Eleven months and counting

Andrew Dysch looks back at the first 11 months, since his son Sam started using a pump

How did it all begin?

It seems almost a dream now. It was August 1996, Sam was not yet two and a half years old, and we were in the middle of toilet training him. He was thirsty all the time and was waking up every morning with a soaking wet nappy, so wet in fact that his bed always needed changing. My wife, Julie, had a doctor's appointment on Monday the 12th, mentioned the bed-wetting and was asked to bring in a urine sample. She did so on the Tuesday morning, and the doctor was on the phone within the hour, basically saying "Get down to the hospital NOW, there's a bed waiting!" I dropped everything at work and met them at the hospital to face the grim reality and start the learning process.

August 1996 to February 2001

The two words that best sum up this period are "discipline" and "stress". Discipline relates to the way our lives had to be structured around Sam's diabetes. This included arranging injection times to fit in with meal times (i.e. just before breakfast and just before tea, in general), working out a fairly rigid regime of snacks and regular meals, trying to ensure that he ate just the right amount at just the right time, and forward planning to make sure that all trips away from home were adequately prepared for any eventuality.

A lot happened in that time, so I will break it down into sections:

- **Fingerpricks** and **injections** were very difficult at first. For the first few days in hospital it took three people to do a finger prick. However, after we let him practice on me for half an hour (!) these became easier. Over time this improved, particularly because he soon wasn't able to remember life before diabetes. Injections on the whole were OK, although he had his favourite sites and would rarely let us anywhere near his tummy. For most of this period he was on two injections per day of different mixes, with the occasional extra injection of Actrapid when he was running particularly high.

- **Mealtimes** were almost always stressful. How can you persuade a toddler to eat something if he doesn't want to? How can you stop him eating if he feels hungry? The hardest part was probably injecting him, waiting for 20 minutes, then trying to sit him down to eat. Birthday parties were worst of all, as a lot of party food was mostly made up of chocolate and cakes.

- **Illness** was a frequent worry. We went through a few episodes of tummy bugs, when Sam completely lost his appetite. Unfortunately, the classic advice at such times is to continue with insulin injections as *BG*s usually rise at times of illness. This advice led to Sam's only hospital admission since his diagnosis, because we injected, he wouldn't eat, and then couldn't keep his *BG* up. It was surprising how little the nursing staff seemed to be aware of the problem and what to do about it. We eventually got through the day without needing to put him on a drip, but made a decision that if this occurred again, we would reduce his dose and let him run higher for a short time. This subsequently worked on the few occasions when we needed to do so.

- **Holidays** since Sam's diagnosis have all been taken close to home, so that we could get home quickly if there was a problem and because he was such a fussy eater that we needed to make sure that his "normal" food range was available. Hopefully, we can increase our "range" as Sam gets older.

First thoughts of trying a pump

One of the first things I did once we had begun to get into a routine with Sam was to start using the internet to find out more about diabetes. After being initially overwhelmed by the huge amount of material available (even back in 1996), I began to find a number of useful sites. We have always had a good relationship with Sam's diabetes team and often discussed some of the relevant articles. As time went by, I began to come across references to insulin pumps and a number of interesting stories, many of which were on the Children With Diabetes website (www.childrenwithdiabetes.com). At the same time, it was apparent that Sam's control on two injections a day was not good, with lots of highs and lots of lows. These combined to give him an excellent *HbA1c*, which of course was not a true reflection of his control as it only gives an average indication. We began to wonder whether it was possible to try Sam on a pump and what it would be like, but dismissed the idea, thinking that he was too young and that they weren't available to us.

The first step

In February 2001, we went along for Sam's quarterly check up and quickly began one of our usual discussions about poor control and whether we should think about increasing the number of daily injections, a step we hadn't wanted to take because of the additional intrusion it would cause on Sam's school day. The unexpected step was when our consultant asked if we were interested in considering an insulin pump. He and our DSN had recently had some training on pumps and had both worn one with saline for several days to get a feel for what it was like. They were now keen to find a family willing to be the first to try one for real. Without wanting to appear too excited, our first thought was that this had to be Sam's decision rather than ours, although it might be difficult to explain to him what this meant. Happily, he seemed keen to find out more, so we agreed to take the next step, which was a home visit from our DSN and the DSN from the pump supplier, which in our case was Minimed. This was arranged for the end of March. Over the next few weeks, I did a lot more research and realised that lots of children in the USA were using pumps, and we began drafting a list of questions for the big day.

