

An insulin pump for Sasha

A look back on the journey to get a pump for a young girl, Sasha

4th December 2004 – THE letter has finally arrived

I am very excited but also apprehensive. This morning we received a long awaited letter from the Gloucestershire Royal Hospital, asking us to bring Sasha for a “Paediatrician’s opinion” from the Gloucester consultant Dr Matthai about pump suitability, necessity, etc. The appointment is on December 29th, 2004, making it almost one year ago today, when we wrote to Sasha’s previous consultant for a second time about an insulin pump. This time we presented him with a detailed dossier on the list of problems that Sasha was having and explained in detail how we thought that a pump could help Sasha. It has actually been two years since we first told Sasha’s previous consultant that we were interested in an insulin pump trial; unfortunately our consultant was not willing to support us and said that insulin pumps were not safe. He agreed to refer us to Oxford (they couldn’t see us in the end) and then later suggested another hospital, but we had heard that that this hospital was not pro pump either. Then we found out that Gloucestershire Royal Hospital was setting up a paediatric pump program so we asked for a referral. After several more long months of asking and more letters, this referral was eventually made.

Sasha Jacombs without pump



29th December 2004 – The new hospital

It looks like brilliant news and Sasha should be getting a pump, providing we pass all the other “tests”. Firstly, Sasha has to wear a CGMS (Continuous Glucose Monitoring System) device for a few days and the psychologist has to come and meet us all to ensure that we’re suitable parents and that Sasha is a suitable candidate for having a pump. We’ll have to lock the mad teenager in the attic! Possibly a mad mother too! I just hope Sasha doesn’t suddenly have several days of perfect blood sugars levels when they do the CGMS! We also

have to attend two three hours sessions of carb counting. This is done in a group.

The Gloucester clinic appointment was very different compared to our previous clinic. They wanted a urine sample and they also took Sasha's blood pressure, which they had never done at our previous clinic. Apparently they do that for every clinic visit at Gloucestershire Hospital. They also have an HbA1c machine that gives a result in 6 minutes. They did an HbA1c test for Sasha which was about 7.3%. We went in to see Dr Matthai shortly afterwards. We were talking to her for about 45 minutes. Dr Matthai said that because Sasha has severe hypos with seizures and fluctuating levels and does not wake at night when her blood glucose levels fall, that Sasha meets the NICE guideline criteria for a funded pump. Great news! The consultant wants to be sure that Sasha is keen on a pump and has no psychological problems about having one. Dr Matthai emphasized that the pump would be there 24/7. Sasha didn't seem bothered – just excited. I feel totally exhausted now after the stress and excitement of the consultation. We have waited so long for this decision.

30th December 2004 – The next day

I felt better today when I woke up but I still feel exhausted and very tired. I guess it's all the worry and stress. I don't feel hungry and can't eat much.

We now have to wait until dates are set up for the psychologist, CGMS and for meeting the pump nurse, Paula Jones from Medtronic. We will be pumping saline for a while before we go "live". Dr Matthai was asking Sasha about other children and pumps and we told her about the people we had met with pumps. Dr Matthai was saying that we probably know quite a lot of the basics, because of speaking to other pump users and that Sasha would soon know much more than her about operating a pump because she would be using a pump all the time.

On the 18th of Feb we have to attend carb counting classes and again on the 25th. At some point we will meet the psychologist at the hospital and later it will be arranged for him to come and visit at our home. Then they will decide if we are still suitable!!

28th January 2005 – Things are moving fast

I phoned the Gloucester Royal today to see if anything was happening about the pump. The DSN said that she was just about to finish a letter setting out some dates. Sasha gets to be hooked up to the CGMS on February the 8th.

8th February 2005 – Continuous Glucose Monitoring System

I was very apprehensive when I woke up today and wondered if Sasha would be OK. Before school this morning Sasha was getting a bit hysterical over something trivial. Not like Sasha at all!

Just after 3pm we were taken in to a treatment room with two of the DSNs, Jill Gethin and Helen (Helen had come in on her afternoon off, which was kind) to help fit the CGMS. There was also our trainee DSN from Cheltenham, Kate, and a student nurse, plus the psychologist popped in to say hello and to take some notes. With me, Terry, Beckie and Sasha in there as well, the room was quite full. The DSNs did ask Sasha if she minded all the others being in there and watching. Sasha said that she didn't mind and seemed happy and was chatting away.

