Insulin – the sharp end of the needle: experiences of 48 years with diabetes

HUW ALBAN DAVIES

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Introduction
One hundred years ago the first human life was saved by the injection of insulin. My story is not about the remarkable doctors and scientists who developed this life-giving treatment and made insulin injections possible. I am going to tell you about the 14-year-old boy, Leonard Thompson, who received that first injection and about one of those who came after him. Leonard had been kept alive for three years after developing diabetes by being restricted to a diet of grapefruit, meat and thrice-boiled vegetables which amounted to as little as 450 calories a day. On admission to Toronto General Hospital he was desperately unwell, with his hair falling out, his abdomen bloated and his 1.8m frame cadaveric at 29kg. His body was producing ketones from fat metabolism and he was nearing coma. Leonard’s parents, Harry and Florence, agreed to experimental treatment with an extract of foetal calves’ pancreas. The first injection produced little response and he developed an allergic reaction. However, the pancreatic extract was purified and this proved effective, with his blood sugar showing a steady reduction from a very high level. Leonard’s condition stabilised and he was able to leave hospital and continue with school and, later, to earn his living (Figure 1a). The dramatic impact of purified pancreatic extract on the children treated is illustrated by the examples shown in Figure 1b and 1c.

Personal experience
My own story covers nearly 50 of the 100 years since that first injection, and I will give an idea of what it has been like to have had diabetes during that time. My symptoms developed in Zululand during my elective period as a medical student in 1974, and diabetes came to light a few months later when I was asked to provide a urine specimen for the staff medical at University College Hospital, London (UCH). Such is the power of the mind to ignore unwelcome facts that only when I had the specimen bottle in my hand did I realise that I had diabetes and that I had known that I had had it for some time although the knowledge was suppressed until it was

Address for correspondence: Dr Huw Alban Davies
Chairman, Diabetes Care Trust, (ABCD) Ltd
Otford, Sevenoaks, TN14 5PH, UK
E-mail: albandavies@me.com
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Figure 1. a. Leonard Thompson, who received the first injection of insulin on 11th January 1922 when he was 14 years old. This photo was taken of him in later life. b&c Two children with T1DM in early 1922 before and after insulin.
forced on me. This was despite the fact that I had been revising for medical finals and had diligently studied the pages on diabetes.

With the diagnosis confirmed I was admitted to a ward. The consultant on the team responsible for me was not at all understanding about the needs of a person who has developed a condition that will affect their life profoundly, although not necessarily cut it short. Fortunately, his second in command, the senior registrar, had a different idea about how to communicate with someone who has to come to terms with an event that significantly alters his life and who needs to be told what life with diabetes will be like. He took the time to tell me that I would be able to do everything, or almost everything, that I wanted to do and that I needed to absorb a good deal of knowledge. I wouldn’t remember it all at first because I was in a state of shock but that was understood and it would be repeated. This doctor showed a great deal of empathy and from the start I felt that someone had an understanding of my own particular needs and didn’t think ‘well, he’s a doctor, so he’ll know what it’s all about’.

This is the first theme I want to address: what people with diabetes want from those who look after them. I believe that they want to feel that they are on the ‘inside track’ and that the advice that they are given applies particularly to them and to their own situation. The great changes that are affecting the lives of people with T1DM at the present are technological but I would argue that the movement that happened in the 1980s, towards patient-centred care, had an equal if not greater effect. To explain the relationship a person with diabetes wants with his carer, I would look to my own experience as a sailor. You are in command as the helmsman, but you want an expert navigator whispering in your ear to advise the course and to warn of dangers ahead. I have had a number of expert navigators, and I am grateful to all of them.

The next theme I would like to take up is the balance between food and insulin. When I first developed diabetes this was resolved in a straightforward and authoritarian way with a diet sheet and a single injection daily of lente insulin. There were six prescribed meals and snacks, which needed to be closely followed in order to stay out of trouble from the insulin which was active for the whole 24 hours. The UCH diet was derived from RD Lawrence’s weighed diabetic diet with black and red lines (or rations) which was introduced in 1925. Since then it had been successively modified so that the black (weighed) portions became 10g exchanges of carbohydrate. The 10g exchanges could be interchanged with others, which were found on a different page of the UCH ‘Notes for Diabetics’ (Figure 2). However, my first diet would have been a lot more generous than the 150g diet shown here because of the need to gain weight as a newly diagnosed person with diabetes. Ten gram exchanges were the building blocks from which diets were constructed and I look back in awe to those rigid early days of weighing and strict carbohydrate counting using the kitchen scales (Figure 3). But I am also grateful for the discipline that came with it, which sets one up well for a life with diabetes. It is certainly true that in the early days the food that was staple for a person with diabetes was unexciting, as shown by a selection of meals given to patients in hospital in the 1980s (Figure 4). The need to count carbohydrate exchanges and if necessary to weigh foods was enormously eased when commercial food packaging began to print the carbohydrate and energy contents of foods. This also allowed a far greater variety of food choices because for many of the things that it was tempting to eat there was no information available from other sources. Packaging gave information about more sophisticated options like puddings and ready-made meals.

