

Personal Statement

Alexandria Moseley

24 September 2007

My 9 year old daughter was diagnosed with diabetes shortly after her third birthday. She presented with acute diabetic ketoacidosis, but was initially treated for asthma due to general ignorance of the condition by her GP. She spent 3 days in hospital, 48 hours of which on intravenous insulin.

For the first year after diagnosis, we struggled to maintain glycaemic control on 2 daily injections of pre-mixed insulin. Her control was appalling with variations from 1.4mmol to 33.3 almost daily, and HbA1c of 8.8- 9.1. Eight months after diagnosis, she suffered her first of several hypoglycaemic events requiring hospitalisation. She had convulsions and loss of consciousness, followed by paralysis on one half of her body for 48 hours after the event. I cannot understate the fear of hypoglycaemia experienced by the whole family as a result.

We suggested MDI or CSII to our paediatric consultant as a means to achieve better control, but were told that it would be cruel to subject a child to more than 2 injections a day. He was adamant that pumps were not indicated in paediatric diabetes. We switched to another clinic much farther from our home, but where the consultant was current with modern insulin regimes. She thought my daughter would be a good candidate for CSII, but said that she was bound by NICE guidelines to give MDI a chance before considering the insulin pump. She changed us to MDI with glargine as the long acting insulin, and 3-4 daily injections of fast acting insulin to cover meals. We saw an immediate improvement in control and quality of life.

The main difficulty was administering the lunch time bolus at school. The school marginalised her from the beginning; forcing her to march to the medical room to test her blood, sometimes in the presence of very ill children, and requiring me to come to school to do the injection although my daughter was fully capable of injecting herself. I was mandated by the school to accompany every school outing she went on, and was incapable of working full time, and had to go self-employed.

Although glycaemic control was better, within one year she had two further hospitalisations for hypos where she lost consciousness and had seizures. She has had a few less severe hypos which I have been able to treat at home with injections of Glucagon. These were all deeply disturbing events that filled her with fear and lack of confidence. After one year on many different permutations of MDI, the consultant applied to our PCT for funding for a pump.

Since my daughter was the first child in her paediatric clinic to go on CSII, the learning curve was very steep. I was impressed by the diligence shown by not just the consultant, but by the nurse, dietician, registrars, and the pump manufacturers to make our transition to CSII smooth. Her first HbA1c after starting on the pump dropped to 6.5 from 7.6 on MDI.

The pump is liberating in so many ways. I can give my child insulin doses over the phone, or she can work out insulin doses for herself with the built-in calculator. My husband can participate in diabetes management now that his needle-phobia can be

avoided. I don't need to hire and train expensive specialist babysitters to oversee injections when I am working or away from home. My daughter has the freedom to eat or not eat, go on school outings without mummy, and participate in active sports without needing constant snacks. Her teeth are healthier from not having to consume glucose at night. We can easily adjust the basal rate for time zone travel. Most importantly, she has not had one serious hypo or hospital stay in the nearly four years she has been on CSII.

Studies show that complications become problematic 16-18 years after diagnosis. I would not like my daughter to be on dialysis when her peers are starting their gap years. I wish we had not had to mess around for over a year on MDI to satisfy NICE guidelines before going on to CSII. I strongly believe that more children should be offered CSII to manage their diabetes. In the long run, the higher cost of the pump will be more than offset by the reduction in hospitalisations and complications, in addition to the dramatic improvement in quality of life.