Demonstration day

The list of questions had grown to about 20 by now, as we hesitantly opened the door to Jenny and Susan. We were soon sat round the kitchen table looking at a pump and several different types of insertion sets as Susan carefully explained the major points we needed to know, answering nearly all of our questions before we had said a word. Sam didn't say a lot, but looked a bit wary when he saw the size of the insertion needle for the Silhouette. (He wasn't the only one!) He was able to have a go at inserting it into a block of rubber. Susan explained that the trial would start with two weeks of using saline in the pump, to get used to it, followed by a month on insulin. She left us some literature to read through before we made our minds up.

Decision time 1

It didn't actually take very long to decide to go ahead with a trial. We talked it through with Sam and he was keen to try a pump - possibly the tiny remote control had something to do with it! Susan had explained that we would need to buy the pump up front, although we would get a refund after the trial if we decided not to carry on.

The next problem was arranging a date to suit everyone involved, i.e. ourselves, Susan, Jenny, and our consultant. We wanted it to be during the summer holidays so that one of us would be with Sam at all times and that school would not be an issue. Eventually we agreed on 24 July, moving on to insulin on 7 August. I was able to book time off work, but we did have to cancel our summer holiday. Then we started planning and reading in earnest.

24 July 2001 - starting on saline

Here we were at last, feeling somewhere in between excited and nervous. Julie's Mum had come to stay to deal with any callers and to occupy Sam's sister Faye, as we had a busy morning ahead of us. We couldn't believe the number of people when we opened the door. Accompanying Jenny and Susan were Andrea, another DSN, and Juliet the dietician. Susan went through most of the basics again, reminding us that we would need to forget a lot of the training and experience we had built up over the last five years as we would now be learning new rules and procedures. She had another look at Sam and decided that he would only be able to use Silhouettes, which could only be inserted in his bottom, as there wasn't an ounce of fat on him. Julie had the first go at filling the reservoir and priming the insertion set with saline, then Susan inserted the first set to show us how to do it. She asked us to keep a record of everything Sam ate and drank over a three day period and to send this to Juliet. This would be used to calculate the initial settings for the pump. Susan left us a list of questions to answer and functions to try on the pump, to make sure that we were confident in its use when she returned in two weeks.

25 July 2001

Sam found no problems in sleeping with the pump, clipping it to his pyjamas. We found it quite easy to get into the habit of keying in different boluses and investigating the different functions, especially the child lock to prevent "accidental" boluses. The big surprise came when we went shopping later in the day, when we suddenly found Sam sitting on the floor with the pump in one hand and the reservoir in the other! He had decided to see how easy it was to take it out. After a swift lecture, and a subsequent telling off from Susan, he hasn't done that again. We realised that Sam was too small and too active to safely wear the pump in his pocket or clipped to his belt, so we ordered a couple of cases for him to try.

26 July to 6 August 2001

Over the next two weeks, we diligently worked our way through Susan's homework and the pump manual. We also began to realise how hard the first few days would be after the switch to insulin, with finger pricks required every two hours for at least the first two days. Happily, we didn't have any other major problems - Sam didn't repeat his reservoir removal exercise. We also discounted the idea of using the remote control, as the possible boluses could not be adjusted finely enough for Sam and it wasn't always possible to hear the associated audio tones clearly enough to be sure of the programming.

7 August 2001 - the switch to insulin

The big day dawned with more feelings of excitement and trepidation. Following earlier consultation with Susan, we only gave Sam a small morning injection of Actrapid, in order to minimise the amount of long acting insulin in his system. It was hard to know what Sam was feeling - he didn't say very much. Then the doorbell rang and we had a kitchen full of medical professionals again. We went through the basics again to make sure that we had taken the important elements in. Susan explained that she had calculated our initial basal rates, which we then programmed in, and gave us the two ratios for how much insulin to give for food and for corrections. Then it was time to get going in earnest. A quick *BG* showed that Sam was on 19.0 *mmol/L* (342 *mg/dL*). Under Susan's careful watch, Julie filled her first infusion set and inserted a new Silhouette, expertly, considering the number of people watching at the time. We worked out Sam's first correction bolus, administered it and he went off to play for a while. The final hour or so was taken up with more instruction in the rigid procedures to follow and the basic guidelines. An hour and a half after the correction bolus, Sam's *BG* had come down to 9.6 *mmol/L* (173 *mg/dL*) and we realised the potential of the pump. Then it was time to say goodbye to everyone and we were on our own.

8 August 2001 - Day 2

So far so good - there were no problems overnight, although it felt like having a new baby in the house as the alarm went off every two hours for a finger prick during the night. Sam had a lie in and had breakfast two hours later than usual, with no noticeable effect on his *BG*s. We decided to take the children out for the day and ended up at an indoor activity center. Sam always goes completely wild there, so we removed the pump for the two hours he was running, jumping, climbing and sliding. His *BG*s were OK during this session and lunch was a picnic in the car on the way home. The shock was when we got home and his *BG* was 24.8 *mmol/L* (446 *mg/dL*). A quick check revealed blood in the cannula - he had obviously damaged it during his activity. Following the guidelines, we gave him a correction bolus using a conventional syringe and then changed the entire infusion set. Within a few hours, his *BG* was back to safer levels, and we breathed a sigh of relief having had a good early lesson in how vigilant one has to be with a child on a pump.

