

Well here is the story of Melissa's dx. Sorry it is so long but once I started I could not stop! It probably makes no sense, I just rambled on reliving it all. I actually did this in word and pasted it over and so this makes it even harder to read, with even worse spacing than I did originally. I really understand if no one wants to read, but I did say I would do it.

Melissa had always drank loads but it was when she started waking in the night crying for a bottle (something she had not done since 6 months old) and flooding her nappies that I thought we had a problem. With no diabetes in the family and no knowledge of the disease it did not really cross my mind. It was when her breathing started to sound laboured on the 13th December 2005 that I took her to the GP surgery. I was advised that she had a respiratory virus and was given a nebuliser. I explained that she was drinking loads, the GP asked me if she was also urinating a lot, to which I answered yes. He advised me that was good. He never mentioned the possibility of diabetes and never offered to test her for it. I later found out that this GP holds Adult diabetic clinics. The Nebuliser of course had no effect. Melissa stopped eating and would scream when you touched her. I tried to let the "virus" run its course but after 3 days I could take it no more and took her back the GP's. I saw a different GP who again confirmed that it was a respiratory virus and that it would just take time and that this is very common. The weekend was awful. Melissa would not walk at all, her breathing sounded worse than ever, she was not eating, not sleeping and appeared to be getting weaker all the time. I phoned the GP as soon as the phone lines opened on Monday 19th December 2005 at 8 30 and got an appointment for 9 30. I sat there looking at my baby girl and thought that she was dying. With less than an hour to go before GP's appointment I decided that we should take her to A&E.

On arriving at the hospital we went straight to the children's A&E and were assessed by a Nurse before we were to see a doctor. She listened to everything we said and tested Melissa's oxygen level which was 99%. She told us that this led her to believe it was not a respiratory problem and the next thing she did was a finger prick blood glucose test. This was of course through the roof and she told us there and then that Melissa has diabetes. Within 10 minutes of us arriving at the hospital they had diagnosed Melissa, we had been seen by a doctor and were waiting to go to ward. Melissa just lay there, not even crying anymore. I will always be so grateful to Polly the nurse who had the sense to do the blood glucose test which I understand is not part of their standard procedure. She basically saved Melissa's life.

Once transferred to ward the care was sadly not as good. The paediatric doctor was

actually very competent (we knew him from other issues when Melissa was younger). He sorted all the necessary drips and treatments with hourly blood glucose tests to be taken. The nurses however were awful, they were not even able to do simple blood glucose tests. They used the disposable prickers and decided that the adult ones would be more affective (Melissa was 17 months old). They could not hold her fingers still as she was too upset and so used her feet. They would struggle to get any blood and would be pricking and squeezing her poor feet whilst Melissa screamed and screamed. It would take about 20 minutes to settle her after each test. As these hourly tests were to continue for 24 hours I decided to lay her on the bed with the side guard up rather than in the cot and here I could lay with her and comfort her and maybe she could get a little sleep between the tests. This went on all day and continued in to the night. At this time though her drip line gave out and a new one needed to be fitted. It was night however and junior night doctors who would struggle to fit a line in an adult had to fit one to my little baby whilst she screamed and I held her down whilst holding back my own tears. Two junior doctors later and her arms having been used as pin cushions for what appeared to be forever the line was finally fitted. They decided due to the amount of upset Melissa had and how inconsolable she was that we should be put in a private room so the other patients could sleep. In this room there was no cot and the bed was really high with no side guards. I asked for guards each time the nurse came in the room to do the hourly tests but none were given. I therefore spent the night staring at Melissa in case she fell out of bed.

The next day Melissa was able to come off the drip and I was visited by the diabetic specialist nurse who gave me a small booklet about diabetes and explained that we should be able to go home hopefully on Christmas Eve. She was a really nice lady and listened when I told her about the nighttimes horror we had just had and how there was no way I would attempt to sleep whilst my daughter who could not even sit up on her own anymore let alone walk was in a high bed with no side guards. She went away and came back later telling me that we could take Melissa home that evening if we wanted and she would come to our home each day to help with Melissa's care. Although it has later transpired that this nurse is very dated in her diabetes management (she mainly uses mixed insulin's, does not appear to even understand carb counting and has no pump users), she was wonderful to us at this time. She realised that Melissa was not getting the care she needed in hospital and we would cope easier at home. She told us Melissa would be on two injections a day and asked how we thought we would cope. I replied fine that I had no problems with giving her injections. I was determined not to have an issue with the injections or prick tests, they would be a part of our lives and I would just have to accept it (I had never previously even been able to watch Melissa have standard injections etc). The important thing for me was that Melissa would live – I really had thought they she

would die. I was actually relieved to find out she had diabetes as I thought this could be controlled (!).

We were never advised about alternative insulin therapies such as pumps and MDI and the benefits etc. We was only told that she would be having 2 injections a day and that in some cases this did not work as well as others and additional injections may be needed. I maintained that was fine, I would do whatever was needed. We were shown how to do a blood glucose test and how readings under 4 were hypo. Melissa never ate (refused) sweet foods and drinks and so I was told I would be given Hypo stop when we left and to rub it on her gums if needed. We were advised that after Melissa's evening

injection and meal we could take her home. At this stage I did not even know how to give an injection, but the DSN was to come to our home first thing in the morning to show us how.

The ward nurse came round to do Melissa's Blood glucose test shortly before her dinner and evening injection was due. Melissa was 3.6. This was her first hypo and I just stared at the nurse who told me that it was OK because dinner would be here soon. I was a bit startled as I thought this meant she should have the hypo stop, but then thought maybe I had misunderstood as I had a lot to take in. Melissa's meal came about 20 minutes later. I now cringe at leaving this hypo but was ignorantly just following the ward nurses advice. The only carbs in the meal was chips (nothing fast acting), but again the nurse was relaxed and said this was fine. Melissa had not eaten for days at this point and must have been feeling a little better as she tucked in to her chips. She still could not sit up on her own though or stand even with help (the hypo could not have helped). Her blood glucose was not taken again, her insulin was just given and we were sent home.

In the car Melissa was in severe discomfort every time the car went round a corner or over a bump, even in a protected baby seat with padded straps.

The DSN visited us at home 8am the next morning and the next chapter of diabetes started and lots more emotional scars were obtained. It was several days before Melissa could sit up or stand, weeks before she stopped complaining of hurting in the car seat and a lot, lot longer before she could walk.