin is made, the artificial hormone will have to be injected. In Type 2, which is most commonly diagnosed in those over 40, the pancreas may still be able to produce some insulin, but it may either be insufficient or defective. Some extra insulin may be required, but it is usually treated with exercise and diet and possibly tablets.

It is likely that Jake's cells had been destroying themselves for several years before the appearance of symptoms. Friendly professionals tend to favour motoring imagery: a fuel tank without a gauge that slowly runs out of petrol, a battery that runs down far earlier than it should. But is there a fault here - a bad driver, a troubled production line? Inevitably one asks: Why me? Why him? Why not the other 998 in the 1,000?

The precise cause of diabetes is still unknown, but it is widely believed to be partly genetic and partly environmental. The destruction of the pancreatic cells may be triggered by a virus that causes an auto-immune response - the body's own defence system begins attacking itself. There is a genetic predisposition, but it is by no means certain. In a pair of twins, only one may be diagnosed.

Among the literature that surrounded Jake's hospital bed, there was a list of myths about diabetes. It is caused by eating too much sugar. After diagnosis you can never eat sugar again. You have to eat special foods. You will not be allowed to drive. Unfortunately, it was also a myth that you can be cured. Soon the tubes and wires would be disconnected, and Jake would have to manage his condition by himself. It looked daunting. Diabetes UK, the principal care and research organisation, produces a wallchart with details of the paraphernalia Jake now had to avail himself of. In his four days in hospital, he learnt the basics of self-care swiftly, and acquired a toolkit in a neat fabric pouch; I wondered briefly if a gang on Hampstead Heath would mistake this for something they could use or sell, the way they once did with his football. The kit held everything you needed for regular maintenance: a meter that looked like an MP3 player, a supply of absorbent strips resembling blotting paper, a tool to prick your finger. After a few sessions with a nurse it became a familiar routine. You place the paper into the tip of the machine and prick the side of a finger. The machine beeps when it has enough blood to measure, and within a breath it provides a digital reading of your glucose levels. You may then have to adjust the level by injecting insulin into your stomach, arm or leg with something resembling a fountain pen that holds its supply like an ink cartridge. For most people this procedure will occur several times a day.

There are other, scarier tools, such as glucagon, the diabetic's panic button. This is an emergency syringe kit with a hormone that may be administered by friends or family when the person with diabetes is hypoglycaemic, a condition caused by a dangerously low blood sugar level that may lead to coma. There is also a gel that can be rubbed into the cheek (a milder 'hypo', with symptoms of dizziness or confusion, can be treated with a quick sugary drink or dextrose tablets and then a snack).

All of this made me consider how intricate our body's natural mechanisms are, and how, in a normal situation, it makes immeasurable calculations each moment to adjust cellular and hormonal imbalances. It also made me think: what a pain, what an interminable ordeal. Jake's friends came and cheered him up. One, slightly confused, brought cakes. Others brought diabetes newsletters from their siblings. Jake's brother Ben, two years older, told him about a friend who had Type 1 who would be happy to talk to him. And then, after we told the lodger of Jake's diagnosis, she said that she had diabetes, too, and hadn't mentioned it before. We saw it as a sign that it was easy to manage without fuss.

The fridge is currently full of things it has never seen before: two packs of Glucogel ('Formerly known as Hypostop'); six boxes of NovoRapid penfill; Lantus OptiSet injection solution cartridges for night use; and a GlucaGen HypoKit in its orange plastic box with the syringe and a glucagon vial. We used to keep olive paste and tomato puree on that shelf. But how did we get here? 'My grandfather used to inject himself with insulin from a syringe,' Dr Iain Frame tells me at his office in Camden Town. 'It was second guessing and piling it in, a very crude way of controlling a finely balanced physiological mechanism.'

As research manager at Diabetes UK, Dr Frame is responsible for overseeing an annual grant allocation of £6.5m into wide areas of care, prevention and treatment. These include studies into the management of Type 1 patients who also have an eating disorder, a trial on the effects of exercise in patients newly diagnosed with Type 2, the relationship between diabetes and non-alcoholic fatty liver disease, and the effect on diabetics of the imprinted genes on chromosomes 6 and 11. Perhaps most significant is a 3,000-patient multinational trial examining whether the taking of statins, the anti-inflammatory heart drugs used to control cholesterol, affects diabetic complications.

In short, the organisation is concerned with anything that might be beneficial to diabetics, including the estimated 500,000 to 750,000 who have yet to be diagnosed (about 90,000 new cases are diagnosed each year). The key lies in education, and enabling those with diabetes to look after themselves with the best possible evidence as to how to avoid long-term complications, such as liver or heart disease, or damage to the retina. And it is also concerned with the possibility of finding a cure.

When I visit Dr Frame two months after Jake's diagnosis, the news is full of stories about the beneficial effects of pumpkins on diabetes, and an automatic insulin pump that is being hailed as an 'artificial pancreas'. Frame is cautious about the breakthroughs that turn swiftly to false dawns: 'I think we're in a golden period, and have been since the Eighties - these huge leaps and bounds on how to control the development of this condition. But some private companies are trying to oversell their new projects, and some journalists believe it, but a lot of trials are very small and don't follow up... You shouldn't give people false hope.'

He is particularly hopeful for the work being done in Canada on transplanting islet cells into the hepatic portal vein, providing insulin that aids the digestive system and keeps blood sugar levels regulated. The first success stories emerged in 2000, with reports of young people freed from their insulin jabs. But it is at an early stage, with patients still needing to take immunosuppressive drugs to help the cells survive.

