Diabetes UK Family Weekend

Seven-year-old Sam Dysch went with his new pump on a Diabetes UK Family Weekend. His father Andrew Dysch tells us all about it

Swindon: 12 – 14 October 2001

Introduction

About to leave home



Sam is seven years old and was diagnosed at the age of two. He started pumping insulin in August and his control has started to show a significant improvement. We had actually applied for a place on this weekend back in February, before we had even thought that Sam might use a pump. We suspect that he was the first pump user to go on a Family Weekend, so thought that a diary of our experience might be of interest.

The Weekend

Friday 12 October 2001

Arrived early to miss the motorway traffic and in time for a swim before the welcome meeting. After the first meeting, we were quickly pounced on by Liz, the senior nurse, who wanted to meet Sam and find out about the pump. We went off to a quiet room for 15 minutes to talk things through and to explain the basic guide and bolus charts that we had prepared in advance.

Just before the first children's activities began, Liz introduced us to Sean, who would be looking after Sam during the weekend. At the end of the evening, we met up with Sean again and talked him through the basics of what he needed to know, eventually making him late for the staff meeting (sorry Sean). It turned out that the children had all had snacks during their session, but Sam had missed out because Sean didn't yet know how to give the right bolus. After a quick finger prick revealed a *BG* of 3.7, we let Sean decide on how much dextrose to give and to work out the bolus for the delayed snack. Full marks to Sean left us feeling confident about the following day's excursion.

We eventually got upstairs and changed Sam's infusion set at 9.30pm, the latest so far by a long way! Sam and sister Faye finally went to bed, leaving Mum & Dad very impressed with things so far.

Saturday 13 October 2001

The overtired children still managed to be up at 6.30am. Amazing – they never manage it on school days! Down early for breakfast to miss the rush. Carbohydrate counting was a little more challenging than usual as Sam decided to try some new cereals, but we didn't have any real problems.

Inspecting Sean's scars after ice skating



We handed over the children at 9.00am, looking forward to six hours peace. Sean came over for a final recap on what he needed to do. We made sure he had our mobile and pager numbers, just in case.

The morning was taken up with a series of discussions in small groups about a variety of topics, followed by a nice peaceful lunch (50 parents, no children) and fewer guilty feelings than usual about having gateau for dessert.

After more discussion groups, the children returned just after 3.00pm. Sam was absolutely fine on the trip and handled all his own boluses, supervised by Sean. Ten out of ten to Sean, who certainly looked ready for a rest. Little did he know – nearly everyone went for a swim after that, with Sean getting most of the attention from the children, especially when they found some water pistols.

Boluses for the evening meal were harder to judge, as the food came from the restaurant buffet and also because we knew that Sam would again be staying up much later than usual. Sean joined us for a while to discuss the following day's ice skating trip, to learn how to disconnect/reconnect and the ideal *BG* level to aim for before disconnecting. The ice rink was just across the road from the hotel, so we weren't too worried if a problem occurred.

Bedtime was more of a problem, trying to get two even more overtired children to bed. Finally, peace and quiet, followed by: "Dad, I feel wobbly". A quick *BG* test later, 2.8 followed by four dextrose, another teeth cleaning session and it was back to bed again.

Reaction after day two: even more impressed with the staff and their care – the children are having a great time. Not many opportunities to talk about Sam's pump, but it hadn't really been appropriate to raise it in the discussions so far.

Sunday 14 October 2001

Fun and games



Good job that we set an alarm for 7.00am – everyone found it hard to get up. We handed over the children again at 9.00am, with another recap for Sean to make sure he was happy with everything.

This was followed by a talk on the subject of "Looking to the Future", given by the senior doctor on the team. Many subjects were covered, including pancreas transplants, islet cell transplants and closed loop mechanical systems. One lady asked about pumps for children, which gave us the opportunity to say something about Sam and his pump.

Shortly after this it was time for coffee, and we were quickly approached by a number of people who were interested to hear more – many of them doctors. Thirty minutes went by in no time, as we dealt with the questions and explained how things worked. Sam's control had been excellent during the weekend and it was very pleasing to be able to show this. The previous Wednesday had been a bad day, with infusion set problems, so it was good to demonstrate the difference when everything was working well.

The rest of the morning went very quickly. There were some final discussion group sessions, followed by a general summing up and presentation of certificates for the children, before saying a fond farewell to all our new friends.

Overall impressions

Hard work, this weekend



- 1. As parents of a pump user: we were very impressed with the effort made to learn about Sam's requirements, despite the lack of pump knowledge and experience. We were also glad to have the opportunity to tell our story so far to those that were interested (especially the doctors).
- 2. As parents of a diabetic child: we would recommend such a break to all parents. It was a wonderful opportunity to give the children some independence and for them and us to meet others in the same situation. We were already quite confident with our routine, but it was very good to be able to meet other parents and discuss common issues.
- 3. From the children: "Do we have to go? When can we go again?"

Andrew & Julie Dysch

PS Comment from Sam Dysch to Frankie Frog:

Dear Frankie Frog,

I want to tell you about my insulin pump. I've had it nearly three months.

The best thing is I can have food whenever I want to. The bad thing is I have to have nearly 8 arm pricks or finger pricks every day (sometimes more – Dad!).

I've already worked out the child lock and I can bolus myself, though I need an adult to check it before I "activate".

I am seven years old.

I think my pump is GREAT.

Love from

Sam

Author: Andrew Dysch <<u>AD@dysch2000.fsnet.co.uk</u>>. Andrew Dysch is not a medical professional. 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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