

Life on a pump

Richard Oppenheimer tells why he decided to use an insulin pump, and gives extracts from his diary over the first few months

Introduction

Photo of Richard Oppenheimer



I was diagnosed with Type 1 diabetes in February 1993. Like many people I found control in the early years relatively easy, but over time things were getting harder. Minor hypo events were all too frequent and my blood sugar varied far more than I wanted it to. I suffered very much with fatigue and I eventually managed to pinpoint feelings of depression on blood sugar variations.

My conviction remained that the chronic fatigue and emotional symptoms I was having was in some way connected with my diabetes. At the beginning of November 2000, quite by accident I discovered about the insulin pump: a microprocessor controlled device which you wear 24hrs a day. It drip feeds you with insulin at the correct rate every 3 minutes, thereby attempting to mimic the body's natural insulin secretion. Having done some investigation, largely on the internet and through personal contacts I discovered that a chronic fatigue syndrome type reaction to diabetes is, although not universal, certainly not uncommon. The pump manufacturers claimed to have come across the problem before and treated it successfully. The manufacturers offered a one month free trial and I was determined to establish if use of an insulin pump would resolve the problem.

Basically, insulin works together with other hormones as part of the body's control mechanism. It has three functions:

- a. Insulin helps controls the level of glucose in the blood. Insulin causes sugar to be stored into the liver from where it is gradually released back into the blood. With Type 1 diabetes, the body's natural insulin production capability has been destroyed and insulin has to be delivered artificially, or blood sugar rises, Diabetic Ketoacidosis (DKA) develops and the patient dies. The pump attempts to deliver insulin at just the right rate to balance the sugar released by the liver.
- b. Insulin helps the body's tissues to convert glucose into energy. As you start to exert yourself the

sugar in your blood gets used up, your natural insulin production reduces a little allowing the liver to release more sugar into the blood to supply the tissues with more energy. The pump has an override function so that you can reduce the infusion rate by however many percent while you are exercising thereby allowing a more sugar to be released and keeping *BG* levels fairly stable. Under the current regime of injections you have to eat sugar if you exert yourself, otherwise your sugars drop dramatically after about an hour and it can take several hours to recover.

- c. Insulin controls the storage of fat. With Type 1 diabetes you can develop insulin resistance in response to the artificially large doses of insulin several times a day. Therefore the dose has to be increased and you put on weight. Using a pump, insulin resistance tends to recover and the total daily dose can reduce significantly and fat deposits should return to normal.

Hormone levels, and hence the amount of sugar released the liver vary during the course of the day as part of the normal body clock mechanism. Fortunately, the daily pattern is fairly predictable (<10% variation day to day) so it is possible to program the pump with a profile of insulin delivery to suit the individual and therefore keep the balance fairly stable. This is known as the basal rate. It simply isn't possible to maintain this balance with multiple daily injections – in fact if you can get within range 50% of the time you're doing very well. (Using injections I can typically managed to maintain my levels within the range 4–10 *mmol/L* (72–180 *mg/dL*) about 50% of the time. Experienced pump users should be able to achieve this range 90% of the time.) So not surprisingly the body's other systems try to make the best of a bad job, your hormones constantly fluctuate and you can feel pretty miserable much of the time. And for me waves of fatigue and waves of sleep came at odd times during the day.

In a nutshell, I was hopeful that the pump might help me return to how I used to be. The drawbacks: there are very few pumps in use in the UK today (about 700 at March 2001) and hence a shortage of expertise within the *NHS*. So direct support had to come from the pump vendor. And the *NHS* has yet to resolve its position on funding of insulin pumps so there was no guarantee that the health authority would provide me with the consumables or other financial support.

Diary

6 Dec 2000

I took delivery of the pump. The rep from the supplier helped me to set up the pump and we spent a day going through its operation. Transition from traditional therapy to the pump is a little awkward as there is a period when there still remains a pool of slow acting insulin in the body, so the amount of insulin you need from the pump will be affected by that.

The first thing that hits you is that control using the pump is dramatically different to what you have been used to with daily injections. With injections you have your dose and then you can eat more or less what you want while the insulin is active. The process is somewhat hit and miss but with a bit of luck your control is not too bad. With the pump bolus doses are much smaller than what you have been used to. Typically 4 or 5 units with a meal, depending on the carbohydrate content. What's more you have to account for every single bit of carbohydrate that you eat. Even a single biscuit needs a bolus of 0.5 units.