The work being done in Cambridge with automatically regulating pumps is also exciting. As Dr Frame describes it, 'There's a pump on this side [taped to the skin] and a Palm Pilot on the other, and the mathematics behind it has the two of them talking to each other.' The study, which is being funded by the Juvenile Diabetes Research Foundation, uses a computer programme to calculate the amount of insulin to be administered automatically, without recourse to manual meters or injections. In time, the pump might be made small enough to insert beneath a skin flap, not unlike a pacemaker. 'At the moment it's still an academic research project,' Dr Frame says. 'If it was so good, the people who made the pumps would be piling an awful lot of money into it and trying to speed it on. It's a huge advance, but there's a question mark over where it's going to go.' (Insulin pumps, attached externally to the stomach, have been available for a few years, but operate in a pre-programmed way determined by manual meter readings.)

As ever with medical advances and the NHS, there are problems with affordability. If an automatic pump was commercially available, would the relative freedom it offers be enough for it to meet the efficacy and costing guidelines of the National Institute for Health and Clinical Excellence (Nice)? The pumps presently available cost several thousand pounds. Insulin sprays that have come under scrutiny by Nice were found to be about four times as expensive as the cost of injections, and were recommended principally for those who were needle-phobic or unable to control their glucose levels by other means. Sprays are also less effective in delivering an exact dose and, because they enter the bloodstream via the lungs, take longer to work. A family of tablets are also available which help Type 2 diabetics make better use of insulin or overcome insulin resistance.

And then there is stem cell research, the light at the end of so many chronic ailments. No one has yet made an artificial pancreas from stem cells, and at Diabetes UK there is general caution after the hype that accompanied the great advances in molecular biology over the past 20 years. 'Huge potential,' Dr Frame tells me, 'but the reality is somewhat different. Not long ago we interviewed one researcher in this field, and he was asked, "How long will it be until you're standing up in front of our volunteers to say, 'We've cracked it?'" He answered, "Twenty years." I was shocked, because I thought that was an awfully long time. But a former director at the Wellcome Trust went in front of a House of Commons select committee and said, "I'm an expert and I can confidently predict that there will be a stem cell cure for diabetes within the next two to five years." That was in 2002. It's not close. But tomorrow, someone may just go into the lab and find something.'

The week after I meet Dr Frame, there is another significant advance. Nature Online announces the discovery of a new gene that indicates a child's predisposition to Type 1 diabetes. In a study involving 1,000 children with diabetes and their parents, and 1,200 healthy children, two research teams in Montreal and Philadelphia isolated three distinct changes in one gene on chromosome 16. Eight other gene variations had been found before, and it is not clear why the changes occur. The race is now on to find out the function of the protein produced by the gene, and to explain why the presence of two of the gene variations indicate a 50 per cent increase in the chance of getting diabetes, while the third appears to reduce the chances of getting it by the same percentage.

We have travelled far. Not so long ago, diabetes was still a death sentence. Although the symptoms were first noted on papyrus about 2,500 years ago, as late as 1850 physicians were describing it as a condition of the liver and advising the consumption of as much sugar as possible. The link to pancreatic cells was made in 1869, and in 1921 the announcement of insulin's role was made by Canadian and US researchers at Yale. Initial experiments were performed on a dog, and the first human patient was treated successfully the following year, although artificial insulin, the form used today, wasn't commercially synthesised until the Eighties.

The timeline is studded with significant developments: the recognition in 1959 of the two major types of diabetes; the production of home testing kits in the

Seventies; the insulin pen delivery system in 1986; the publication of a study in 1993 describing in detail the optimum blood sugar levels and frequency of self-adjustment needed to avoid long-term complications for Type 1 patients.

At the beginning of the last century, the American diabetes specialist Elliott Joslin considered diabetes to be 'the best of the chronic diseases... clean, seldom unsightly, not contagious, often painless and susceptible to treatment'. A hundred years later, this holds true. Many people have told me that diabetes can be considered 'the healthy illness', not least as it demands a balanced diet and regular exercise, but also because it demands the regular monitoring of all aspects of one's health.

Two months after my son's diagnosis, I share with his mother a sense of relief and pride that Jake is handling his condition so well, but also a concern that he will continue to remain healthy in the future. We are worried that he is eating too much fatty and sugary food, and that he needs to control his diet more strictly. We're aware that it may lead to other health complications in later life. But Jake has always displayed great fortitude.

'Initially I didn't want it to become too big a thing, with my exams to focus on [they were rescheduled and went fine]. At first I felt quite unlucky that I had to deal with this every day. It wasn't like one of those things you can fight and overcome. No matter what I do, it's going to be there. But I don't think it took long to accept it.'

Jake keeps a chart monitoring his blood sugar levels, and injects between two and six times a day, depending on his intake of food and levels of exercise. He managed fine during five days at Glastonbury not long after his 17th birthday. Now, two months after his diagnosis, he says, 'The two concerns I have are having my pen with me after I've eaten, and the whole nagging thing about having to think about it a lot. It's not a major problem. I felt a lot worse before I knew what it was. I haven't had to change my diet or life that much, and it's not a big deal for my friends or a problem socially.' What he'd really like is to limit the number of times he has to inject. 'Oral sprays sound so good, and that pump. Things are improving all the time.'