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Practice

The patient's journey: living with diabetes

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Setting out

When I was diagnosed as having type 1 diabetes in 1984 at the age of 12 it came as a shock. I didn't know it at the time but all the signs were there: in the weeks before the diagnosis I had been losing a lot of weight, I was drinking far more than normal, I often felt unwell, and I recall my mother commenting on my constant mood swings. Eventually she got me to our general practitioner who, after discussing my symptoms, seemed to know what the problem was even before running tests.

Forty five minutes later I was in hospital, where type 1 diabetes was confirmed. In retrospect it would have been helpful if the specialist had explained the implications of the diagnosis instead of just saying that I had diabetes and that there was protein in my urine. Had I been told about the risks of kidney failure I would have been more vigilant and avoided taking ibuprofen, a factor in the development of my subsequent renal problems. It was a hard way to learn that I should always ask questions if I do not understand what doctors say.

It may seem funny now but the first thing that came to my mind on being told the diagnosis was "Will I ever be able to eat a McDonald's again?"

I spent eight days in hospital, but once diabetes and its treatment had been explained to me I was confident that I could cope with it. I was determined that it would not affect me in a dramatic way. I told myself that I could still have fun.

My condition didn't affect my relationship with friends. They came to visit me when I was in hospital for those eight days, and I am still friends with most of them. One friend did say he felt guilty eating sweets in front of me, but I was never bothered.

I am sure my mother worries about me but she has never stopped me doing anything and I let her and my sister do my injections early on in my illness. At one time I did have a problem at school, because the head teacher did not understand that being diabetic made it necessary for me to eat carbohydrate. I was told I would get fat eating so much bread—that upset me, because I had only been aware of being diabetic for four months, but it was because people knew little about the illness in 1984.

I spent my teenage years doing everything my friends did, including socialising and drinking.

The journey becomes more complicated

When I reached 24 things started to change dramatically. Out of the blue I started getting a terrible

burning sensation in my legs; it was so painful it kept me awake at night. I was diagnosed as having neuropathy in my legs. It suddenly corrected itself—one day the burning sensation went away and I thought that would be the end of it.

When I reached 28 everything started to go wrong and I experienced my first severe hypoglycaemic attack. Ironically, at the time I had made the decision to do everything in my power to manage my diabetes effectively and to maintain a healthy lifestyle. After so many years of almost burying my head in the sand about my condition, I thought "Right, you've got away with this for so long; maybe it's time to try harder and start controlling it better."

My first severe hypoglycaemic attack caused me to black out. It happened while I was shopping in Harrods department store in London, of all places. I vaguely remember feeling unwell and throwing up everywhere, but I do not remember anything after that until I woke up.

I had my second severe attack two months later in a London shopping centre—Whiteley's in Bayswater. The scary thing was that when people saw me collapse they thought I was drunk because of my slurred speech. This has taught me that it is important to carry identification cards detailing my medical condition.

Road rage

Then, early in 1999, something even more frightening happened: I had a car crash. My diabetes was not the

Things that doctors should be aware of when dealing with people with diabetes

- Most people with diabetes know their bodies well and should be listened to carefully
- Waiting to see a doctor can feel like going to see the head teacher—I have often sat outside a clinic with sweaty hands because I know my blood glucose levels may be high
- Diabetes may be hard to self manage, especially during difficult times in a person's life
- When type 1 diabetes is diagnosed in a young patient, it is not just his or her life that changes, but the whole family, so parents need support for the changes they have to make
- Nurses specialising in diabetes are approachable, friendly, and helpful, and have time to talk (they are easy to contact by telephone for minor queries about drugs or health)

Things I have withheld from my doctor

- Saying that my blood glucose levels are around 4 to 7 when I know they have been running a bit high
- The number of hypoglycaemic attacks I have had
- When I have been overweight, being economical with the truth about my alcohol intake and the amount of chocolate I eat, and not owning up to that cream cake

cause of this but the paramedics presumed I was responsible for the whole thing when I said I had diabetes. They presumed I had had a hypoglycaemic attack and lost control of the vehicle. The crash led to my licence being revoked and it took seven months to get it back. I had to fight tooth and nail for this, having the medical evidence re-examined and writing letter after letter to the authorities involved. As I am a self employed children's entertainer and depend on my car, not being able to drive made a huge impact on my life.