Control is a bit different too. You check before your meal to see where you are, make an assessment of the carbohydrate content of the meal and then bolus accordingly. Then you check after about three hours to see if your blood glucose has returned to normal. I soon decided that snacking isn't a good idea because you have to go through the procedure of making sure that your blood sugar has returned to normal each time.

There are a number of critical numbers you need to know: the first is by how much one unit of insulin will reduce you blood sugar, in my case by about 2.5 *mmol/L* (45 *mg/dL*) during the day and about 1.5 *mmol/L* (27 *mg/dL*) in the evening. Secondly you need to know by how much 10g of carbohydrate will raise you blood sugar, in my case around 2.5 *mmol/L* (45 *mg/dL*) and then by implication how much insulin you need to balance the carbohydrate you eat. Again in my case about 1 unit for each 10g during the day, and about 1.5 units in the evening. The only way of finding these figures is by trial and error, but mine are fairly typical.

Getting the basal rates correctly set is a critical part of the pump setup, and in my case took quite a long time, partly because over a number of weeks my basal requirement dropped dramatically which meant that I was constantly having to miss meals and test every hour to see how things were going. With hindsight a

large part of the problem was not being bold enough with making basal rate reductions. But once stability had been reached things improved dramatically.

11 Dec 2000

I didn't get the sudden miracle cure I was sort of hoping for, it's taking a bit of adjusting to. But over a few days things are gradually getting better. I'm starting to get periods of feeling better which are gradually getting longer. Also it's a very different regime to live with. Insulin seems to behave very differently when using a pump to how it does with injections and that is taking a bit of getting used to. As does the freedom from having to eat at fairly regular intervals.

I suppose in hindsight it's fairly obvious that changes take a little while to take place. The main difference seems to be that with injections, you can have an injection and then eat more or less what you want – within reason – and it doesn't seem to make a lot of difference to the outcome. With pump therapy this is not the case and you have to match the amount of insulin to the amount of CHO that you eat fairly closely, or your blood glucose will fluctuate. So I think that the apparent return to carb counting has to be seen in this context. Also, the period of adjustment doesn't always run smoothly, and without the support of someone helping you through it, it might be easy to become disheartened.

We went out for a pizza last night. I'm told that pizza is notoriously difficult to control because it not only affects your blood sugar very rapidly, but it continues to do so for some time because of the high fat content. It did cause me a bit of a problem, but the pump has a function where you can temporarily increase basal rate by up to 100%, and that seemed to fix the problem bringing things under control again after about three hours.

The other big thing at this stage is control during the night. There is a long period out of the 24 hours during the evening and the night where you are not influencing your blood sugar by eating and taking insulin. The pump, however, is programmed to give you the right amount hour by hour. So in the morning, whereas previously you might have woken up with your blood sugar doing all sorts of horrible things during the night, with the pump you can be sure that it has been stable – and of course you start to feel better. I slept like a log last night, which is unusual for me, and this morning I feel better than I have felt for a long time.

20 Dec 2000

Day 14 and time for another update on how life is progressing on the pump.

Last time I wrote my diary I was feeling down, the overnight miracle cure I'd hoped for didn't happen. The process of adjusting to life using a pump was taking a lot of my attention and energy, and I didn't seem to be seeing a big lot of benefit in return. With hindsight perhaps I was naive to expect it all to happen overnight – but I was so desperate for a change that I had to have a dream to cling to.

Now things are different, I'm getting a better feel for how my body behaves with the pump and also the fairly dramatic changes which happened during the first few days seem to have settled down somewhat. During the first few days my insulin sensitivity returned with a vengeance, I now have a basal rate of about 18 I.U./ day where we started off with about 25 I.U./day. My total insulin usage is now about 35 I.U./day whereas before the pump I was on about 65 I.U./day. This is all good news, but the period of adjustment is frustrating. As my sensitivity increases it means that my basal rates are constantly too high, my blood sugar keeps drifting downwards which is unpleasant and frustrating. Horrible mood swings ranging from very calm to intensely irritable, miserable, sensitive and tearful. Now, thankfully, we seem to be past all that and hopefully getting very close to having a stable basal rate. I'm regularly missing out meals and monitoring my sugars as I do so to ensure they remain stable – we're getting there. And my weight has dropped from about 81.5kg to 79 – that's good too.

