

Jacqui Double tells Tom and Joe's diagnosis stories

I can date the time when things started to be a bit strange in our household because it coincided with a frightening experience. It was Halloween in 2000. Joe and Tom were in the front room watching children's television. Tom was 16 months old and Joe was a few months off 4 years. I knew it was Halloween but I had forgotten to close the curtains in our front room. We live in a small fisherman's terraced house which has its front wall directly onto the pavement. I heard screams of terror from the boys; Joe was beside himself but Tom was utterly traumatised as two boys, not meaning to be cruel, had looked in through the window with skeleton masks over their faces. It took about twenty minutes to calm both my children down and show them it was just a mask. They did settle again, but from that moment I remember life began to change.

Tom began to drink more. He ate ravenously and kept over-flowing his nappies at night. This didn't happen every night but off and on for a few months. By Joe's birthday on the 1st of December, Tom was constantly begging me for drinks or food. I thought he had had a growth spurt as he looked longer and thinner. But mainly I was fed up of his whinging and felt cross he was spoiling Joe's birthday. (Oh the sting of guilt now is still painfully strong). I decided to take him to the GP's on the next available day and in the mean time looked up what I thought were his symptoms in a Children's medical conditions self-help book. That Monday I went to the GP taking Joe and Tom with me. The chart I had followed in the medical book had taken me to 'Diabetes Mellitus, seek urgent medical help' but I had felt silly to react so strongly when Tom was still toddling around and eating. So I went to the GP and explained about the weeing and drinking and eating. My Gp smiled as if I was one of 'those' parents and reassured me that it couldn't be Diabetes as Tom was too young. He asked for a urine sample in a little pot, which he would send away the next day. I spent the rest of the day relieved and chasing Tom round the house trying to catch some urine. It was duly sent off the next morning.

That night Tom started to be sick. He was still eating and drinking large amounts, but he had no energy now and was spending most of his time in his pushchair or lying on the sofa watching TV. I could feel myself tensing every time I looked at him. I called the doctors and asked for the test results, as Tom seemed even more ill. Another doctor spoke to me and I was told the results had come back as negative for diabetes and that Tom most probably had gastroenteritis. I should only be worried if he stopped eating and drinking at all. Of course this wasn't the case with Tom so I spent another day with him being sick whilst I tried to keep family life ticking over normally.

The next day I called for another doctor to see Tom. Tom was looking very thin and was now not keeping any food down. The other doctor came, though he was a locum who seemed very put out that he had had to come out on a house visit when we lived so close to the surgery. Tom was lying on the sofa quite still and very pale with dark circles around his eyes. The doctor watched him struggle up to drink his water and said I was over-reacting and was causing a fuss. He told me not to take Tom to the hospital or call the GPs unless he stopped wanting to drink. He said I might call in the morning to see someone if Tom was still listless.

The remains of that day are the worst of my life. I cried a lot. I couldn't sleep in the same room as Tom as I just wanted to pick him up and run with him to the hospital. Every fibre of my being was saying I should take him to Casualty. But the words of that GP kept going through my head and I was too worn down with lack of sleep and worry to contradict him. The next GP who came to see Tom came fast when I described what had happened whilst crying. She brought a BM kit and tested him. Of course he was off the monitor's scale of readings. She told us to grab Tom and Joe and to rush to the local hospital and that we shouldn't wait for an ambulance as we didn't have the time. We ran hardly clothed to the car and got there as fast as we could.

She had phoned ahead and a team was waiting to take Tom from us when we came in. He was instantly surrounded by a huge number of people. They tried to get lines into his body but he was so ill by then they had to go into his jugular vein. The consultant looked up from his work and said in a very straightforward way, 'Oh yes, he is diabetic.' when we asked. They began to give him insulin and a drip to rehydrate him, in tiny amounts though as they were very worried about him having a brain swell - a rare complication of diabetic ketoacidosis. He was kept in the high dependency unit on the children's ward as there was no intensive care for babies at our hospital.

All that day we waited by Tom's bed as he woke fitfully and then lay still again. A female doctor came in and kept saying she couldn't tell if Tom was asleep or unconscious. They began doing tests on him. By this time my mum and dad had travelled down from Staffordshire to come and look after Joe for us. We had been in the hospital all day and the night. My mum and dad wanted me to go home and get some sleep whilst they left Olly on duty with Tom. After much persuading I agreed. We had been home for less than an hour, and I had just gotten into bed and tried to relax, when the phone went. It was Olly. He told me that the thing they had most dreaded happening had happened to Tom. His brain was swelling and he had dropped into a coma. They were going to have to put him onto a ventilator and get him retrieved by a team from London so that he could go into

intensive care. We were told that his chances of surviving were getting ever slimmer as time passed.

The team from Guys spent almost the whole day working on Tom to stabilise him before they could get him ready to travel. He had lines sewn into his body. He was on a ventilator and was heavily sedated. The ketones in his blood were so high they couldn't be counted. The sticks I saw them dipping went dark dark black, not even enough violet in there to see. His blood sugars had been over 59mmol/L when he arrived at the hospital and they were finding it impossible to bring them down and clear the ketones. Olly and I read *Maisy Mouse* stories to Tom and waited for him to leave in an ambulance full of strangers. There wasn't room for us. We couldn't let Olly drive, as he hadn't slept. My dad was trying to get some sleep so he could be fit to drive us but it was looking impossible. Finally the consultant came into the waiting area of the intensive care ward and said he was sending us by taxi and that it was time to go. We watched Tom leave and then got into the taxi to follow him. We had absolutely no idea whether he would still be alive when we arrived at Guys Hospital.

