

Not controlled, but in control!

Claire Sneddon describes how she finally confronted her diabetes at university, and gained control using a pump

Introduction

Well, I'm rather unremarkable as individuals with diabetes go. I haven't done anything in the public eye to be an ambassador for diabetes neither have I struggled with disabling microvascular complications as many individuals have done though I am humbled by their courage. But, the great thing is that whether or not you stand out because of your successes or problems with diabetes, insulin pump therapy could make a real and significant difference in your life.

Diagnosis

I was diagnosed in June 1991 at the age of seventeen just 3 months before I was due to move away from home and start a new life for myself at university. Although the prospect of my new life was exciting I was truthfully terrified at the thought of going it alone. On top of this I was unsure of how I was going to introduce myself to strangers and fit into a new social culture when I didn't know who I was any more. All of a sudden I was "a diabetic" and I just wanted to scream "no I'm not I'm just me!"

Battles

I have only recently realized that I continued this battle with my identity for the next 8 or 9 years. I started by simply avoiding the issue and trying to hide my diabetes. This wasn't particularly easy because I had to be given a fridge in my room at halls to store my insulin. Everyone else had to try to keep their milk fresh by hanging it out of their window in plastic bags while I had a whole fridge! It is the reason why so many students drink black coffee. Anyway, I knew that for safety's sake I would have to confide in someone but I limited it to a very small group of close friends. However, even in the early days when stable control seemed a piece of cake there were times when my diabetes was not obedient to my wish for secrecy. For example on occasion I would forget an injection, or have to wait too long between meals and end up feeling ill. I also suffered from frequent mild hypoglycemia, which I tried to hide or dismiss. There were also certain social situations that drew attention to my diabetes such as an impromptu decision to go to someone else's house for a meal after lectures or, to go out to a restaurant. In these situations I would have to make my excuses having thought it unnecessary to carry my insulin with me. Some of these situations could be easily remedied or avoided however with every little incident, miscalculation or mistake that exposed my diabetes, I felt vulnerable and my friends and flat mates would increasingly feel that they had to intervene, putting me under constant interrogation. "Have you remembered your insulin?" "Have you taken your insulin?" "Are you okay?" "Do you need to eat something?" I realize now that they were acting out of concern but I began to feel more and more like an invalid and consequently I really started to resent my diabetes. This was purely a psychological problem until the frequent mild hypoglycemia began to take its toll and, I started to lose my hypo awareness. This increased my friends' concern for me, which in turn increased my resentment, and made me more determined to keep things to myself. So instead of acknowledging that I had a problem with my diabetes I started to blame others. Meanwhile the hypoglycemia steadily became more and more severe as did my paranoia and my blood sugars started to swing out of control with the perpetual cycle of hypo, post-hypo rebound (or over treatment), increased insulin dose, hypo etc.

New start

I moved down to London in 1996 to start my Ph.D. I thought I would make a fresh start and begin an exercise regime to promote my general health and fitness, as I seemed to be feeling sluggish and tired all the time. However this was another variable, which, on top of the unpredictability of life as a science Ph.D. student, didn't help the blood sugar problems, and so things did not improve. I was also becoming less and less inclined to test since despite my constant efforts my blood sugar seemed to have a mind of its own. So, how did I release myself from this vicious cycle? Well it was a day I will never forget; I was going out for the evening so I had an early tea and went out at about 6.30pm. At the end of the evening, on my way home, I had to run to catch my train. When I finally reached my destination and disembarked I

felt exhausted; "another long stressful day," I thought. I arrived at my front door but there seemed to be something wrong with my front door key as it wouldn't fit in the lock! Eventually my flat mate opened the door and asked me if I was okay, "I'm fine" I said as I sat down on the couch. She suggested that I should maybe test my blood sugar and without any protest I went to fetch my meter and strips from my room and started to go through the motions of testing my blood sugar. I don't remember much after that, I don't think I lost consciousness but I was getting there fast. My flat mate apparently struggled for ages to get me to eat something but by then, I was incapable of doing very much of anything. When I finally came around an hour or so later my flat mate, who had been with me, was standing in the corner of the room, red eyed and looking rather shell shocked. Meanwhile my other flat mate, who she had summoned from a meal out with friends, was feeding me undiluted Ribena from a teaspoon. It really was a wake up call for me but it was what I overheard my flat mates say while I was still semi-conscious that gave me the final push I needed. They said that I would never be able to live alone as I couldn't take care of myself.

