From boiled up needles to insulin pumps: **a trip through time with diabetes**


Dr Tony O’Sullivan

Having lived with diabetes for 40 years, **Dr Tony O’Sullivan** has experienced great strides forward in the management of his condition and has been an active advocate for others living with diabetes, both with Diabetes Ireland and internationally

1970s
Diagnosed
at age 14

I’m coming up to 40 years living with Type 1 diabetes, and I’m expecting a medal! I feel like a survivor, not only of the condition but of the treatment, and I am certainly lucky to have stayed reasonably intact until now. I’m in my early 50s, and if you believe as I do that life begins at 70, then I’ve got to keep working at it for many years to come.

I was diagnosed in the 1970s, when I was 14. The usual story, peeing all the time and wasting away. I was in a boarding school, so why should anyone have noticed? In hospital my diabetes education consisted of being given a medical text in which I read “people with diabetes do not usually survive beyond the age of 40”(I don’t think Type 2 diabetes existed at all back then).

My treatment was a mixture of insulin extracted from cow pancreas, given using a glass syringe which I kept in methylated spirits. I had to boil up the needle once a week and could start with a new one every two months or so. Testing was a tablet dropped into a urine sample, followed by a volcanic reaction which always came out a disappointing yellow (high glucose). In my boarding school going to the loo to do the test meant running into the smokers, so diabetes started me smoking as well (I’ve given up since).

I never had a problem about injecting in public, even though the process was quite long. I opened my travel pack, took out my syringe and squirted meths out of it until the alcohol dried out; then I shook my insulin bottles and carefully drew it all up before injecting. I remember doing this on a ferry on the Irish Sea once, and when I looked up after injecting it seemed as if the whole ship was staring, I think they thought I was a teenage drug addict.

Progress finally started to impact on my life: first came disposable needles, then a disposable insulin syringe with needle just like we have now. I found it hard to throw them away at first. Before leaving school I was given an actual glucose meter. It was a little bit fiddly, but great. The only problem was, because I was on a mixture, I was never told

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how to adjust my insulin. The finger pricker was designed by a specialist in the art of torture – a big swinging guillotine which whacked a needle deep into my finger, drawing great quantities of blood – maybe that’s why I did so little testing in college.

In 1980, I went to study medicine in Dublin, and discovered there was life beyond diabetes. I attended the Mater Diabetes Clinic where we all sat around making up some blood results, passing around different coloured pens and even blood-staining the pages to add realism. Of course I was kidding nobody but myself. However, at this clinic I came across the most significant technological leap forward in all diabetes care – the diabetes nurse. In my case the wonderful Deirdre Cregan, who gave me the first sense of hope and optimism in my struggle with diabetes.

Being a doctor with diabetes doesn’t make you a better doctor, nor any better at managing diabetes, but it has its moments. On my first day as a medical student on the wards, we were introduced to a patient, a young man who told us about his symptoms of thirst and going to the loo a lot. The tutor asked if any of us had an idea what might be the problem with this man – needless to say I was top of the class that day.

My training hospital was the Adelaide, where I met Prof Gerald Tomkin, who was of course one of the foremost diabetes specialists in Ireland, and still is. He brought the artificial pancreas machine to Ireland in 1987, and while it was huge and cumbersome, it gave us all some optimism about the future. I spoke at some Diabetes Federation events around the country about the machine, and the positive reaction to this technology had a big impact on me, driving me into involvement with the Diabetes Federation of Ireland, and eventually with the International Diabetes Federation.

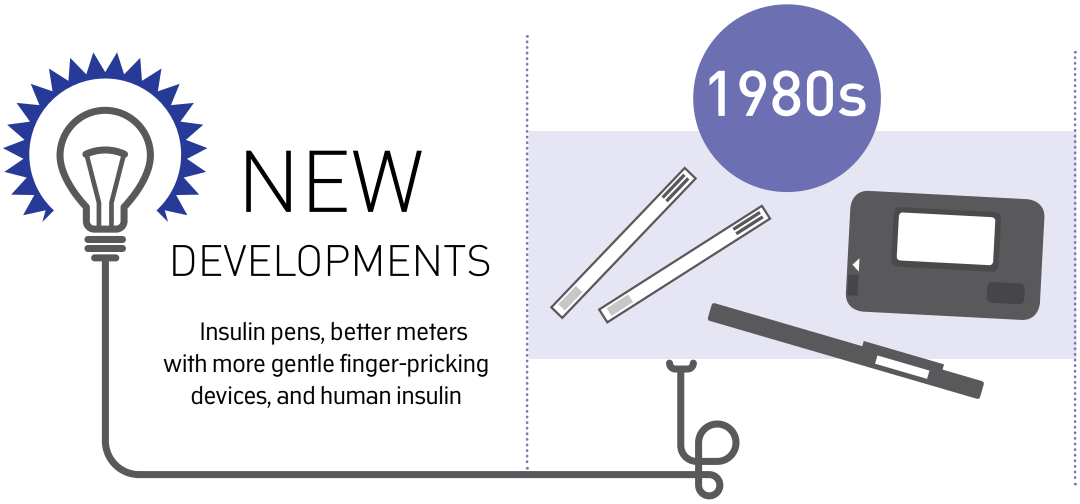
New developments came thick and fast in the 1980s: insulin pens, better meters with more gentle finger-pricking devices, and human insulin. I remember breathing several sighs of relief as these innovations arrived. One of the best was the MediSense meter which used an electronic strip for the first time. It was lightning fast and I thought it looked so cool.

