

# 100 years of insulin; 50 years of diabetic life\*

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*'With insulin the stone was rolled away and diabetes became about the quality of life rather than the avoidance of death.'* Bliss M. *The Discovery of Insulin*, (utoronto press.com, Toronto, 2021.)

A juvenile-onset type 1 insulin-dependent diabetic living for 50 years only because of and in spite of injecting the purified hormone insulin, living with diabetes means existing on a battlefield for quality of life while coping with the avoidance of death.

The insidious nature of diabetes changes and threatens in a deteriorating constant state of flux. Diabetes is unpredictable and remains an insurmountable foe.

I recall vividly what still is assumed to be the beginning of my life with diabetes. In fact, it marks the first time my life was saved by using injected insulin. Assumptions and guesses become part of life for a diabetic child, adult and healthcare professional too when faced with diabetes. Despite the enormously negative impact of incorrectly made judgements by all parties for the assumed reasons behind diabetic disease progression, diabetes and its treatments remain an inexact science.

Following an interminable bout of flu, a determined set of two worried parents took a pale, thin and fainting, thirsty and lethargic 10-year-old daughter on a third repeat visit to their family doctor. Contrary to the excess of loving care and extra glasses of glucose-laden cellophane-wrapped Lucozade, sold solely in a chemist and given to build her strength, their child was still losing weight. It was 1972, and I was that child.

## This is a brief outline of my story

Over a fizzing tablet in a test tube in a kit similar to one that would later adorn, like a mini laboratory, our family bathroom windowsill for years to follow, the doctor pronounced in hushed tones in case I overheard (which I did) to my shocked parents that I was 'a diabetic'.

They were instructed to take me straight to hospital. Mustering all that 10-year-old child's polite manners I responded unasked with a flat, "No thank you. I don't want to be a diabetic." The doctor ignored me. It was not the last communication with a health professional that would be ignored, difficult, mismatched or just not great.

## First hospital admission

Torn from my family at the doors of the then modern ward 1 in East Birmingham Hospital, I was reluctantly left – frightened distressed and very unwell – in the care of my first diabetes hero. Many incredibly talented and dedicated professionals would, fortunately for me, follow in the wake of this particular male nurse.

Few would know it was that male nurse who taught me to take control, to question and understand, and to insist on involving myself in decisions about my health. Performing or directing my own care wherever possible. A shy well-behaved child, I had an innate independent streak and from a very early age my favoured phrase was 'Me do it!'

The second morning in hospital at 6 a.m. my parents were not allowed to see me straight away. They were kept waiting in the chairs at one end of the corridor while another soon-to-be-ritualistic fizzing tablet test was done in the urine-smelling sluice room. Returning to bed with a nurse I'd never met, accompanied by a larger than necessary glass and metal syringe in a blue and white enamel tray (amusingly those now used for chips in trendy bars), I was less than impressed. My parents appeared when permitted in my room, just in time to see the needle being pushed into my tightly gripped, unwilling but acquiescent arm. This syringe was daily filled up with an opaque fluid from a little dense rubber-topped bottle which was placed upside down on top of those thick needles and helped to blunt them. This equipment I was to continue to use at home. It would in a matter of a few months be responsible for removing muscle from my thin shoestring thighs by inflicting fat atrophy, huge craters of well...of just 'missing'.

It was that same male nurse who, after that horrific first experience of an insulin injection, encouraged me to take the syringe off my visibly nervous and suffering mother at 6 a.m. on my second week in hospital. My mum, learning to hurt her own child for the first time ever, looking pale and perceptibly shaking, was overtaken by her 10-year-old's hand relieving her of that needle and perform-

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\* The editors deliberately refrained from editing text because whilst some health beliefs referred to may not concur with current scientific understanding it is important for readers to hear an authentic account of the experiences and thoughts of someone who has lived in the shadow of diabetes.

ing the injection herself. It hurt a lot less. In my head was a vision of adult independence and freedom. I had already understood this was for life. Determined self-care began.

The fizzing of Clinitest colour-changing tablets and later Clinistix testing strips was the only inaccurate and imperfect guide to judge the amount of insulin required in those once-a-day insulin injections. A doctor was required to adjust those large doses. Autonomy and understanding were neither requested nor required from a child. What followed was a true rollercoaster.

Standard measures of doses of insulin given once only daily at 6 a.m. were injected into my arm and thighs; that load of insulin required a huge carbohydrate intake for me to stay upright. I did not stay conscious long in any day that first week. I have scant recollection as a result. Doses crept downwards but hypoglycaemic attacks increased.

### Discharge home

I was spewed out of hospital and found a house full of strangely holed and water-filled oranges used to try out injecting technique. This amused me, as by then I routinely administered my own insulin injections unless very unwell.

Our kitchen was ruled by a tiny weighing scale upon which sections of Nimble white sliced bread or half a semi sweet biscuit were weighed to the correct carbohydrate allowance. What I ate was dictated by 'anorexic looking' dieticians who controlled my restricted diet selected from lists of a tiny number of incorrectly named 'good' and 'bad' foods. 'Diets' were turned rapidly on their heads by new fads and theories. A straitjacket nowadays alien to the majority of young people with diabetes, adjusting flexible treatment to more accurately responsive data to fit their socially acceptable lives.