I had never really been comfortable with my diabetes but until now we had managed to tolerate one another. However it was beginning to take control and it was time for a confrontation! Having acknowledged that I was having problems, I finally asked for help at my diabetes clinic. I was referred to a specialist nurse who began by re-engaging my interest in frequent blood sugar monitoring, four times a day and occasionally at 3am. Of course this revealed what I already knew, frequent hypoglycemia interspersed with high swings. However due to the hypoglycemia, Ph.D. related pressures and low self esteem, I found I was extremely tired and depressed for much of the time. I had lost interest in food (my diet left a lot to be desired) and my motivation was waning. I felt completely overwhelmed and unable to cope.

Learnt about pumps

Cue the British Diabetic Association and their magazine article on insulin pump therapy. When I read it, it was like someone had switched a light on. My relationship with my diabetes didn't have to be one of constant antagonism; it is my body's physiological need for insulin, not my enemy. My pancreas is unable to do the job that the pancreas of a non-diabetic individual does. In simplistic terms, if I could just learn how to do the job of a pancreas and find a method of delivering externally produced insulin in a physiological way, then perhaps I could finally strike the proverbial balance that I had heard so much about. It may sound bizarre but at bottom, this is what the treatment of insulin dependent diabetes is all about. So when I read about other people's experience with insulin pumps I realized that this would be a step in the right direction. As it happened it was not only that but it was the doorway to a fresh start in life. The first thing that I did was to telephone the insulin pump therapy group, INPUT, who contacted the appropriate people in the insulin pump companies (Minimed and Disetronic). I received a large information pack from each company, which I eagerly read; I also scoured the literature and the internet for as much information as I could get my hands on. Not only on insulin pumps but also on hypoglycemia, insulin action, and the physiology of glucose metabolism. Based on the available information I decided which company I was going to approach and I e-mailed the company representative. They recommended that I discuss pump therapy with my healthcare team, which I did, and despite the cost I expressed my desire to be put on an insulin pump. Fortunately they were already giving care support for insulin pump therapy and a free trial was arranged (a facility provided by both insulin pump companies). I was given the necessary training and was started on pump therapy.

I took to it straight away as I had a very clear idea of what it would and wouldn't do for me but I think the biggest plus and the major reason why I was so keen to try it was that for the first time I was in control. I had managed to grasp the basics of playing the role of a pancreas but most importantly I had the right tools for the job. First of all a fast acting insulin with a predictable absorption rate and secondly an insulin pump providing a continuous supply of insulin which could not only control the uptake of sugar from my food but also the release of sugar from liver and muscle stores. Although I'm not brilliant at my new job as a pancreas, I'm learning every day and with the flexibility the pump gives me I can immediately apply my newly acquired knowledge and experience to controlling my diabetes. In summary, I now know that I can deal with any situation even if not first time and, the more I experience the more I can do. Oh and the other thing is that normal blood sugar can be achieved without hypoglycemia!

Financial cost

As for the cost, well I am a keen advocate of NHS or even Healthcare Trust funding for pump therapy but that was not an option for me. I could never put a price on the peace of mind and the freedom that the

insulin pump has given me so, I decided to take matters into my own hands and I started fund raising to help pay for a pump. I would like to pay tribute to all those who so generously gave of their time and their means because without them it would have been impossible for me to purchase my own pump. I am currently awaiting delivery of my pump and am taking measures to secure employment so that I can afford to live and pay for the pump consumables while I finish off my Ph.D.

HbA1c

One more thing that I would like to point out is that my *HbA1c* value has remained almost constant since I was diagnosed. I feel that this suggests very strongly that although a "normal" *HbA1c* may be a valuable indicator allowing health care professionals to monitor the relative risk of microvascular complications, in no way does it reflect the hour by hour, day by day, every day struggle that many diabetics experience. So my advice to everyone with diabetes is – don't be controlled, take control!

Author: Claire Sneddon <claire.sneddon@cwcom.net>. Claire Sneddon is not a medical professional. She has Type 1 diabetes and uses an insulin pump. The information given here is based on her own personal experience. [More about Claire Sneddon...](#)

Created: Mar 2000; Last updated: Friday 28 September 2001