Tiredness: well, I still get tired, but it's not the terrible impenetrable wall of fatigue that I used to get. Sometimes I can go for a whole day without getting unduly tired, and there are becoming increasing periods when the world takes on what seems like a horrible clarity after so many years living behind a net curtain. Also interesting, on Monday I went back to the ice rink after a break for a couple of weeks, my sense of balance seemed suddenly better. Manoeuvres with which I previously would have struggled I could manage noticeably better. I was tired by the time I finished a couple of hours skating, but physically tired not mentally drained, and much happier.

Life on the pump is very different, but it suits me because it makes my body seem a bit more like an engine and I can cope with that. Insulin and carbohydrates take on a precise mathematical relationship to one another. Every time you eat, you bolus. Even if it's just one biscuit – 0.5 units of insulin. Eat a meal and you do some sums and push the button. Get it right – as I am increasingly doing – and your *BG* will be fine. Get it wrong and it's obvious what you do to fix it. Get a bit hypo and I only need a minute amount of sugar to fix it – 5g maybe – and I recover far more quickly than before. Very different from the comparative sloppiness of injections where you eat what you want after a bolus and it makes hardly any difference. It doesn't fix your diabetes, but it's a powerful tool which gives you precise control. There's no escape from who's in charge. It's like driving a powerful car, treat it with respect and skill and it will reward you with its obedience and flexibility. But screw up and you have a wreck.

It seems strange not dragging a pen around with me all the time, not having to inject before each meal – although I'm getting used to that. And only needing one type of insulin (Humalog), so no worrying about where am I going, will I be away overnight? For how many nights? Do I have enough of both types of insulin? Wearing the pump is no big deal, during the day it's just like part of your clothing and I'm getting better at inserting the infusion set so it stays comfortable for three days until I change it. I hardly notice it at night now either.

So has it achieved my objective? Last week I would have had my doubts. This week I'm a lot wiser, and more optimistic too, it takes determination, but we're getting there.

17 Jan 2001

My basal rates have continued to give me trouble. Even though I have been gradually reducing them I'm constantly finding that I'm going hypo, sometimes quite suddenly and all the missing out meals, testing and writing everything down is getting tiresome. There were times when I felt like giving the whole thing up. Eventually I spent some time on the phone to Rita at Disetronic and after some discussion she attacked my basal rates with a chainsaw, something I'd never had the courage to do, but it did the trick. A couple more days fiddling around and things suddenly came right. My 24 hour basal requirement settled at 10.2 units – tiny compared to the starting value of 25. One day I was able to fast all day without my blood sugar drifting. But then the hunger got too much and I finally cracked and went to Burger King! I was jubilant, but I won't go there again.

From then on things took a dramatic turn for the better. Typically my blood glucose will not vary by more than half a unit overnight, even if I wake up and test it in the middle of the night it seems stable. Gradually I've been getting more adventurous and trying eating different things to see if I can control my glucose. One evening I ate about five chewy cereal bars, then walked into town, had a Haagen Daz, and walked home again. By the time I got home *BG* was 8.0 *mmol/L* (140 *mg/dL*). I had managed to keep under control, but it was hard work. You can do it if you really want to, but not something to make a habit of.

27 Feb 2001

My first clinic appointment since being on the pump. My *HbA1c* is 6.7%, (May 2000 – 6.4% – no change) Which didn't surprise me: less highs, less lows, good anyway. And my weight has dropped by 8.3kg since my last appointment in May 2000. I'm now around 75kg, slightly below average for my height and build.

I had a fairly long chat with Dr Paton. And as we talked he seemed to convince himself of the value of pumps. I left him with the graphs from my Medisense before and after, he was impressed with the dramatic reduction in the number of minor hypo events and with the substantial weight loss since May 2000. We talked about the need to use it with care and attention to detail, like driving a Porsche – used with skill and care it can give you the ride of your life – if not, you can lose it big time. We didn't get to talk about the changes in mood or energy levels. But he said he would be interested to see how things were in a couple of years when the novelty has worn off.

He understood that the running costs of the pump are not a lot different from basal bolus, (both from my calculations and other sources he has) but felt that it was clearly only suitable for a small number of well motivated patients. That the frightening cost was not the capital outlay, or the running costs, but the initial education. (I agree.) I hope it makes the difference when he talks with the pharmaceutical advisor about *NHS* funding for my consumables....