The next few weeks

Over the first few days we had a number of long telephone conversations with Susan, discussing how we were getting on and deciding on the first small changes to the basal rate. Although we had been told not to expect a huge improvement in Sam's *BG* levels in the early days, we were amazed how much better they were within a week. This was pretty much the pattern as time went on, with Susan's coaching aimed at getting us to try and make the decisions about the changes, with her advice proving to be very helpful. The next hurdle was what to do when Sam started school again in September. There were two training days just before term started and Julie was able to go in with Sam and demonstrate his pump to all the staff. Unfortunately, this did not translate into any practical suggested solutions for what to do each day. When term did start, Julie was asked to sit in school each day, just in case there was a problem, and to do Sam's *BG* tests and boluses. This did not go down well at home, and we had to seriously contemplate whether it would be possible to carry on with the pump, if this carried on for much longer. We were also not helped by the fact that the pump trial was only for one month, which expired the day after school started. In view of this, we were able to negotiate another week or so, but with hindsight think that two or three months would have been more appropriate. Thankfully, during the second week, Julie was eventually able to spend more time away from school, but still had to return to programme Sam's boluses. The welfare agreed to perform fingerpricks at morning break and just before lunch, phoning Julie if the results were too high or too low. Unfortunately, this still kept Julie very tied to home in case of problems. The light at the end of the tunnel came one day when school phoned to say that Sam was high and needed a correction, but she was too far away to get back in time. Instead, I was able to instruct them over the phone, with one member of staff relaying instructions to the other. Sam, of course, was listening to every word and had worked out how to work the child lock within two days. This was actually the best thing that could have happened, as it meant that he was now able to programme his own boluses, under adult supervision.

During this time, we had a phone call from Debbie Hanscombe, who had been given our details by John Davis of INPUT, and runs the INPUT parent support group. We quickly arranged to meet up so that Sam and her son Jamie could get together. It did everyone good to meet someone else in the same situation, particularly as Sam and Jamie had both had their pumps for about the same length of time.

Decision time 2

When the time came, it was virtually impossible to say no. Sam was revelling in the extra freedom, testing the limits at both ends by either seeing how much he could possibly eat in one go or by missing a meal altogether. He thought his pump was great and didn't want to give it back. Also, he was feeling much more independent as he was looking after his own boluses, taking great pleasure in demonstrating it to anyone who was interested. It had been a difficult time for us, because of the steep learning curve and the fact that we were pioneers with few others to compare notes with. I compare it to how it felt after Sam was a few months old – complete exhaustion!

September 2001 to July 2002

Before we had any idea that Sam would be getting a pump, we had booked to go on a Diabetes UK Family Weekend in October. We were nervous before we went, as we realised that Sam was going to be different (again!) from all the other children and it would be the first time apart from school that he would be away from us during the day. Thankfully, our fears were unfounded and we all had a wonderful time. You can read our diary of the weekend at www.insulin-pumpers.org.uk/weekend

We have now established a pretty good routine and have had very few problems with the pump. Sam has grown and we have had to make several changes to both food and correction bolus rates, but feel confident in doing so. We have been in touch with or met up with a number of parents who are contemplating trying a pump, and are more than happy to share our knowledge and experience if this will help others. The first few months were very hard work, but we feel a real sense of achievement in seeing how much better Sam's control is now. Most of the time, if his *BG* is suddenly too high or too low, we can look back and work out the reason why – a far cry from his previous regime, when two successive days could be completely different even if his diet and activity were the same. Life is much less stressful than it was before.

Sam's hospital check ups have been interesting, since we are still the only family with a youngster on a pump and Sam has taken great pleasure in showing his pump to numerous medical professionals who had not seen one before. Equally, we have all been pleased to show them his *BG* records and demonstrate how good the pump is when everything works well. We have found, possibly because Sam is so young, that we need to be constantly vigilant and that we never seem to have more than four or five days at a time where there is a constant pattern. Several times, we have been about to make a small basal rate change only for things to correct themselves before we could do so.

Note

At the moment, we are funding the pump ourselves as it is proving to be a slow process in getting a funding application off the ground. Please also note that our experience as "pioneers" at our hospital may be very different from what could be expected at a hospital with an established pump programme, and the resources to run it.

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His son has Type 1 diabetes and uses an insulin pump. The information given here is based on his own personal experience. *More about Andrew Dysch...*

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