

- When you were diagnosed (how old were you and how long ago was
- The impact your diagnosis had on you and your family
- Your treatment in the beginning
- Your treatment now, emphasising how things have improved...if they have (?)
- What developments you are excited about for the future and why....preferably something JDRF related such as the Artificial Pancreas
- And finally, what a cure would mean to you...end with a bang ;)

My Lords Ladies and Gentlemen, I was diagnosed at age 4 with insulin dependent diabetes and am now 16. Contrary to popular belief my mother did not feed me an inordinate amount of sugar when I was a baby and I was walking at a year so it was not lack of exercise! In fact the cause of type 1 diabetes to this day is still not fully understood, but one of the things that is thought to cause it is an immune response to a virus, causing the body's own defences to turn on themselves and destroy the insulin producing islet cells in the pancreas.

I was lucky that my mother spotted the symptoms early, and took me straight to the GP with a urine sample. The GP sent us directly to A&E where they told us that they do not normally see children as well as me as they are usually seriously ill before anyone realises what is wrong. I was in fact so well that my two year old brother on seeing me laughing and joking with the nurses when I had my first injection proceeded to pull down his trousers and call "my turn"

The impact my diagnosis had on my family was enormous. My mother made it her mission to find out everything she could about diabetes and potential cures, join and support charities such as JDRF and Sugar free and was one of the first members of UK CWD an online support group for parents of children with diabetes. At first my father found it very hard to come to terms with and accept. He would not talk about it and preferred to use my little brother as an excuse to leave the room whenever the nurse came round. After a few weeks my mother phoned a friend who is a doctor and spoke very loudly so that my dad would hear from the next room about how he wouldn't talk about it. He then started talking and the next day my mum overheard him telling another friend that he felt bereaved. This is apparently not uncommon with parents mourning the loss of their healthy child. My mum on the other hand had been so busy researching and dealing with it all, that it was only a few months later that she allowed herself to get upset about it. Fast forward 12 years they are just normal parents of 2 delightful teenagers, one of whom happens to have diabetes!

Some people with diabetes have more than one autoimmune condition. I have asthma and have had various other medical problems over the years and have a string of consultant visits under my belt! In fact throughout my life I have missed 20-25% of my schooling.

My primary school had never had a child with diabetes before and although they allowed one of the teaching assistants to look after me I was not allowed to test in class but had to go to the medical room, even when aged 7 I was able to inject myself they insisted that one of my parents or grandparents supervise this as they would not take responsibility. My

mother or grandmother had to come on every school trip even residentials, consequently it was hard for my mother to work more than part time.

At first I was on two injections a day of mixed insulin. This is not conducive to good control as the pancreas does not dump all the insulin for the day into your blood stream in one hit, but reacts to changes in the body. My consultant was insistent that the problems we had with my control were all my parents' fault and did not like my mother questioning him. We had to go and see a different consultant privately in order to have my regime changed and I was then put onto multiple daily injections which was an improvement but meant 5 plus injections every day (at age 7). Eventually we were referred to UCLH for an insulin pump which I wear to this day. The pump also known as continuous subcutaneous insulin infusion allows far more flexibility as you can tailor make the dosage to suit your own metabolism and routine.

The insulin pump gives a slow drip of insulin via a cannula in my stomach which has to be changed every 3 days or so. Whenever I eat I have to count the carbohydrates and give insulin accordingly. Blood sugar levels are not only affected by food but also stress, exercise, illness, heat, hormones... basically life! This means that I am constantly thinking about my diabetes. The pump is not a cure but a tool to help manage; it does not stop blood sugars from dropping too low or running too high. Low blood sugars can be debilitating and I have friends who have seizures from them as well as one who died. If I have a low blood sugar in the night, I am frightened to go to sleep until I have raised it significantly – this is not just paranoia, it's a genuine fear.

When my blood sugars drop it is not always the same feeling, I can be really low and appear to function normally and other times I can be just a little low and be almost unable to move. My hands will always get shaky and often my legs will feel tingly and heavy. I can struggle to even open a bottle to drink because of the lack of energy I feel, which is a real problem if I am alone, as I need to have a sugary drink to bring my levels up quickly. It can take up to an hour to feel better. As a small child I used to tell my parents I felt wobbly.

I cannot always tell if my blood sugars are rising, but my parents tell me I become pale and get really moody – of course this is not the case because I am an angel! If my levels run high for any length of time, I will get headaches and be incredibly thirsty. It becomes very difficult to concentrate on anything.

Fluctuating glucose levels impair cognitive function. Therefore during exams I have to be particularly vigilant and random blood sugars can have a detrimental effect on my abilities. For example during my GCSE's last year on one particular day my blood sugar levels were running high all day for no obvious reason and despite giving extra insulin I could not bring them down. I managed to achieve an A* in my RS paper that day as the subject is not logic based. However I was unable to concentrate in my maths exam as it is logic based, and therefore ended up with a B and not the A I had hoped for.

My secondary school have been very supportive and I have access arrangements in place for exams. I am allowed to take supervised breaks, whereby the clock stops on my exam if I feel that my blood sugar levels are changing and need to test or treat. I can then leave the room, deal with the

situation and when I go back in the clock starts again. If it is at the beginning of the exam I can delay the start. Although this is helpful it cannot compensate for the loss of concentration by needing to leave the room or for the fact that it is not always simple or quick to deal with a high or low blood sugar.

After my GCSEs I went on a month long youth trip, the first time I had been away from home for more than one night alone. Unfortunately the trip started badly with an engine fire on the plane causing us to turn round and return to Heathrow. As it was a night flight all of the ground crew had gone home so we were left sitting on the plane for hours, we were then put on another night flight the following night which meant that we arrived at our destination without having slept for 48 hours. We all know about people picking up bugs on planes but combine that with lack of sleep and weak immunity and the effect can be disastrous. Within 24 hours of arrival my blood sugar levels had gone completely out of control from a virus I had picked up and I ended up in hospital on a drip (the first time this had ever happened). My mother flew out to look after me but when after a week I was still on 2-300% insulin in order to get some semblance of control, it became obvious that I would not be able to re-join my group and we flew home. In fact it was over a month before we were able to completely regain control of my blood sugar levels at which point I began to finally feel better.

Having had a lot of experience around hospitals, I would like to pursue a career in medicine. I like most people am not sure I will get the grades to get into medical school, so one alternative I looked at was being a paramedic, however having Type 1 diabetes means that although I could qualify I could never get a job as people with Type 1 are excluded from driving an ambulance and this is a job requirement. I am also banned from the armed forces should I have wanted to join as a doctor.

Scientists at Cambridge with support from JDRF are working on an artificial pancreas which will automatically adjust insulin levels without the need for intervention or in fact the patient having to think about diabetes all the time. If something like this had been available last summer, I may have got my A in maths and been able to enjoy my month long trip with all of my friends, just like any other normal teenager.

For the last 30 or so years scientists have claimed to be 5 years off a cure, the JDRF are trying to make this a reality. The long term complications of diabetes include blindness – I already have very poor eye sight (-7.75) not diabetes related so I can't afford to have further problems with my eyes, heart disease, kidney disease and limb amputation. I am one of the lucky ones I have a lot of support from my family and my parents stay up at night to test my blood sugars ensuring that I am safe during the night, this however does not mean that I am assured that in time I will not have complications, but by keeping good control we are minimising my risks. In fact despite night time testing a good friend of mine was found dead in bed about 6 years ago the day before her 13th birthday, Danielle was beautiful and a lovely person, I often think of her and think if only there had been a cure