They showed us which buttons to press and how to calibrate the monitor. I had a cold and was trying not to cough over everyone and one DSN was asking me something while the psychologist was trying to make an appointment to see us later. With everything happening at once and people speaking at the same time it was a bit confusing. Anyway, they got Sasha to lie on the treatment couch and she wanted Beckie, her twin sister, to hold her hand, not me! They fitted the electrode using some sort of insertion device. They didn't use any numbing cream or spray, but Sasha said it didn't hurt, just stung a little, like an injection, and then hurt for slightly longer. She didn't seem very bothered about it all really! I was amazed she was so laid back about it all.

More good news!! The DSN told us that they are ordering the pump, Sasha chose a blue pump. They said we should receive it in the post in a couple of weeks' time. We have to go to several carb counting sessions during the next couple of weeks and will start pumping saline on March the 8th!!! And insulin shortly afterwards. The psychologist is coming to visit us next Wednesday. The DSN said that the psychologist just wants to check that we are going to be able to manage things OK and that Sasha is happy to have a pump and all it entails and that we are not forcing her into it! Anyway Sasha looked really pleased when they said they were going to order the pump and was beaming from ear to ear!

It looks like everything is happening very fast all of a sudden.

Sasha was able to press all the buttons on the CGMS monitor in the right order after only being shown once. You have to key in BG levels and when you eat, take insulin, food, or exercise. I am still unsure of what to press!!! You have to do a certain number of blood tests on the first evening to calibrate the system and you have a chart to mark the exact times when you take exercise, insulin, food and make a note of your blood sugar levels. You also key events into the monitor as these things happen.

Sasha went to sleep quick enough tonight with the monitor in a pocket so it didn't seem to be bothering her too much!

Earlier in the day we were also able to meet the other child pumper at Gloucester who is aged 7. He and his mum happened to be in hospital on the ward that day. Sasha was impressed as he had the same colour pump as she had chosen. Sasha is quite excited. We had a few hiccups with the CGMS and in the end it kept alarming and wouldn't work any more so we had to take it off before 3 days were fully complete. We also experienced some unusually high levels of blood sugars, especially on the first evening and after nearly all of the evening meals, which was not very good. In fact all the time that Sasha wore the CGMS we had very odd readings. I was really worried that Sasha would hate wearing the CGMS which would not bode well for wearing a pump. However my fears were unfounded and Sasha was fine.

16th February 2005 – An upsetting phone call

I feel so upset today. The diabetes nurse from Gloucester Hospital has phoned us saying that the results of Sasha's CGMS were "interesting". This sounded ominous and I wondered quite what they meant.

We had worried that the graphs wouldn't be of help in being able to adjust anything because we had three days where we had some extreme BG levels at odd times. But of course that's one of the reasons we wanted a pump. Sasha also appears to have a cold or viral illness.

The diabetes team seem to be suggesting that our carb counting and insulin ratios might be wrong and they need to think again about the date of the pump start because we

needed some weeks of accurate carb counting “under our belts” before we can even think about pumping. It sounded worryingly like they were having doubts about giving Sasha a pump at all! I was very anxious and upset. The first evening on CGMS Sasha’s BG had gone sky high after the sensor was inserted and we had a job getting the levels back down. This could have appeared that we had miscounted the carbs in the evening meal. We have always had problems with insulin for the evening meals on injections.

There were also two hypos below 3.8 mmol/L (70 mg/dL) that showed up on our meter but no hypos shown on their download of the CGMS. The diabetes team questioned why we had treated these lows that didn’t show up on CGMS.

The blood sugars were especially unstable after the evening meals and supper snack.

When we removed the sensor it wasn’t straight but curled over, quite bent. I don’t know if this could have caused some of the odd readings.

Anyway, when we eventually got to see the graphs they really didn’t show any helpful patterns, but it was quite shocking to see just how much the BG spiked up post breakfast, regularly reaching over 16 mmol/L (300 mg/dL). Another interesting thing was that on some mornings recently, we had had some unusually high levels which I was pretty sure were not rebounds, even though this had been suggested in the past. In fact the CGMS graphs showed that on several nights Sasha did NOT go hypo and rebound at all, the blood sugar levels just increased due to lack of basal insulin. Once we were on a pump a dawn rise was very apparent.