As I've been getting more familiar with the pump I've also been getting more adventurous. But also maybe a bit complacent too and the immediate result of that was an increase in the number of high *BG* readings I

was getting. It brought it home that you can't cheat. You have to count every bit of carbohydrate you eat, and manage your insulin delivery accordingly. But it also changed my attitude a bit towards *BG* monitoring. I had been too concerned to keep score – reduce the percentage of high or low *BG* readings I had, but now I came to realise that what really matters is making sure that a high or low *BG* is corrected as fast as possible. Lows are easy – because the pool of insulin in your body is so small *BG* comes back up very rapidly. One glucose tablet will raise my *BG* by 1 *mmol/L* (18 *mg/dL*) and very quickly, so I don't over correct anymore. For the highs I made myself a ready reckoner – a *BG* of X needs a bolus of Y units to bring it back on track and I carry it around in the wallet of my Medisense. You need that because a high takes an hour or two to come right, although in my case about a half of the reduction happens in the first 60 mins. The rest takes a couple more hours. But you need to be able to estimate fairly accurately in case you go hypo sometime later. If I take a correction bolus I can check an hour later, test to see if I am on track and then not worry about it.

If things won't come right, I bolus three units and go for a run round the block. That way I can recover from 15 to 6.5 *mmol/L* (270 to 120 *mg/dL*) in half an hour.

March 2001

I've been living with the pump for three months now and it is becoming a familiar part of my daily life. Getting my basal rates correct was a major step forward. But even now I find that you have to keep on top of it. I test my *BG* half a dozen times a day, slightly more than I used to before the pump, the difference now is that I have the means to do something about it if I want to make adjustments. I'm constantly doing mental arithmetic working out how much of my last bolus remains, how much I want my *BG* to go up or down, how many carbs I've eaten.

But did it achieve the things it set out to do?

Q: Does it give me better *BG* control

A: Yes. I used to get *BG* readings below 3 *mmol/L* (54 *mg/dL*) every couple of days, sometimes more than once a day. Now it happens once or twice a month. Below 4 *mmol/L* (72 *mg/dL*) maybe a couple of times a week. Highs still happen, generally if I've miscalculated my carb intake, but the difference is I can now correct them within an hour or so. On injections I used to get about 50% of my readings between 4 and 10 *mmol/L* (72 and 180 *mg/dL*), now with care I can manage about 80% and I quite frequently get days when I stay between 4 and 10 *mmol/L* (72 and 180 *mg/dL*) all day.

Q: Can I eat what I want when I want?

A: Yes and no. If I want to eat 'naughties' I have to plan for it. You have to work out your extra boluses and then monitor your *BG* for three hours afterwards to make sure you're still under control. *BG* is very sensitive to what you eat and you have to get it right. It's not something you would want to make a habit of.

Q: Do I still get tired or irritable?

A: Not as much. I definitely have more energy, I'm less inclined to get depressed and although I still have times when I get irritable and fed up, I don't think it's as bad as it used to be. Tiredness used to be a major problem for me. I would face a wall of fatigue in the middle of the day, sometimes I still get tired, but not so much. It's not a complete cure, but it's a lot better than it was.

Q: Do I feel better?

A: Generally yes. And also because managing my diabetes is no longer such a full time job I've been starting to take more of an interest in other aspects on my health, like vitamins and exercise which before always seemed a bit secondary.

Q: Would I recommend it?

A: Yes, but don't expect a miracle cure, or a plug and play solution. Whilst setting up throughout December, January and February I did 714 blood tests. After that you still have to keep on top of it and you can't cheat. You still, by and large, have to stick to the same dietary constraints as you did before, it's just a bit more flexible. Generally *BG* is more stable, but you have to be ready to react to the unexpected at any time. It's less frustrating than being on injections because you really can control your *BG*, whereas injections are fairly hit and miss and when things go wrong there's not that much you can do about it. Generally I feel better and I wouldn't go back to the old regime.

Q: What would you improve?

A: I wish I had a system for continuously monitoring *BG*. Getting basal rates correct means missing meals and checking *BG* every hour to see if it is stable. If it isn't, you have to adjust the pump and try again the next day. A continuous monitor would take away a lot of the stress of living with diabetes and I am convinced that together with the pump I would be able to keep my blood sugar in

range 100% of the time.

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