

I want the best for my son

Alison Richard pushed hard to get a pump for her 11-year-old son Simon. She fought and won.

"Life is sent to try us" my mother always told me. But how much "trying" can a little boy take? By the time Simon was school age he had had various operations, including having his adenoids removed. He had also attended speech therapy and had emotional/behavioural problems. At 8 years old this child was moody, irritable, wetting the bed and had an unquenchable thirst. He was unbearable. At school his teacher called me in because she was concerned about Simon's lack of progress – he was losing concentration mid morning. A relative visited and commented that Simon was looking thin and gaunt – something I had not really noticed which I put down to being with him everyday. A visit to the doctors followed. A urine specimen was taken for analysis. "Phone for the results in a week's time" I was told. Having a sister with diabetes raised my suspicions about a diagnosis for Simon's condition but I was reluctant to believe that this could be true. We didn't have to wait for the result of the urine test. I remember it vividly – as clearly as the day he was born.

"Get me to the hospital – I'm going to die" screamed Simon as his lips turned purple, he vomited all over the carpet and struggled to get his breath whilst holding his stomach in agony. November 24th 1998. 5.45pm. He'd just finished his tea. A phone call to the doctor's surgery confirmed there was sugar in the urine sample and a visit to the doctors for a blood test confirmed diabetes. Before we knew it my other two children were farmed out to a relative and I was sat in the local hospital casualty department with Simon.

This child had changed forever.

An intensive course in diabetes management and care rapidly filled any remaining brain cells I had spare as a single mother with three children. Two injections per day. Short acting insulin, long acting insulin. What dose? What time? Breakfast at 8am, snack around 10.30am, lunch at 12 noon, snack around 2.30pm, tea at 5pm, supper at 8pm. Where was the flexibility of a morning lie in? What about eating our lunch mid afternoon if we wanted to? What if we want to have a Pizza and video one evening? These things seemed to be gone forever – for Simon and the rest of the family. Don't forget to do blood sugar monitoring, alter his insulin doses for exercise and illness, record his readings in a book together with comments, the list goes on. Diabetes – the dripping disease.

I'm the sort of person that doesn't accept things lying down. I need to have all the information to make an informed decision. This includes diabetes care. I'd already experienced living with diabetes with my sister and seen her lifestyle and health worries over thirty plus years – since she was diagnosed at the age of 12.

It seemed logical to join the local diabetic children's support group. As a single parent I needed people to talk to, to learn from their experiences and share my own concerns. I met "like minded" people who want the best for their diabetic child as well as support for themselves and the rest of their family.

At a support group meeting, pump therapy was mentioned. The members of the group wanted to know more so we arranged for a representative from [Minimed](#) to come down to talk to the group. We also obtained information on [Disetronic](#) pumps for comparison.

By this time my sister was having diabetic complications even though, so far as she was aware, she had "looked after herself" over the years. She isn't overweight; she plays sport, keeps her blood sugars within "normal limits" and generally adheres to the medical advice given over the last 30 years. Like all people – she is only human and has rebelled on occasion, for example, by eating three chocolate bars and feeling so ill afterwards that she vowed never to do it again.

She was the first person I knew personally to go on an insulin infusion pump, funded by herself and with the support of Minimed. A while later, a friend's daughter (at the time aged 10) went on a pump due to "brittle diabetes".

Simon's HbA1c was rising. His behaviour and mood swings were unbearable. He used his diabetes as a weapon to manipulate me and life in general. He was an unhappy child. He felt different from everyone else, with a big chip on his shoulder. Life was a nightmare. Holidays were no longer holidays.

I began to consider a pump for Simon. What were my reasons for considering pump therapy?

What are the benefits?

- Better blood glucose control.
- More flexible lifestyle.
- Reduced risk of long term complications due to better blood sugar control.

Simon is approaching his teens. He wants to fit in with his friends. Quality of life as well as better health now and in the future matters. Adolescence is creeping up which I anticipate will be a difficult phase in his life without the added complication of diabetes.

What are the drawbacks?

- Being connected to a device 24 hours a day.
- The need for more frequent blood glucose monitoring.

A lot of soul searching followed. How would Simon feel? Was I doing this for Simon, me or the rest of the family? I mustn't want a pump for Simon just because it is the latest development in administering insulin. It won't take the diabetes away, but we do want a more "normal" life.