18th February 2005 – Sigh of relief

I am breathing a big sigh of relief. The hospital have not changed their minds about Sasha having a pump after all and this is still going to happen, but the dates have been moved for the pump start. It will now be April.

The carbohydrate counting sessions were very well presented and we talked to the DSNs and dieticians and they all knew their stuff and were all for giving extra insulin for extra snacks, being careful not to let boluses overlap. I think for people hearing about carb counting for the first time it must still be a bit daunting. We had been carb counting before for a number of years having taught ourselves as carb counting was not taught or encouraged at our previous hospital. We were pleased to find that we had been carb counting correctly all along, but it was nice to have some extra practice and meet other parents who were learning too. We had forms to fill in documenting the carb counts of all the meals and the insulin given. We then had to check the blood glucose levels 2 hours after meals to see if the correct bolus ratio was being used. We never seemed able to get the evening boluses to match the carbs. I hope a pump will solve this problem.

8th March 2006 – What – no pump???

I have just phoned Medtronic about Sasha’s pump as it still hasn’t turned up. They say they have no record of the order and no account has been set up for her. Neither are there any letters, faxes or telephone orders from Gloucester Royal for a pump!! So I still don’t know what is going on here!

Gloucester had told me that they ordered the pump on Friday 25th of February. I have phoned Gloucester hospital and left a message on the answer phone!

11th March 2005

Just had a phone call from Paula Jones, the Medtronic Pump Nurse and she has also been through to Medtronic and it's been confirmed again that no order has been received. She phoned Gloucester Hospital and found that there is no one in who could help today. She seems to think that it is possible that the order is still sitting on the desk in Gloucester – probably in the finance department – waiting for approval!!

The good news is that, although the hospital haven't told us yet, Paula Jones has pencilled in a provisional date for starting Sasha on the pump on April 12th on saline and 19th live!!

8th April 2005

Things are now moving in the right direction.

I have spoken with the hospital and they say to turn up on Tuesday the 12th and they will do the pump start on saline with the demo pump if ours hasn't turned up. However we did have a phone call from Medtronic late yesterday afternoon and then the Medtronic pump nurse, saying that the pump should be here on Monday morning. So if it does come we will get a quick look at it!

The DNS said that she wants to visit the school to tell them about the pump and also will go and see the secondary school before Sasha starts there in September. I told the pump nurse that Sasha was quite keen to use the Silhouette infusion sets and she seemed pleased and said that they seem to work well with thin kids because the cannula goes in at a shallow angle. We shall see. I am getting very nervous now but glad that we are starting on saline because we have not had long to look at a pump and have a play with the buttons.

Sasha Jacombs with pump



12th April 2005 – Sasha is pumping saline!!

I can hardly believe we've got to this point, after all this time. Unfortunately Sasha will be on saline for two weeks, because next week, when we were due to move to insulin, most of the doctors are off to a conference and Jill, the DSN nurse, won't have any back-up if there

are problems, or if she is busy with other patients' problems. So the hospital are having to postpone the insulin start until Monday the 25th. So I am hoping all the extra trouble of being on a pump, but with no real benefit, won't be too off putting for Sasha. All those set changes and bolusing but still having to have injections!

Sasha was great with the pump and button pushing. She was scrolling through the menus to get to the right place long before I got off the first screen. I couldn't believe how quickly she picked it up! Although kids are good at button pressing and hand held computer games, this was the first time she even held a pump or anything similar.

We were at the hospital from 9am to 12 noon. Sasha and I both held demo pumps and were talked through setting it up – date first, etc. I was supposed to be helping Sasha, but she was just so quick that it was me looking to her for the next move!

Sasha chose to try Silhouette infusion sets as opposed to the SofSet, though they did say we could try both type of sets. We went through the process of setting dates, times etc on the pump and just two basal rates for now. We learnt how to fill the reservoirs with saline and remove the bubbles; this was the bit I found trickiest to begin with. I am certainly glad we are having a practice with saline to begin with; there was so much to take in. I had used the Medtronic Pump school-on-line several times, so it did make things a lot easier to understand when Paula Jones went through everything. My head is buzzing a bit at the moment! Sasha is just sooo laid back!!