No talk about diabetes in those early days would be complete without showing the instrument of torture – a glass syringe that
was cleaned with alcohol (Figure 5). The large-bore, non-disposable needle was painful and it was a relief that you only had to inject insulin once a day. Later on came twice-daily regimens with mixed soluble and isophane insulins. With the new regimen insulin activity was pre-ordained 12, rather than 24, hours ahead and with it came a different approach to diet. The proportions of fast- and longer-acting insulins could be varied and it was the job of the dietitian to fill in the area under the curve of the insulin action profile with meals and snacks so that the exchanges added up to an amount that was appropriate for insulin activity. This gave a more flexible choice of diet options but it still seemed that it was the area under the curve, rather than the individual, that was in control of their diabetes. A big breakthrough came in 1985 with the Novopen. The Novopen was an absolute wonder with its modern, slick, state-of-the-art, dial-up precision (Figure 6). Injections could be made in company, into the calf, without any fuss. It is hard to over-emphasize what a difference it made to our lives, getting away from the bother and stigma of ampoules and syringes. The Novopen was revolutionary, rather than incremental, one of the greatest improvements in my life with diabetes.

The evolution of testing systems has been a journey from exploring the past to being able to foretell the future. When I started, chemistry experiments were conducted using Benedict’s copper reagent, which changes colour in urine from blue to yellow in the presence of reducing sugars: 2 drops of urine and 10 drops of water in a test tube with a tablet of reagent (Figure 7). The problem with urine tests was that the contents of your bladder give an indication of what your blood sugar had been in the variable time since you last urinated, making them of limited use for future guidance. In retrospect I am sure that urine tests were more useful to diabetes doctors rather than to their patients because, flawed as the tests were, they gave some basis for giving advice which was, after all, the object of the consultation. At this time, to keep myself in reasonable shape I tended to bounce off hypos because my hypo awareness was so good. Hypos have been a constant theme in my life, as they are with everyone who takes insulin. For the first couple of decades my sensitivity was exquisite, and I could hold my fingers up to look for fine trembling before any other symptoms developed. As years went by the symptoms blunted but I have always been able to spot my hypos. At present an awareness of cognitive misfiring and a feeling of failure or doom are sure signs of a low blood sugar.

Self-monitored blood glucose systems were introduced in the early 1980s, part of the enormous technological revolution that changed the experience of having diabetes from that time on. These systems were an enormous advance and they made possible the multiple injection regimens which were facilitated by the Novopen. With the ability to monitor blood sugar in real time the amount of carbohydrate eaten could be balanced against a calcu-
lated dose of insulin. I worked out for myself the ratio of insulin that was required for an amount of carbohydrate, as well as the units of insulin needed to correct a high blood glucose, long before formal education came along. The principles of this new approach which featured dose adjustment for normal eating are absolutely liberating and they put everyone who follows them on the inside track. The introduction of DAFNE courses and their widespread availability means that all people with T1DM are able to liberate themselves from fixed portions and predictable meals.

The situation today, with flash monitoring systems, has advanced the ability to match insulin to the body’s needs to a different league altogether. This is demonstrated by the sugar graph on my iPhone Libre app (Figure 8). The trace is obtained instantly, without trauma, and there is no limit to the number of times I can do it. This makes it possible to make any number of adjustments with corrective doses and interruptions of insulin delivery. Importantly, it shows a trend line which indicates what my sugar is likely to be some time into the future, and the out-of-range alert enables me to take action when my attention is otherwise distracted. This is an enormous advantage which gives a great feeling of control and has given me a considerable improvement in my HbA1c without extra effort.

The introduction of insulin pumps in the early 2000s was an important advance in the treatment of diabetes but my own relationship with pumps did not get off to a good start. I was an early adopter but didn’t get on with my first pump, mainly because I found it a bit of an intrusion, particularly in bed at night. However, I came back to pumps and I am now an enthusiastic user. The freedom from injections, the capacity to stop basal insulin delivery and the ability to deliver dose adjustments at will and with no fuss are all a boon. The ability to adjust basal levels during the night helps to avoid hypoglycaemia when unguarded. Pumps plus – those with artificial pancreas features are the future and I am looking forward to having one.

Credit where it is due
Before finishing I have to acknowledge and give credit to my partner in all this, good times and bad. And there have been some bad times, such as the time when I needed help with a hypo fit in the middle of the night. My wife, Jenny, has been the helmsman’s first mate and she knows as much about my diabetes as I do and has advised, reminded and at times taken over the steering when the helmsman has gone ‘off duty’. Her instinctive awareness of my developing hypos would more than equal a trained hypo hound, I am quite sure.

A last word about Leonard Thompson, who we celebrate as the pioneer for all people with T1DM. Leonard lived for 13 years after being saved by insulin. He worked as a clerk for a drug company and died of pneumonia, no doubt a complication of poorly controlled diabetes. After Leonard’s death the Beach Metro, a newspaper from where the family lived, reported that Dr Banting asked a family friend if the boy had had any fun.

“Yes, he had some fun. He used to get drunk nearly every weekend.”

“Well, I’m glad he had some fun,” commented Banting

And who are we to disagree? Leonard was the same as his peers and what a person with diabetes asks is to live a life that is no different from those who do not have diabetes.

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