Government bodies such as Britain's Driver and Vehicle Licensing Agency do not seem to understand diabetics. It may be different elsewhere, but here they seem to suppose that everyone with diabetes is the same. They need to understand that each person's body is individual and that diabetes therefore affects people's lives in different ways.

After that everything was fine for a while and I was quite confident that I had reached the point when I knew how to manage my diabetes well. I was also happy in my personal life: meeting a partner and maintaining a happy relationship when you have a long term condition such as diabetes can be a challenge, but in April 2001 I met my partner and was hopeful for the future.

In the eye of the storm

Unfortunately, the following September my health became a major cause for concern yet again. I haemorrhaged into my right eye and the blood leaked into the eye gel. Retinopathy is a complication of diabetes, which affects the blood vessels of the retina. Diabetes causes the capillaries in the retina to become blocked, resulting in inhibited sight. Diabetic retinopathy is the leading cause of blindness in adults of working age, but it can be successfully treated if picked up early.

I was told that I needed to have a vitrectomy in July 2002. Another operation followed in September that year. I was terrified that I would lose the sight in my right eye, as I went through periods when I couldn't see out of it. I only just had time to recover from my operations when I started developing problems in my left eye. In all, I ended up having four operations.

After the last operation I felt unwell and put it down to a cold or the common flu. Then as I was showing no sign of improving I sought medical advice, and my hope of a quiet life was dashed. The doctors came to the conclusion that my kidneys were failing. I'd caught a virus that led to blood clotting in my kidneys, haemolytic uraemic syndrome. The fact that I'd been taking ibuprofen for the flu-like symptoms made the problem worse. Under ordinary circumstances ibuprofen would have been fine but it should not be taken by

people with renal problems. My blood pressure was 190/120 mm Hg and I was scared.

I was admitted to Northwick Park hospital for four days of hell. My condition was so bad that my family started to worry that I would not survive. I was transferred to St Mary's Hospital in Paddington where I stayed for about a month. During this time I gained a lot of weight. My body wasn't removing liquids properly, so I accumulated a huge amount of fluid—about five stone in total. I went from a size 12 to a size 20. A course of water tablets helped deal with the weight gain though and I lost five stone in seven weeks. My condition started improving and I started to feel hopeful again.

A gift

As it turned out in March 2003 I was diagnosed as having kidney failure and doctors told me that I'd either need a kidney transplant or need to start dialysis at some point in the near future. My mother and father had been discussing donor possibilities in case it reached that stage, so when the news came they put themselves forward immediately. My mother, then 61, was the right match and she had no hesitation.

In June 2004 I had my transplant. Just before the operation I was worried that the removal of my mother's kidney might endanger her health. The hospital staff were able to tell me before I was anaesthetised that the procedure had gone well, which put my mind at ease. I was terribly sick the next day but I was able to sit in a chair. By Sunday, two days later, my mother and I were able to walk. By Tuesday my mother was home. I stayed another four days. Everyone at St Mary's hospital was efficient and supportive.

Several months after the operation I still have to visit the kidney clinic, but the need for check ups is becoming less frequent as I am doing well. My eyes have settled and I go for check ups every six months at Moorfields eye hospital. I'm still taking antirejection tablets, tablets to lower my cholesterol, and some others, but my cocktail of drugs has gone from 38 tablets a day to 13.