We had a skin coloured rubber bar, the size of a large bar of soap, which you can practice doing a site insertion on. Unfortunately you don't get to take this home!!

Sasha was asked whether she wanted to do her own insertion the first time, or for me, or Terry to do it. Sasha chose Terry thankfully!

I was getting very nervous by now. What if Sasha hated it and it hurt her too much? Terry's first practice on the block thing didn't go in quite right and the needle was all bent, but then he did the site insertion on Sasha and she just kept saying, "Wow! Wow! That didn't hurt at all"!! They didn't numb the site at all. She said it was just a flicking sensation. Afterwards, at home, Sasha did say that she was scared after Terry had done the first insertion into the block and bent the needle! Just before we were going to leave for home Sasha went very, very quiet and looked extremely pale. I thought that she looked hypo and the nurses thought she seemed unusually quiet and pale too; she had been chattering away most of the morning. I checked her BG but she was 9.7 mmol/L (175 mg/dL), so not hypo. She still seemed very subdued and I had a bit of a panic that she didn't like the pump at all and perhaps it was dawning on her that she would be stuck with this forever!!! On the way out she would only walk slowly and said she felt sick and unwell!!!!

Beckie has a cold this morning so maybe Sasha is coming down with it. I don't know whether this was just the emotion of the morning and all the new stuff to deal with, or whether her BG and sitting about was making her feel a bit unwell. Anyway she perked up a bit on the way home, ate lunch and bolused 3 units for a small piece of pizza and toast plus injecting of course!! She didn't want to go back to school this afternoon and I wasn't sure whether it was because she was still feeling a little shaky or unwell or whether she had a sudden panic about what her friends would say about the pump.

Just after lunch I gave Sasha Pumpernickle the Pumping Monkey, a soft toy monkey with a toy insulin pump in a pouch. Sasha perked up even more and was playing with that and making a cardboard bed for the monkey. She said that the site had tingled for about 20 minutes after the insertion, but was OK now and not hurting. However she was still holding herself a bit stiffly as if afraid she might pull the site out for several hours.

16th April 2005

Things are going OK so far!! Both sites we put in seemed OK, though it's only saline, so not the same as pumping insulin, but I assume that if we had a bent cannula or something the pump would have alarmed. Managed to fill the reservoir and get out the bubbles and feel more confident about doing some things now. The pump itself is intuitive and easy to use. Sasha was doing all the boluses immediately and took to the pump as if she had always had one. I am much more pleased with the ease of operating the pump than I thought I would be.

I have found some things a lot easier than I expected and also the pump is a lot easier to understand and use than I thought that it would be. It's doing the site changes that bother me the most at the moment. We won't be pumping insulin for at least another week from Monday. Then the fun starts!!!

25th April 2005 – D-Day is here at last: PUMPING INSULIN

We arrive at Gloucester Royal around 9.15 am. We are given a room on the ward which we can use all the time we are there.

The pump nurse, Paula Jones, spends a long time explaining things and going through all the steps and protocols that we need to know. We are going to be there from 9.15 AM and we hoped that we would be able to go home at about 3pm.

Before we started on insulin therapy, we were instructed on pump operation, insertion and care of infusions sets and troubleshooting once more.

The pump nurse and diabetes team calculate the insulin requirements by adding up the total daily dose currently used for the injection regimen. The total insulin requirement for the pumping is usually around 80% of the patient's requirements prior to beginning insulin pump therapy. The amount may be reduced further for those who were on very high insulin doses. Half of the amount will be given as the basal rate and the other half divided into three premeal doses.

The basal rate was set up at 0.5 until 10am then to 0.4 for the rest of the time.

The bolus rate for pre-meal boluses was going to be 1 unit to 20 gram of carb.

We had been told to give a reduced dose of insulin on the morning of the insulin changeover, so that Sasha would start with a higher blood glucose level. We started off with a BG level of 16 mmol/L (300 mg/dL). The hospital wanted her BG level high to start with. The bolus we gave as a correction dose dropped her too quickly. So the correction factor was changed. I was amazed how quickly the blood sugar levels came down.