At this stage of Simon's development and from the information I had obtained, I did not feel that his current regime of two injections per day was the best treatment available in terms of adequate blood sugar control and reducing the risk of long term complications, together with the inflexible lifestyle he had to adhere to. I was open to suggestions for improvement. My thoughts turned to multiple injections or pump therapy. I talked at length to Simon and he was keen to try an insulin pump. We talked to my sister and my friend's daughter about how they felt being on a pump.

I approached Simon's hospital consultant. I was trying to keep an open mind on the best treatment for Simon. The consultant didn't think pump therapy was a good idea. When asked if Simon could try an insulin pump, the consultant made the following point and I quote –

"What kind of car does your mum drive, Simon?" (Consultant)

"A Spacewagon." (Simon)

"Well, having an insulin pump is like getting a Ferrari and not all of us can have Ferraris. Some of us have to settle for a Spacewagon". (Consultant)

I was quietly angry. If my son needed a Ferrari then he would get one. Somehow.

Other arguments used by the consultant were that there might be a risk of radiation with the pump just as there is suggestion of this with mobile phones. Also, there was a risk of infection at the infusion site. I spoke to a Minimed representative who told me that there was no medical evidence to support these arguments.

I had had "run ins" with the consultant and his team on occasions before. I would leave the paediatric diabetes clinic crying, feeling that they always were trying to undermine me or catch me out, instead of giving help, support and constructive criticism. I was labelled as a "single mum struggling to cope with the pressures of raising three children" when I answered the staff back in clinic. They could not see that I just wanted the best for my child.

I visited my GP. I asked to be referred for a second opinion on Simon's care. I had already researched which hospital I wanted to be referred to – somewhere that at least had knowledge of insulin pump therapy.

I asked about pump therapy on referral. After talking things through with Simon and myself, together with doing the necessary medical checks on Simon, the Consultant had no objection to trialling an insulin pump with the full support of the Specialist Diabetes Nurse, but it was made clear that funding wasn't available for the pump through the hospital.

I spoke to [INPUT](#). They were very helpful and supportive and gave me ideas for raising funds. I had a decision to make. Did I feel that a pump would benefit Simon enough to warrant the cost of the pump and the consumables should funding not be available and I had to find the money myself? As a single parent I would struggle to find the money but if it was worth it I could do it. Simon's father didn't agree with Simon having a pump at the time and wouldn't help out with the cost.

When Simon's previous Consultant found out that we were going ahead with the pump, he wrote a very

nasty letter to his new Consultant saying that he totally disagreed with pump therapy for Simon saying that amongst other things, he could overdose easily. The new Consultant wasn't put off by this letter (although he is reluctant to give me copy of the letter as he suspects I am likely to make a formal complaint about the previous consultant if he does.) Once again I had to do some soul searching as to why pump therapy was a good idea. Was the previous consultant right? After all – he is a qualified professional (but I believe not a diabetologist). Simon had mixed feelings at this point – he wanted to try a pump but was scared that if I couldn't afford to pay for this treatment at some point then it would be taken away from him. I reassured him that if pump therapy was the best thing for him and he was happy with it then it would not go back. I felt under pressure for things to go right so that the original consultant couldn't say "I told you so."

Simon's Consultant was ready to start Simon on a pump. We accepted that if Simon tried a pump and he didn't like it or things didn't go well, it would be all right to send it back and try another form of treatment, for example, multiple injections.

I spoke to Input – what should I do? – no funding was arranged at this point. I was advised to get Simon on the pump and then sort out funding. This turned out to be a good decision!!

A three-month pump therapy trial commenced on 19th October 2001. The pump was sent to us a week before to "play with it" and get used to programming and priming it. At first it felt like Rocket Science but within the week we had mastered many of the skills. Eleven-year-old boys with their knowledge of computers and game consoles can be remarkably quick at picking up the skills needed to use a pump.

I felt like an athlete preparing for a big race – psyching myself up for weeks of sleepless nights doing random blood sugar monitoring, together with erratic blood sugar readings, but it was easier than I anticipated. I had close telephone contact with the diabetic nurse for support and advice. Simon's doses were worked out before commencing with the pump. Simon's HbA1c was 8.9 at the start of the pump trial. 3 months later it was down to 7.8. There were few problems with Simon adapting to the pump. Occasionally, in a tantrum he would take the pump off "to show he could". Diabetes was no longer this big tool he could use to get his own way. We were controlling the diabetes rather than it controlling us! Quality of life!

