

Personal Statement

Lesley Jordan, Patient Expert representing Insulin Pumpers UK

I was diagnosed with Type 1 diabetes in 1968 aged 1. I have been using an Insulin Pump for 5 years.

In the last few years prior to commencing pump therapy, I had great difficulty in achieving good glycaemic control. I was on multiple daily injections (MDI) and had attended courses on carbohydrate counting, sick day rules and dose adjustment. However, my injection sites had lipohypertrophy, despite following the usual advice for avoiding this complication. This meant that the injected doses of insulin were absorbed erratically and this caused erratic blood glucose levels. My HbA1c was usually over 9%, which meant I was likely to suffer numerous complications of diabetes in the long term. I had already had to have a lot of laser treatment for diabetic retinopathy, and had lost my driving licence because the laser treatment reduced my field of vision. My odd behaviour when hypo caused me great embarrassment if I was in a public place, and trips to the gym or swimming pool made my efforts at blood glucose control even less successful. I had frequent night time hypos with convulsions, and needed assistance from my husband to treat them.

The diabetes specialist nurse (DSN) at my local clinic suggested I should consider insulin pump therapy. She arranged for the company reps from two pump manufacturers to come and demonstrate their pumps to me. I made my decision with the help of the DSN, and started insulin pump therapy just over a month after it was first suggested. This was in September 2002, prior to publication of NICE Technology Appraisal number 57, so I paid for everything myself with the intention of applying for funding once I was sure this was the right therapy for me.

My local PCT took over funding of my therapy in June 2003 and backdated repayments to cover all expenses I had incurred since starting insulin pump therapy.

Initially, insulin pump therapy took much more effort than had been required for MDI. I had to do many more finger prick blood tests than I had done previously, and make more frequent decisions about adjusting my blood glucose levels. However, even in those early days, my day-to-day blood glucose levels were normally in a smaller range than they were on MDI, and much more predictable.

I found it quite frustrating at first that excellent control was within reach but only after a steep learning curve. I had to make sure my overnight basal rates were right first, then adjust the day time basal rates. Finally, I could fine-tune my insulin-to-carbohydrate ratios. However, having only a rough idea of my ideal insulin-to-carbohydrate ratio meant that it was difficult to get sufficiently stable control to test the basal rates, resulting in catch-22 situation which only time, practice and patience could solve. I had lots of help from the pump company nurse advisor, whom I could contact 24/7 in the first couple of weeks.

Within a week my overnight blood glucose levels were stable, which enabled me and my husband to enjoy a good night's sleep. My employer also commented that I looked well.

My HbA1c levels also improved immediately, and haven't gone over 7.8% since I started insulin pump therapy, with my best result being 6.3%. This has greatly reduced my risk of complications.

My quality of life has improved greatly. I have more energy, a more even mood, am more able to deal with life's other problems as well as enjoying hobbies and activities again.

As I am here to represent Insulin Pumpers UK, the rest of this personal statement includes views which are shared by the wider pumping community, with some anonymous quotes from conversations within the email support group run by Insulin Pumpers UK (ie not solicited for this report).

We know that insulin pump therapy initially costs more than MDI. There is the up-front cost of the pump itself, followed by the ongoing cost of consumables. In my experience, pump users tend to do more finger stick blood tests than they did on MDI, so there is an ongoing increased cost of blood glucose sensors, too. However, if these costs are offset against even one emergency admission to hospital each year then they are not so steep. Offset the costs against the cost of potential renal dialysis, coronary bypass surgery or amputations and the long term value of preventative care can be seen.

The cost / benefit to society is also difficult to measure. How much is it worth to keep an individual healthy enough to stay at work and pay income tax and national insurance, and to function as part of a family and part of a community? Surely this should be the goal of NHS diabetes care, not just a good HbA1c – after all, a good HbA1c can hide a wildly fluctuating blood glucose level and many disruptive hypos.