Things seemed to be going fairly well but wondered if 0.5 units basal might be a little high to start with as they said they wanted to start conservatively. The consultant and DSNs calculate the amounts to set up. We went down to the café for lunch. Sasha has to bring her own food as there is usually nothing suitable for a gluten free diet. After lunch, at 1.00 pm, Sasha bolused 2 units for 40 grams of carbs. We had to hang around until 3pm and then go back to our room on the ward. Sasha complained of a headache at 2.45pm and she had dropped to 3.1 mmol/L (55 mg/dL)! So we gave her 10 grams of carb (Lucozade) and her blood sugar came back up to 4.5 mmol/L (80 mg/dL) within ten minutes. Then Dr Matthai and the D nurse came back again to review things. Because of the hypo we then had to stay until 5.30pm so they could check the new basal rate of 0.4. Sasha was getting very, very bored now because there was nothing to do, no telly to watch or anything, though we

walked around the hospital and looked in the shop several times and we had brought books and crayons with us. My legs are aching from sitting down for hours.

The diabetes team changed the basal rate to 0.4 then 0.35 from midnight to 7.00am and back to 0.4 again during the day. They also changed the bolus ratio to 1 unit to 25 carbs. However two hours after the evening meal she was 13.7 mmol/L (245 mg/dL) so it looks like the insulin to carb rate needs changing. We had to give a correction dose to bring the levels down a bit. It's all very confusing at first.

We have to check the blood glucose levels every two hours, including through the night. This checking continued for several days and is very tiring. Sasha doesn't wake at all when we test her and just sleeps on!

26th April 2005 – The following day

Off to the hospital again right now, so they can review the numbers and make some more decisions about the basal rates and bolus ratios.

They tweaked the bolus ratios a bit increasing the insulin to carb rate for breakfast. Back to school in the afternoon.

26th April 2005 – No Delivery Alarms

Terry had not long got back from returning Sasha to school and overseeing her lunch bolus when Sasha phoned to say that her pump was vibrating and beeping and the pump showed a "No Delivery Alarm"! I had to go and collect Sasha from school. We did the usual troubleshooting, checking for bubbles in the tubing, site problems, but couldn't find anything wrong. We don't know if the earlier highs were caused by a no insulin delivery and the bolus history showed that the pump had stopped after delivering only half the bolus. We detached the pump to do some more checks and still couldn't find anything wrong. We decided to change the cannula just in case. The cannula looked fine when we got it out, no kinks or bends. We couldn't see any obvious bubbles in the tubing.

Sasha is still very laid back about it all. Telling us how well we handled it!!!! If only she realised how tired and nervous we really are!!!!

We have another "No Delivery Alarm" at around 10.30pm and decide, after doing all the other checks, to change the infusion set site.

Have phoned the DSN on her mobile to tell her what we have done.

We had then had another "No Delivery Alarm" first thing in the morning when Sasha bolused for breakfast. We checked the pump to see how much has been delivered and only half the amount went in. Again we check and there is no obvious reason for the problems. It is still early, around 7.45am so we phone the Medtronic help line in the USA. We give them various details and they talk us through various things and do some pump checks with us over the phone. After quite a long discussion and several checks to make sure that there is no pump malfunction, they tell us it's possible, that because Sasha is a slim, fit child that the cannula is going into muscle or is too close to the navel area. They tell us that the backside is probably a more suitable place for the Silhouettes in a thin child. We decided to switch the sites now before Sasha goes to school. Sasha was not at all keen to have the site in her bottom and was quite worried. However she was a star and we put the new site in. It is easier to insert the infusion set if she is in a standing position rather than lying on a bed. I was very impressed with Medtronic 24 hour help line. Poor Sasha must be feeling like a pin cushion!

This change of site area seems to have done the trick and we have no further problems with “No Delivery Alarms”.