Then came the battle for funding. Thank goodness for computers! With the help and support of Input who sent me specimen letters and Charity addresses, I was able to compose a letter then adapt it according to who I was sending it to. I sent it off to as many people as I could think of who were likely to be able to help with funding. I wrote to the Primary Care Trust, the GP practice, the Head of the local NHS authority, and the local MP. I made an appointment to speak to my MP at one of his surgeries. He was very supportive and told me that he would chase this matter up with the relevant NHS bodies and that my job was to go home and care for my child – he would do the rest. He kept his word. The process seemed to be moving very slowly and I was conscious that the pump trial had only been agreed for three months. I wrote a second round of letters to the Primary Care Trust, the local NHS authority and this time to the Practice manager at the GP's surgery. In this particular letter I pointed out that I kept getting different information from each person I had written to, as if they were passing the buck to someone else. The Practice Manager telephoned round the different bodies and reassured me Simon's case for funding was looking promising.

There were times when I felt like I was hitting my head against a brick wall. It appeared that no one was really interested in helping and that we were just another number or a letter at the bottom of a massive mountain of letters. There seemed to be no co-ordination or co-operation between different sectors of the health profession. At times I wondered if all the time and effort this was taking was worth it.

The first good news I got was a letter from a charity saying that they were prepared to buy Simon the pump. Although they could not help me with the consumables, this was a wonderful breakthrough as even if I didn't manage to secure funding for them I could probably find a way to fund these myself. Simon felt happier knowing that if he wanted to remain on the pump after the three-month trial, then he was able to.

Out of the blue one day, I received a telephone call from my local MP's secretary. She rang to tell me that my MP had held a meeting with the Primary Care Group Chief Executive and funding had been secured for both the pump and the consumables. This was brilliant news. The mechanics of how the pump would be purchased and the consumables paid for still had to be arranged, but in principle the funding was agreed.

Although we have to travel 50 miles to the Diabetes Clinic, it is well worth the travelling to see Simon getting a more normal life – and the rest of the family! Simon throws fewer tantrums – life is slightly more

relaxed than before in terms of meal times and also there is less restriction on what he can eat. Flexibility is the key issue here – breakfast doesn't have to be eaten before 9am every day – indeed breakfast doesn't have to be eaten at all if he doesn't want to. Diabetes is no longer this big weapon that can be used for bribery and manipulation purposes on parents. It's not a magic cure, and there have been times while Simon was getting used to the pump where he would take it off and say that he doesn't want it any more. I'd play it cool and just say ok and that he had to be prepared to feel quite ill as ketoacidosis sets in. After a couple of hours (at most) he would put it back on and nothing more would be said. Simon's blood sugar control is less erratic, but even when he gets a high reading, for example, it is easily corrected by delivering a bolus of insulin through the pump.

Six months on from starting on the pump, neither Simon nor I have any regrets. Simon is a happier child. He feels more normal. Rather than diabetes running our family life we can work the diabetes into our normal lives. This doesn't mean we have become complacent. Simon does 5 or 6 blood sugar readings each day. Also we have to remember when the infusion set is ready to be changed and the insulin reservoir needs replacing. Also, we have to remember to take "spare parts" when we go out or on holiday, and also a back up supply of insulin and syringes. As yet Simon hasn't been ill or the pump hasn't gone wrong, although there have been times when a series of unexplained high blood sugars have meant that he has had to change the infusion set and the site in case of a problem. I'm sure that there will be times when, just as before, the diabetes takes control of our lives.

Simon started High School last September. When his care was at the local hospital, the Specialist Diabetes nurse was in contact with the school to keep the staff informed of the care needed. Now Simon's care team is further away, it is down to me to liaise with the school and also make them aware of how pump therapy works. This is a small price to pay.

I asked Simon if he wanted to go back to injections: "No way! They'll have to come and fight me for the pump to get it off me if they want it back" was Simon's response.

From the first meeting with the consultant to getting on the pump to obtaining funding and then actually receiving the funded pump and consumables, it has taken about a year. Although there has been frustration, anger, concerns and a lot of soul searching, both Simon and myself are in agreement that pump therapy was the right way to go.

Author: Alison Richard <alison.richard@webshowcase.net>. Alison Richard is not a medical professional. Her son has Type 1 diabetes and uses an insulin pump. The information given here is based on her own personal experience. [More about Alison Richard...](#)

The real names of Alison Richard, and her son Simon, have been changed to maintain their privacy.

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