Prior to NICE Technology Appraisal 57 it was very easy for me to purchase my own pump with the approval of my consultant. Following publication, patients across the country have faced many obstacles to getting the therapy they need. Those who most need the help of their health care teams often need to be strong and persevering when actually they feel ill, weak and unable to fight.

It seems to me that there are two areas of difficulty: funding and education.

Funding issues include the handicap of a short-term focus of financial controllers in PCTs, PCTs lack of understanding of their obligations to provide access to the therapy their patients need, and a postcode lottery as to whether your PCT will even consider insulin pump therapy. After a consultant and patient have agreed that insulin pump therapy is necessary, patients often face many hurdles to get approval for the funding. Comments in email conversations on Insulin Pumpers UK include:

I have just been told that the Finance Committee have approved funding for a pump! Dated Sept 2007

Initially, they paid for my pump and the 1st year of supplies (reservoirs and sets etc) and they then approved my 2nd year back in May of this year. Dated Aug 2007

And in addition, despite not having funding approval, they are going ahead and ordering me a new pump to replace my aging Minimed 508 :)
Dated Sept 2007

This was the main argument my consultant put up for getting me a pump it took a while because of the PCT stalling but we got there eventually.
Good luck Sally and don't give up hope. Dated Aug 2007

He also said that it could take between 6 and 9 months since he had to talk to my PCT to obtain funding and although he didn't feel it would be problematic, it could take some time. Dated Jun 2007

In many instances, patients have waited for many months longer than necessary because the PCT has insisted they need to have a committee meeting about each new case or pump renewal, and the committees don't meet very often.

Education issues include health care professionals not realising that ultimately the decision to start insulin pump therapy is a clinical one, to be made by them in partnership with the patient / carer, and not by the PCT. It is also common for health care professionals to misinterpret the criteria set by NICE as shown in the following quote:

However, the Consultant has said to my DSN that my HbA1c is "too good for a pump"!! My last Hba1C was 6.9, but my understanding of the funding issue is that not ALL the NICE criteria have to be met. Surely the fact that I have so many severe hypos counts for something? I don't have much quality of life because of them and it's affecting my work for obvious reasons (I am a nurse!). I also don't have any hypo awareness, and have been as low as 1.5 before someone suggests I check my blood sugar. Dated Aug 07

Some health care professionals set their own criteria on top of NICE criteria, insisting for instance, that patients attend a DAFNE course before they can be considered for pump therapy. DAFNE is an excellent educational tool which should be available to all Type 1 diabetics, but sadly this is not yet the case, and some clinics have waiting lists in excess of 2 years for this course.

Some clinics seem to use the NICE Technology Appraisal number 57 as a reason for not providing a pump therapy service, saying that they can't meet the necessary staffing guidelines, without offering patients access to alternative providers. We agree with The Report of the Insulin Pumps Working Group published by the Department of Health in March 2007 that clinics not offering a pump service should have a clear referral pathway to another clinic that does offer a pump service.

My own local clinic is sadly, I believe, similar to many other clinics. Before NICE Technology Appraisal number 57 was published, they started insulin pump therapy for about 12 patients, most of whom self funded initially then sought PCT funding. Since the Technology Appraisal, they have gathered a waiting list of 30 or more patients needing to start pump therapy, while the local Diabetes Network continues to hold strategic planning meetings with the PCTs, continues to investigate the financial

implications of offering a pump service, and continues to weigh up the pros and cons of insulin pump therapy. Surely this is what NICE technology appraisals (and reviews) are for?

The following quote concludes this statement as it sums up what insulin pump therapy, when appropriate, can achieve:

My HbA1c's had been erratic for many years on MDI therapy. Since starting pump therapy my results have never reached higher than 5.8% - the last one in August was 5.5%. All other test results are on target too. Without pump therapy, I believe my health would have rapidly deteriorated mainly due to constant highs and lows over thirty + years. Now, I feel re-born and healthier than any of my children and grandchildren. No coughs, colds or infections in four years. The best feeling of all is no more fatigue; this I found debilitating working and bringing up five children.

Dated Sept 07

Lesley Jordan
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