I moved to Cambridge in 1988 to train as a GP. Caitriona and I were married in 1990 and the first of our three children was born in 1992. We moved back to West Cork in 1993 and to Dublin in 1994. I met Prof Tomkin again then and at his suggestion I joined the committee of the Diabetes Federation of Ireland, starting a 13-year involvement with diabetes politics.

I was always impressed with the energy of people with diabetes and their efforts to support one another. Over the following years I realised the true extent of this, including meeting people with a lifelong involvement in volunteering.

It is great to see Diabetes Ireland continuing to flourish and develop new services.

Meanwhile, the diabetes clock kept ticking. Analogue insulins arrived, adding further improvement to control in Type 1. In 1999, I attended the American Diabetes Association medical conference. I met many people with



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Type 1 there, all of whom were using insulin pumps. When asked if they would return to injections, they all said they would not. I came home and set about starting pump therapy, and was using a pump myself by June 2000.

My glucose levels were suddenly fantastic, a sign of the greater efficiency of fast-acting insulin, but I also started gaining weight, a downside of this efficiency. I had to start being more careful about food for the first time, but the flexibility of the pump, the lower overall insulin dose, the ability to use a higher basal rate in the early morning or to take a 0.5-unit dose with a tiny snack, all make pumping the optimum way to use insulin.

During this time I also became involved in the International Diabetes Federation European Region. This is a group of diabetes associations from 60 countries including the huge area of Eastern Europe and Central Asia. This involved a huge amount of travel, which eventually I had to give up as I was also running a single-handed general practice at the time.

Meanwhile, I was lucky to visit most European countries as well as Kazakhstan, Belarus and others. We set up an association development course and hired a development officer to support fledgling associations, which were often run from somebody’s kitchen.

We also spent a lot of time working with the European Parliament to establish diabetes as a health priority. We had a lot of support from the Irish EU Presidency and from Irish MEPs.

The IDF European Annual Congress was held in Dublin to coincide with the 40th Anniversary of Diabetes Ireland. The event was opened by President Mary McAleese, who offered a warm Irish welcome to the diverse group of delegates. Our eastern colleagues were especially impressed to be able to chat with the President personally. As her sister was working in Belarus as a nurse at the time, President McAleese had a genuine understanding of their particular difficulties.

In 2007, I had to end my involvement with IDF due to work pressures. I continued to push for greater GP involvement in diabetes care, and ran a course for some years with the Irish College of General Practitioners, helping GPs and practice nurses to keep up to date with the rapidly changing field of Type 2 diabetes.

Recently, the Diabetes Cycle of Care has commenced, where GPs manage uncomplicated Type 2 diabetes in their surgeries. This is good for everyone with diabetes, because the expensive resource of hospital diabetes care will now be more accessible for people with complex Type 2 diabetes, and those with Type 1 diabetes who need that expertise.

Over the past few years I’ve continued trying to improve my diabetes numbers, which have never been fantastic. I’ve learned about carb counting, obtained a sensor pump, used ratios, I’ve even tried healthy eating!

My A1c is still stuck around 60 (about 7.7 in old numbers – everyone’s using the new numbers now, right?). This year, after 40 years of diabetes, I attended a pump DAFNE course in Loughlinstown, and still learned a lot of new stuff from the experts there – both the professionals and the other people with diabetes. Like me, they struggle through each day and have to be good about forgiving themselves – an important skill in living with diabetes.

The sensor pump is an annoying friend who keeps telling you what you’re doing wrong. I was over-reacting to it, and hence swinging from highs to lows several times a day. After the course I’ve backed off a bit and the swings have improved. I’m also using the wizard more, and temporary basals (steady trickle of insulin), which are brilliant when exercising. So I think I’ll be around for a while longer.

Of course, no diabetes story would be complete without acknowledging the support of friends and colleagues, but especially my family – from my wife Caitriona who keeps a steady supply of orange juice cartons everywhere, to my kids Aisling, Maeve and Niall, who chased me around with a glucagon dart when I delusionally tried to go to work at 3am. They share the life and are affected by diabetes as much as I am.

What about the future? As with Ireland, the best days for diabetes are still ahead. I’ve seen so many incredible changes that have liberated people with Type 1 and Type 2, and if anything the pace of change is accelerating, not slowing down.

There are new insulins available this year, and a new rapid-acting one to come. The FreeStyle Libre wearable meter will be a real game-changer for Type 1 when it gets GMS approval, hopefully soon.

That is why, when I meet a young person with Type 1 diabetes, I am very optimistic that they will be able to enjoy a full life, not restricted by inflexible treatments as it once was.

We have an incredible range of resources right now, to help us stay in good condition while we wait for a virtual or actual cure. We just have to use them. Remember, patience isn’t just the wait, it’s how we look after ourselves on the way.

Some highlights of the period during which I was involved with Diabetes Ireland included:

Appointments of Kieran O’Leary and Anna Clarke

Establishment of regional offices in Cork and Sligo

Agreement with the HSE to fund diabetes education

The partnership with Medmedia as publishers of *Identity* now *Diabetes Ireland* of course