

Tom started nursery when he was two and a half and school when he was 4. He took his diabetes with him when he went. This is the same diabetes that nearly killed him when he was 18 months old and suffered severe Diabetic Ketoacidosis; the same that could so easily have damaged his brain when he had severe hypos and I had to give him glucagon injections to stop his seizures. I am still learning about diabetes and I now have 8 years practice, and yet taking it to infant school was seen as warranting, not a Statement or an agreed Care Plan, but only a volunteer and an hours training.

None of Tom's time at school was ever simple, his diabetes was described as brittle, but he was lucky in that the school agreed to regular blood testing done by a volunteer teaching assistant and he had a teacher who saw that learning about his life-long condition was as important as learning to read or write.

But what happens without a volunteer or a caring teacher?

When my older son, Joe was diagnosed in 2005 he was 8 years old. He had 5 weeks left in Year 3, and his teacher's reaction to my lunch-hour training was a smile and 'I know all about diabetes; I had a lad with it a few years ago.' My heart sank and I just knew Joe would have little support and no one supervising his testing or snacking. I was right. My confident, clever boy became a reserved, anxious boy who looked after himself. It is awful to want 5 weeks of your child's life to pass quickly and I cannot imagine it being a whole year, or longer as many parents have had here. A week after diagnosis he had to listen for his new watch alarm to tell him to test his own blood sugars and snack in class despite what his teacher was doing at the time. He had to self treat hypos and worry about highs without

anyone to sympathise with him until he got home. He had to carry an adult sized disease on a little boy's shoulders.

Then Joe was lucky. His next teacher embraced his care and I knew he was safe for a year until the move to the next class.

Tom and Joe were amongst the 83% of children failing to get an HbA1c of 7.5% or below in the United Kingdom. They were finally allowed to move onto multiple daily injections in March 2007 in a bid to get better results and avoid long term complications to their health. Interestingly, this move coincided with Tom being able to do his own injections so we didn't have to ask nicely for a volunteer to help him. Many clinics still feel unable or are not allowed to offer MDI to school age children because of the injection in school issue. Either the children have to be able to inject whilst very young, and hope they dial up the insulin correctly, or the parents have to pledge to be in charge and go in every day to help. This is shameful.

I'm a teacher. This isn't about criticising teachers. This is about adults organising themselves so that there is someone in a school who can help a vulnerable child. This is about staffing and the will to help and recognising a medical condition has a direct effect upon a child's ability to access the curriculum.

Many schools will help, but how can you know. Good schools have nothing in their prospectus about long term medical conditions, nothing said by OFSTED. Tom's infant school gave him good care despite never getting a Statement for him nor any financial help or recognition from the LEA.

At junior school it was a matter of pot-luck depending which teacher they got, with me going in and gently trying to raise awareness of problems as they happened; like finding Tom in the playground alone when he was on 1.8mmol and his teacher had left him to have his hypo treatment and some biscuits. It is frightening to criticise voluntary help in case it is withdrawn completely. You need the safety of agreed responsibility to be able to discuss levels of care with your child's school.

My sons' school woke up to the whole picture of diabetes when my children got insulin pumps. A teaching assistant came with me to the hospital for our pump training, a huge financial and staffing commitment from the head teacher, and she said it was the first time she had really understood the vast complexity and threat of this disease. It needed a hospital setting and a full and frank discussion to achieve what I had been explaining for 3 and a half years.

Again without any LEA recognition the school put proper one on one care in place for both children around PE and lunch time as they started on their pumps. It took 6 months and then they were able to gently back off, thanks to the improved control the insulin pumps gave, as my two children became far more independent and still stayed safe.

Better levels and better support have helped my oldest son Joe move on to High School. There it has taken pre-planning and several meetings with the SENCO, who takes direct responsibility for all Joe's diabetes care, to have the organisation in place to keep him safe. For instance the school is a commute away by train. Joe has to sign in at the reception every day so they know he has got to school safely. No sight of Joe after 8.30am starts up an

emergency procedure to find him. Again unrecognised by the LEA this school is working hard to care for my son.

As a parent I am grateful to all the teachers and office staff for helping my children. As a teacher I am cross that they get no recognition for all this extra support. As an advocate for children with diabetes I am determined that we get PCTs, LEAs and the government to recognise a legal, moral and ethical obligation to keep our children safe for the many hours a week they spend at school or nursery.

Every Child with Diabetes Matters, don't they?

<http://www.childrenwithdiabetesuk.org>