Attaining level blood sugars despite concerted efforts and adherence remained throughout the years almost ethereal, and sadly frequently short-lived, events. Largely unsupported other than through a once-weekly hospital clinic visit with interminable waits, always on Thursdays so I missed my clubs after school, my parents juggled full-time work and the busy demands of family life with four children just for three minutes each week with a consultant or registrar. Difficult to answer questions about why control was so elusive for us to achieve were met with a dismissive, 'We will see you again next week.'

Transferring from primary to secondary school after one year of diabetes, I was the only type 1 diabetic at my secondary school of 1,000 pupils and staff. There were only three diagnosed type 1 diabetics on insulin when I left in 1979.

Soon came disposable needles and then disposable syringes, then combinations of attached needle and syringe. In six months, fat atrophy improved until in 1979 the government decided that those syringes and needles 'if preferred' should now be purchased by people with diabetes. Prescriptions from the diabetic clinic were grudgingly provided to cater for my need for disposable needles. Gladly I let go of the glass and metal syringe; no longer did I need to spend time sterilising syringes and blunt metal-based needles in stinking methylated spirits after boiling them in an enamel saucepan.

Tiny square swabs made stinging red rashes a norm of course and still the peaks and deep troughs remained. Insulin now sat on a shelf in the fridge door in a repurposed Tupperware box. Joined by Lente, a long-acting insulin, two injections daily began. A steady baseline was the aim, and severe hypos kicked back in as doses and evening snacks were adjusted to suit.

Synthetic insulins arrived, the holy grail at the time in the name of added control and avoiding complications. For me and many others this caused or coincided with a loss of symptoms of hypoglycaemic attacks. Another heroic figure of a most uniquely knowledgeable consultant began the use of an old-fashioned bovine-derived insulin, saving my life and facilitating independent living.

### Complications

From those early and continually erratic blood sugars complications of diabetes loomed. They duly arrived in spite of consistent monitoring and continual hospital care. Diabetic retinopathy was diagnosed when I was aged 21, a few weeks into a teacher training year.

Due in part to the severe overuse of very early laser treatment by inexperienced hands on such a relatively young eye I developed burning and a retinal detachment. Obtaining a consultation urgently at Moorfields eye hospital I underwent a vitrectomy and reattachment. Again dedicated staff and technological advances, saved and continue to preserve partial sight in a damaged right eye after a subretinal blister just 'happened'.

I was due to start teaching later that year. I did so by adapting, as diabetes had amply taught me to do, to the situation and this proved key to success. Blood sugar testing methods improved; control and dietary freedom advanced together. Things had begun to take on a feeling of rapid advancement. Since I was included in early trials of a 'James Bond' kit containing a stainless steel injection pen hiding a needle and insulin cartridge in a suave black case and a slim black designer digital blood test pen, I enjoyed flexible injections and meals. A stylish forerunner to the plastic injection pens used today.

Diabetes produces many paradoxes. Since insulin has been used as a lifesaving therapy rather than leading to a that elusive 'cure', its use has resulted in an explosion in the number of individuals suffering long-term complications. Any list of 'so called' diabetic complications covers most medical specialities. After 50 years I am able to tick off involvement in too many hospital departments.

Early childhood and continuing battles for 'control' coupled with many adverse reactions to synthetic insulin, possibly too that bovine-derived insulin, have all taken their toll on my physiological makeup. As has an erratic blood pressure. Is this known as insulin sensitivity? It is more correctly termed all part of suffering from diabetes. Auto-immune disease continues to attack multiple areas of my ailing systems, insidiously silent and eventually fatal.

After 27 years of insulin injecting, I believe that living a packed and high quality adventurous interdependent life was encouraged by having to live with diabetes and realising the insecurity of life. Whilst working and living in the Caribbean and travelling globally, the unpredicted rapid onset of what is presumed, but not to date



### Key messages

- A life of difficulty and disability caused by type 1 diabetes which developed 50 years ago at the age of 10 has been treated with a functioning pancreatic and kidney transplant
- A life with type 1 diabetes can be demanding but with resilience and good care it can be lived to the full
- The keystone of effective diabetes care is shared knowledge and good communication with supportive professionals willing to listen and take account of each person's individual concerns and health beliefs

fully proven, to be diabetes-induced end-stage kidney failure was diagnosed in a routine hospital blood test.

#### **Transplants: transformative treatment**

Chronic kidney disease and end-stage kidney failure has now

been treated for 23 eventful years, which have included dialysis and a stroke, heart surgery, vascular issues and bone disease. I received a functioning kidney and pancreas transplant in 2000, and this has transformed my diabetes and my life.

Living now for 23 years with diabetes induced kidney failure has meant 23 years of the worst of times and the best of times. A story too long to relate here. The worsening side-effects of diabetic damage, some of which are listed, have to an extent halted in their downward destructive spirals but have been replaced by those produced by 21 years of the immunosuppressive therapy needed to preserve a working double transplant. Freedom from that purified alien insulin has been miraculous although an oversensitive immune system persists.

Gazing into the future now, as Albert Camus states in an apt but roughly translated quotation: *"We must 'get on' in an attitude of constant doubt, with provisional commitment only, and a healthy questioning of authority."*

With heartfelt thanks to all who got me here, particularly my family and organ donor who still strive to keep me well.

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