My doctors have asked me to consider a pancreas transplant, but I'm not yet convinced. The success rate for kidney transplantations is high—for pancreas

Additional resources for patients

Diabetes UK (www.diabetes.org.uk)—useful information from the leading British charity working for people with diabetes

American Diabetes Association (www.diabetes.org)—an easily navigable website that carries a great deal of reliable information on diabetes in English and in Spanish

Canadian Diabetes Association (www.diabetes.ca)—reliable information on diabetes in English, French, and Chinese

Diabetes Australia (Queensland) (www.daq.org.au)—easily navigable website with a forum, news, and recipes

Gluciform (www.gluciform.org)—provides links to the major European websites on diabetes

transplantations it is still only 60%, and you are also likely to spend a long time waiting for a donor.

Before all this started my partner and I were making plans to emigrate to Australia. They're back on the agenda now. However, circumstances have changed and I have split from my partner, but I am still eager to emigrate.

Lust for life

I've always tried not to let diabetes stop me from leading a full life. Only quite recently I filled in a form declaring myself "disabled." Looking back I'm sure I stored up problems for myself in my younger years, but I was carefree then, happy and enjoying life. I don't regret that, but I'm much wiser now at 34.

Research into diabetes has come on in leaps and bounds since I was diagnosed and I hope that in 20 years time people developing the condition will not have to endure the complications I have been through. I hope that in the future a cure will be found.

To help raise awareness of diabetes I often take part in media interviews for Diabetes UK, a charity working

to improve the lives of people with diabetes and for a future without diabetes.

Being diabetic has not deprived me of life's pleasures or stopped me doing anything: I eat sensibly and follow a healthy balanced diet and I have travelled and worked in Japan. These days I'm back working full time running my children's entertainment business. Because I understand my body better than anybody else, I can tell if I'm going to have a hypoglycaemic attack and I can manage it. The doctors are happy with my progress so it is just a case of getting on with things. I'm looking forward to my future.

I am going back to college in September to carry on with a counselling diploma. I have just been on holiday to Australia for a month to see my sister and nieces, which was exciting; it was the first time I had travelled since my transplantation. My health is fine—I feel like a teenager again, with lots of energy, and I'm always on the go living life to the full.

Competing interests: None declared.

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Lesson of the week

Normal skull suture variant mimicking intentional injury

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A presumed skull fracture might be a variant of a normal skull suture, especially when bilateral

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We describe the case of a 1 year old boy with no history of trauma but a parietal soft tissue swelling. Skull radiographs showed what appeared to be bilateral skull fractures.

Case report

A previously healthy 1 year old boy was brought by his mother to the accident and emergency department after she had noticed a left parietal soft tissue swelling when he awoke. There was no history of trauma, and she had not noticed the swelling before. On examination the child was alert and the swelling was non-tender with no evidence of contusion, laceration, or abrasion.

The casualty doctor detected an abnormality on the x ray of the skull that was thought to be a fracture of the left parietal bone and related to the scalp swelling. The case was discussed with the paediatrician on call, who advised that the child should be admitted for observation and an intentional injury considered.

The x rays were subsequently seen by a consultant radiologist, who noted a linear skull fracture on the left side underlying the soft tissue swelling and also a right parietal linear skull fracture with no associated soft tissue swelling (figure). As these symmetrical markings were thought to be skull fractures, and an adequate explanation could not be given by the parents, the

child was investigated for other evidence of intentional injury.

No abnormalities were seen on ophthalmological examination or skeletal survey. Computed tomography of the brain found no underlying brain injury, and there was no evidence of a skull vault fracture.

The x rays of the skull were reviewed by another consultant radiologist, who thought that the orientation and symmetrical nature of these lines would be consistent with a congenital variant known as intraparietal or subsagittal sutures.¹

The swelling settled within a few days and was thought to be consistent with an unwitnessed fall at home.

Discussion

The parietal bone ossifies from two centres, one above the other, at around the seventh week of gestation and occasionally may be divided by an anteroposterior suture. Mammalian studies indicate that the two components have different germline origins, the medial component being of neural crest origin and the lateral of mesenchymal origin.² The occipital bone ossifies from six centres, and the more complex developmental pattern may lead to numerous accessory sutures. These accessory sutures may be mistaken for fractures if not carefully assessed.³ The prevalence of this unusual condition is not documented in the literature.