

Rewriting the diabetes rulebook

John Neale discusses how his insulin pump changed his life

Introduction

Photo of John Neale, Bayreuth, July 2001



Twelve months ago I was cured of diabetes. Well, not exactly – but that's what it felt like. I was 32 and had had diabetes for 21 years. My health had always been good – but never really good. I had tried many different insulin regimes, searching for something that gave me the flexibility I needed for my work, combined with the good control I wanted. When I changed back to pork insulin I found things steadier and stopped having bad nighttime hypos. But still I couldn't get a good predictable blood glucose level (*BG*) through the night. Nor could I eat at a time and place that suited me.

Looking for better methods of control

These were meant to be the best years of my life, and they were rolling by in a whirl of irritability, fluctuating *BGs* and weariness. From the point of view of my diabetes clinic everything was just fine: I was articulate, motivated and never showed up in A&E. But I wanted better. I embarked on my own quest to establish what was the very best treatment regime available. I wanted to know what others in my situation did. The Internet was perfect for this. One excellent resource is the main diabetes newsgroup (misc.health.diabetes). One thing repeatedly surfaced: the people who were contented, happy and firmly in control of their diabetes and their lives were those using an insulin pump. I had heard a little about pumps before, and had assumed they were the treatment of last resort for people with uncontrollable diabetes. Nothing was further from the truth. In America and Germany, two countries I know well, pumps were now considered by many doctors to be the treatment of first choice if you lead a flexible life, want good control and are prepared to test your *BG* a lot. That's me.

Plan strategy to get pump

Photo of my MiniMed 507 insulin pump



My NHS diabetes clinic were unreceptive to my concerns about my less-than-perfect control, and knew nothing about pumps. So I saw a private diabetes specialist in London. He too knew little about pumps, but was sympathetic to my needs and concerns. After several visits he authorised my using a pump, but I was essentially on my own. The NHS continued to pay for my insulin and test strips, but I had to purchase the pump and fund its ongoing costs from my own pocket. And I negotiated a one month free trial before I was committed to buying it.

Amazing results

From day one my life was changed. There was no going back. I awoke on the first morning from the deepest soundest sleep I had ever experienced. And I woke refreshed! Previously I had usually woken tired and exhausted. Now I was bounding with energy. I no longer had waves of sleep rolling over me after lunch. And my character changed. This was immediately picked up by my colleagues at work. I became cheerful and contented and exuded enthusiasm. Small health problems cleared up. The persistent small amount of acne I always had disappeared. Athletes foot – gone. A healthy complexion came to my face for the first time. My face changed shape too: it became slimmer and lost that plumpness. That frequent feeling of needing to go to the toilet went. I now ate because I was hungry, and not because I was chasing insulin already in my system. I steadily shed weight, and was eating just whatever I wanted. I've also had no sore throats, flu or other illness since I started pumping. Previously I was always going down with something.

Description of pump

Disetronic HTron+ V100 insulin pump



Enough about me. The pump: it's about the dimensions of a credit card, and just over half an inch thick. It's light, rugged, and sits in my pocket without my knowing it's there. It holds about a week's worth of insulin, which travels by a 24" tube to wherever I have inserted the small Teflon cannula under the skin. This is inserted by injecting a needle with a thin plastic coating into the fat around my stomach; the needle is then removed, leaving the plastic tubing behind in the fat. I change the infusion set every 3 or 4 days. I can also swiftly disconnect it from my body, leaving the infusion set in, to take a bath, swim or have sex. At night the pump just lies safely alongside me in bed.

Humalog allows new rulebook

I use just Humalog – the very fast acting insulin. No other insulin enters my body. This allows me to throw the old diabetes rule book out of the window and write a completely new one. Let me describe the new rules. Two essential figures, and two new words:

- The **insulin sensitivity factor** is by how much 1 unit of insulin lowers my *BG*. In my case it's about 2.5 *mmol/L* (45 *mg/dL*)
- The **carb/insulin ratio** is how much carbohydrate is required for each extra unit of insulin taken with a meal. In my case about 15 grams of carbohydrate requires 1 unit of insulin.
- A **bolus** is the extra insulin you take when you eat carbohydrate. This corresponds to the old pre-meal injection.
- The **basal** is the insulin which maintains your *BG* when you haven't eaten recently. (Remember, even if you've not eaten recently you still need insulin. Insulin doesn't just push glucose out of the blood: it prevents it flooding back in again.) The basal rate is like the old slow acting (cloudy) insulin, but it's given gradually and measured in units per hour.

Correct basal rates very important

Getting the basal rate right is central to good control. Mine's about 0.9 units per hour during the day. I need a lower rate during the night, and a large increase between 6am and 10am. This is all pre-programmed into the pump's memory. The morning increase accommodates a phenomenon called the dawn effect where the body releases various hormones as part of its waking-up process. Unless I take more insulin at this time I wake up with a high *BG*, even though my night-time rate is correct.

Eat whatever you like...

Once my basal rates are correctly set, I can live my life just as I like. If I'm not hungry, I don't eat. Easy as that. My *BG* stays fine. If I'm hungry I eat, and I eat as much as I want. I estimate how much carbohydrate I'm eating and bolus the appropriate amount of insulin (using my carb/insulin ratio). Since Humalog works fast there's no need to take the insulin in advance. And since it's gone from the system quickly, there's no need to snack later to catch that late peak you get with Pork or Human Actrapid. In fact I often put my hand in my pocket and take more insulin during a meal if I decide to have a second helping of apple pie and custard...

Delaying the Humalog

If it's a slow digesting high fibre or high fat meal, I may take a few units with the meal, and a few units later after the meal. Or I may use the slow-bolus feature, which gives you the bolus gradually over the next few hours. This way you can avoid the fast action of the Humalog when you don't want it.

Correcting *BG* as you go

Since Humalog works so quickly, I can also use it to correct my *BG* if it's a little high. If it's say 11mmol/L, and I haven't eaten recently, I can take 2 units of insulin which (using my insulin sensitivity factor) will bring it down by 5mmol/L to about 6mmol/L within an hour or two. This allows me actively manage my *BG*. On the old injection system, if your *BG* was wrong, you had to adjust your insulin the following day, do everything else the same and hope the *BG* came out better. We all know that two days are never the same, and sometimes the *BG* just does what it wants irrespective of your best laid plans. Now I can respond to the situation as it happens.

Is this tight control really necessary?

Some doctors claim that this extra-tight control, with an actively managed *BG*, is unnecessary, as it does not reduce the risk of complications any further. This is irrelevant to me: what I know is that when my *BG* is high, I feel lethargic and irritable, and when it is normal I feel energised and enthusiastic. This is motivation enough for getting perfect *BGs*.

Old pump memories

Many doctors also remember only the "bad old days" of insulin pumps when they were first trialled in Britain in the 1980's. Many of the problems that prevented them being used have been overcome. They are now smaller, lighter, and very reliable. The stainless steel needles that scarred the skin and caused infections have been replaced by much better Teflon cannulas. And the special tubing no longer causes the insulin to crystallise and block the system.

Not perfect, but the best available

Pumping does not give perfect control. Diabetes is not like that. But it gives you the best possible control, and it puts directly in your hands the ability and responsibility to handle situations yourself. I no longer have bad hypos. Ever. I eat whatever I want, whenever I want, if I want. My last *HbA1c* was 5.7%. Well, for now at least, that's almost as good as a cure.

Author: John Neale <jneale@webshowcase.net>. John Neale is not a medical professional. He has Type 1 diabetes and uses an insulin pump. The information given here is based on his own personal experience. [More about John Neale...](#)