We have had a rough few days with Sasha as she has a bit of a cold/virus illness and it is causing her blood glucose levels to run high. With the cough and cold and Thursday's and Friday's “No Delivery” alarms, it's hard to know if we have the right basals or carb rates as there are too many things interfering with the results. Plus today she had Gymnastics training and 3 hours off the pump, connecting up every so often to give a bolus. Because of all of the above-mentioned problems we still haven't got a clear idea of things. Just unfortunate I guess. Sasha is fine though and very positive and although her BG levels are running a bit high she seems in good spirits. Which is just as well as Terry spent until about 2.30am last night trying to get her BG levels below 12 mmol/L (220 mg/dL). Have upped the insulin to carb rate and basal rates to adjust for the current illness

29th April 2005

We had three good blood glucose levels all in a row today hardly a mmol difference. I can't think of a time when this has happened on MDI, the blood sugar was either rising or falling and never stable.

3rd May 2005

Things are jogging along at the moment but we can't really get any clear picture because Sasha's cold has taken a turn for the worse and she now has an ear infection. So most of the carefully logged BG reading aren't that much help in getting stabilised levels and the basals set. We spoke to the hospital over the weekend because Sasha was getting high levels again especially overnight, which meant constant checking after correction boluses. No one except the kids has had a good night's sleep. The hospital have told us to increase the basals which helped, though last night the increase in the basal was too much and we had to revert back to the lower rate.

Off to the GP to see if we can get some antibiotics for Sasha's ear infection. With all the cold symptoms and site problems it's too hard to see what's happening with the insulin needs.

Last night Sasha had quite good levels overnight but the morning insulin to carb ratio is wrong and we have told the hospital that we think it needs changing. They don't want us to change too many things at once and we have had to change basal rates due to Sasha running high due to the ear Infection.

5th May 2005

We can't really test any of the basal rates because all the literature says not to do this if you have an illness or infection etc. Judging by how long Beckie was unwell with her viral illness, Sasha may have a few more days go.

7th May 2005

Things have been going much better (dare I say that!!) over the last two days. Sasha seems to have recovered from the cold or viral infection that was obviously causing a lot of the high blood glucose levels. We have had quite a few lows now and no correction boluses for the last 48 hours. We had to change the basal rate from 12.00 midnight from 0.4 down to

0.35 . Sasha seems to have a new lease of life and we can't keep her still for long!! She had an hour's gym practice today because tomorrow she and Beckie are in a local competition with some other county gym clubs 40 miles away. Terry stayed at the gym and tested before during and after and she went down to 2.9 mmol/L (50 mg/dL) and Sasha didn't even notice (which is not good)!! So it looks like next week we will be altering the basal rates all over again, because of the new sensitivity. Things are beginning to make sense now.

Sasha has said that she already prefers pumping despite the problems so far.

8th May 2005

We drive to the Gym competition and struggle a bit with having to take the pump on and off and do a lot of testing and correcting. A competition is harder to deal with than a straight 3 hours gymnastics practice where the children are exercising intensively for 3 hours.

Sasha won a silver medal for gymnastics today in a county competition!! She is so happy.

13th June 2005

Don't ever be put off a pump by thinking that it's harder work, it is harder work, but it's worth the effort. We didn't have the best pump start, due to Sasha having some sort of viral illness in the first 10 days. You do have to be more aware and follow the protocols because things could go wrong quickly if you encountered a problem and didn't do what you are supposed to do. It's much easier to be able to get meals at a different time or not to eat if you don't want to. Also it is easier to dose for small amounts of food when Sasha wants a small snack. Physically it has not slowed Sasha down at all. She is at the moment cartwheeling in the garden and doing tumbling!!! She says that she forgets that she has diabetes now. The pump, far from being a reminder of having diabetes, gives you more freedom and you have to think about diabetes less. The first weeks are very exhausting and stressful but after that you can relax a lot more.

15th June 2005 – 2 months on the pump

HbA1c: We have just got back from the clinic and Sasha's HbA1c is 6.6.

We are very pleased with that, because Sasha isn't having anywhere near the amount of hypos that she used to have and because we are still figuring things out and tweaking the basals, there is still room for improvement in some areas. She has grown a couple of centimeters and has put on a bit of weight and is 33.3 kilos.

The diabetes team seemed pleased with the progress and Dr Matthai is very, very thorough, which is why the clinic runs late at times. Each patient seems to be in the consulting room for a least half an hour. It's nice to have the time to discuss things. Dr Matthai always goes through the basals on the pump herself checking everything in detail. We discuss increasing the bolus ratios for lunchtime and the evening meal.