Tom remained in a coma for another two or three days. They kept him sedated and kept scanning his brain to see the swelling and what damage it may have caused. At first they wouldn't venture an opinion on whether he would wake up. Then one nurse told us he thought he would live. That little glimmer of hope kept us going for the next few nights. Finally they felt they had brought him into some level of control and would risk trying to wake him up. He still had ketones and was still very high but I could see a colour on the sticks they dipped now; purple. I may dread seeing that colour now but then it felt like a huge relief. Tom took a little time to come round, and when he finally did he just cried and wanted to be cuddled. I had to lean into the bed with all the leads and wires and try to hug him. He was so small and frail he might have been blown off the bed if they opened a window.

Tom was desperately thirsty but they didn't dare allow him to drink. He just kept begging and begging for water. I was allowed to give him a tiny pink sponge dipped in water every hour. Tom soon realised that if he threw his dummy out of the bed it would have to be washed and he could suck the slightly wet teat for relief. It was then we dared to believe he might have come through this without being brain damaged.

We were allowed back to Canterbury another two days later and were reunited with Joe, who was beside himself with fear and loneliness having lost his family for a week without any warning. Perhaps this explains why Joe is so close to his brother now, and is such a sensitive deep boy. Tom continued to recover and we began to learn how to look after his diabetes for ourselves. However, a diagnosis like that will always leave deep scars

and whenever Tom is ill in any way I shrink back to that terrified mother I became. But I would never ever allow a GP to stop me from doing what my instincts tell me are right. I am a stronger advocate for my children now than ever before.

And so we fast forward to June 2005. Joe is 8 and has started junior school. He has just sat his SAT tests and has begun to wet the bed sporadically. At first I allow myself the excuse that it is stress. Olly does the same. Then Joe starts to drink more than usual, not a Lot but enough to notice. Olly and I share awkward glances and begin to worry. Then we are out on a family shopping trip and Joe DEMANDS we buy him a bottle of water. This is so unlike our very calm placid boy that Olly and I cannot wonder any longer. When we get home that evening we ask Joe if he can remember how to do BMs and to show us by doing one on himself. He does.

Olly and I go through to our room and sit and cry in silence. How unfair life can be. Joe is dancing about with Tom in their room, shouting 'I'm higher than Tom!' over and over again without for a moment considering the implication of what he is saying. I go down stairs and phone the out of hours GP, not knowing what procedures to follow though we know exactly what is happening. We decide not to tell Joe it is definite until we are absolutely sure that nothing else could elevate his blood sugars that way. He was 33mmol/L, so we know it is a very long shot. I bring Joe down and sit him on my knee and ask him what it might mean if he has done a BM and it shows he has high blood sugars. My sweet, quiet little boy says 'Does it mean I might be diabetic. But Tom is diabetic, not me. Are you telling me a joke?' I tell him I am not joking and that we are going to go and see the doctor and then we will know for sure. Joe sits very still and quiet and keeps sneaking glances at me. Olly and I are amazingly calm and already resigned to what we know the news will be.

When Joe is finally told he is diabetic he stays quiet again. I tell him he is allowed to shout and swear and get angry if he wants to. And he starts to shout about all the things he knows he is going to have to live with. Injections, being forced to eat when he doesn't want to. Having to do BMs when he is busy and wants to play. Not being allowed to run around at the park without me calling him back for snacks and tests. Being different to all his friend and no one knowing what he is having to do all the time. And this must then make him think of Tom, because he stops and says he wishes Tom was there because Tom would understand what it was like being told you are diabetic. Then he also decides his monkey is diabetic and that he wants a red insulin pen. And we all smile together and carry on again. would have destroyed that hospital searching for a red insulin pen for Joe if I had to but thankfully they had one in stock. I wouldn't let them use a syringe on him, but insisted he have his pen for his first injection from the

very first moment. This gave Joe, a boy who had grown up caring for his little brother with diabetes, ownership of his own condition. He starts to do his own injections from the outset. I also demand Novomix 30 instead of Mixtard. I am told it doesn't exist by a consultant on the ward. I tell him I have been using it for 4 years with my other diabetic son and he backs away and returns with a book a nurse has given him and tells me he might have a different type of insulin to try. I begin to see how much I have outgrown this process already. I insist that Joe is transferred to Tom's consultant's care immediately and try to get them to discharge us. They won't let us go until the morning, even though I know exactly what to do and Joe is the wellesst diabetic child I have ever seen. Still we have to wait.

Finally we get home and Joe and Tom meet as brothers sharing the same condition for the first time. They decide they are going to call themselves the Double Diabetes Brothers and compare BM kits. Life carries on but a little busier.

Hope that is useful. I can safely say that is the last time I will write out what happened with Tom. It is especially painful to put it down on paper again. At least if it goes on a web page I don't have to say it again. I do actually feel that is all in the past for us. It hurts but it doesn't haunt so much now. I just feel sorry for us all, like you would of characters in a film. I 'see' myself getting that phone call and wish I could tell myself it will all be okay and let myself see the happy, healthy Tom and Joe on their insulin pumps now.

Pump story will have to follow. I should have been writing my talk but had to get that out of the way first, obviously!!!