17th September 2005

Sasha's HbA1c was 5.8 this time, so we are extremely pleased. We are still checking at 2.30am and I suspect that if we didn't, we would not pick up the occasional highs that need correcting and some hypos that need fixing. We have the nighttime basals set low to avoid

any hypos but this also means that any high BG levels earlier on in the night also have to be correct. Once we hit levels over 9 mmol/L (160 mg/dL) at 11.30pm then we do have to correct otherwise we would get high levels on waking.

Beckie & Sasha Jacombs



1st January 2006

It's nearly a year now since we started pumping and looking back we had a bit of a difficult pump start due the various viruses and ear infections during the first weeks, plus a few "No Delivery" alarms, due to the sites not being in the best place for a very slim child. You learn a lot during the first 6 months because you come across many different problems, which you learn to deal with as you encounter them. We did use the temporary basal rates to deliver lower basal rates of insulin quite a lot in the spring and summer, but not until November and December 2005 did we get proficient at using the temporary basal rates for illness and weekend inactivity. It was quite a surprise that illness and inactivity often needed an increase of 30 – 55% in the basal rates.

Sasha really likes having a pump and it has made a lot of difference. She feels much less tired and has much more stable blood glucose levels. She likes the fact that she can eat her lunch with friends and doesn't have to go and get her insulin pen at lunchtime as she always has her insulin with her. She can eat when she feels hungry and doesn't have to eat if she is not hungry. Before on injections even walking around town used to make her go low. Now when she goes to town with me or her friends she doesn't usually go hypo.

Sasha is now entering puberty and is beginning to have higher insulin needs and there is evidence of growth hormones causing more fluctuations in her blood glucose levels, especially overnight. Her insulin needs have increased from 28 units a day to around 37 units a day.

7th March 2006 – Looking back over the last year

Sasha's HbA1c in earlier years was always around 7.3%, which is an acceptable level. However this seemingly good HbA1c concealed generally unstable blood glucose control with widely fluctuating blood glucose levels. In a typical month there were worryingly regular episodes of hypos and hypers. This meant that on many occasions we would be apprehensive about what was going to happen during the day especially at school or when Sasha was playing outside. Nights were always a problem due to Sasha's lack of hypo awareness when she is asleep. Unfortunately although a pump has not solved the night time hypo awareness, it does mean that at least we can run a low basal rate at night, which

was not possible on injections without causing the waking blood glucose levels to be very elevated.

In the last few months we have had a lot fewer problems using pump therapy and we are a lot more confident dealing with exercise and illness. We haven't had any "No Delivery" alarms since the first week when Sasha moved from saline to insulin and we stopped using the stomach as an area for infusion sites. Sasha is growing well and we are having to make frequent changes to bolus and basal rates as she enters puberty. Surprisingly, this is not always an increase in insulin and on some occasions we have had to reduce the basal rates at a certain time. The first few months were stressful and hard work, but now we are seeing much better results and having got through the winter months with various illnesses and learnt to use temporary basal rates to deal with illness, we feel much more confident. If we have problems now, we can usually work out what the problem is much more easily than when Sasha was using an injection regimen. Sasha is much happier and the pump makes life a lot easier for her and we don't have the same unexplained hypos and hypers. In the past before pumping we had weeks where the blood glucose levels were never the same from one day to the next, even if Sasha ate the same food and took the same amount of insulin. Pumping isn't a magic solution by any means and we feel that it requires more work and commitment than some injection regimens, but in the end, the results are worth it. Although we have to work harder with pump therapy, generally life is less stressful because the blood glucose levels are finally much more predictable.

Sasha likes the fact that she can lie in bed later at the weekends and doesn't always have to eat at set regular times. She always has her insulin with her and doesn't have to leave her friends to go and inject insulin at lunch times.

She has said that she never wants to go back to injections again and loves her pump.

Author: Jackie Jacombs <jackie.jacombs@childrenwithdiabetes.com>. Jackie Jacombs is not a medical professional. Her daughter has Type 1 diabetes and uses an insulin pump. The information given here is based on her own personal experience. [More about Jackie Jacombs...](#)

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