



Living with Diabetes

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Before the turn of the last century, Type 1 diabetes where you ran out of insulin altogether would be entirely fatal. And the first real breakthrough in understanding diabetes was the understanding that we all need insulin for managing our food stores in the body.

Insulin was discovered really at the beginning of the 20th Century, but nobody could get hold of it properly until it was isolated in Canada by Banting and Best in 1922. And from that moment onwards, with the availability of insulin, originally from animal sources, Type 1 diabetes changed from being something which was universally fatal to something that could essentially be treated. Now, it was rapidly realised that although if you can give people insulin you keep them alive, nevertheless, there seemed to be some sort of sting in the tail. And the sting in the tail was that unless you got blood sugars reasonably under control for long periods of time, you started to get other things going wrong.

You are much more likely then to get heart attacks, or get renal problems, or that your nerves don't work properly, and so you get peripheral neuropathy. Or, the blood supply to your feet doesn't work very well, so you get complications with foot ulcers. That the blood supply to your eyes doesn't work very well, so that you can then potentially go blind. So after the initial success of diabetes euphoria of thinking 'gosh we now know how to treat this', there then comes a point where you start to say 'well we're not quite so sure about that'.

Now, what then started to emerge is that as well as Type 1 diabetes, the Type 2 diabetes, which was relating to people who got diabetes later in life, which was not so serious and wasn't life threatening in quite the same way, but was certainly many times more common than the Type 1 diabetes.

Type 2 diabetes, turned out to be also rather a dangerous disease. Because again, if it wasn't well treated, then you've got all of the problems that I've just mentioned.

So unlike Type 1 diabetes, where your Beta cells have just wiped out, Type 2 diabetes starts rather insidiously slowly. So your blood sugar starts to go up, because your Beta cells don't produce quite as much insulin as they might otherwise do. So the blood sugar starts to rise. If it's not detected early, then you get all of the problems of the complications of diabetes, simply because your blood sugar is going up. You may not get symptoms. And so quite a lot of people find that when they're diagnosed with Type 2 diabetes, they've already got problems. Indeed the big study, the United Kingdom Diabetes Prospective Study, showed that 50% of people at the time of diagnosis of Type 2 diabetes, had already gone some detectable change in tissue complications.

Patients today are treated very differently from the way that they would have been treated even fifty years ago. Today, we are interested in making sure that risks for complications of diabetes are reduced. So the way we treat that now, is to say 'can we get your blood sugar well under control?' 'Can we get your blood pressure well under control?' 'Can we lower your blood fats?' And 'Can we get you to stop smoking?' If we can do all of those things, then you can have diabetes and no complications.

The scientific method really started many hundreds of years ago, when people started to make systematic observations that said 'Okay, the world works like this.' People like Leonardo da Vinci for instance, understanding what the anatomy of the human body was like.

Once you understand the anatomy of the human body, you can then start to say what's going wrong with, say, injuries. Once you start to understand the physiology, which is the mechanisms of the way that metabolism works, then you can start to interfere with those and say 'if we know what goes wrong, we can put it right'. Now the scientific method is to say 'well you need to do more than one observation, because you can't be sure that one observation will be enough'. So how many observations do you need to be sure that what you're looking at is a real phenomenon? And then how many observations do you need to say, well if you've got this going on, like a collection of people with a high blood pressure, how many people do you need to treat with an agent to be sure that it's reducing their blood pressure? And that's the statistical basis of longitudinal randomised controlled trials, that that's how you set this up. Once you've done that, you can be pretty sure that, on average, what you are going to do, is going to have an effect. That's called 'evidence based medicine'. I know that if I give you this substance, then on balance, you are going to have less of this complication. If I give you a statin if your cholesterol is high, I know on balance I can reduce the chances of you having a heart attack by more than fifty percent. That's what the evidence shows.

The Biomedical model has achieved a huge success in the 20th century and into the 21st Century. Understanding pathio-physiological processes means that we can actually direct therapy at precisely the mechanisms that we want. So for instance, if you look at statin therapy, everyone knows about statins reducing cholesterol. Statins are HMG CoA Reductase Inhibitors. That means that we know exactly where they work. We know how that interferes with cholesterol production in your body. We know that those are likely to work. You try them out in animal models, you then try them in man, you then try them in big trials. They reduce cholesterol by 25%, your heart disease drops fantastically in the trials, you can demonstrate with clear blue water between the two that you're much better off on the statin than not.

Similarly the Biomedical model has produced insulin, which keeps people alive. It's produced antibiotics. It's produced blood pressure lowering tablets. It's produced new tablets that affect Beta cell function. It's managed to dissect out a whole collection of pathological pathways that we can actually address. The outcomes are spectacular, compared with what they were years ago. There isn't anyone in the UK today that hasn't probably benefited from the Biophysical model.

Some people criticise the Biomedical model on the basis of saying that there's a hierarchy, so that there are professors of medicine at the top who storm around with a stethoscope and tell everybody what to do. And then underneath them are the minions and servants of the nurses and the health care professionals who are desperately trying to do the caring, pushed around by the Biomedical autocrats. This is a cartoon of the reality of health care today.

The reality is that if I'm putting people on to insulin, despite the fact that I'm a professor of diabetes, I know that I can't manage to do that. I liaise carefully with my diabetes specialist nurses, who are the people who are much more capable of transferring you on to insulin treatment than I am.

Similarly, I might spot that you are grossly over weight, in which case you had better go and see my dietician. But my dietician knows a great deal more about food and food values and carbohydrate counting and a whole collection of things. That I really would fail an exam if I was sat down and said 'what do you know about this?'

There's a real need to be sensitive to cultural differences. One of the things that you can say to people who have been brought up in a pop culture and have gone off clubbing in their

teenage years, and then reached thirty five and decided to retire to the sofa and put on weight, is that you need to take more exercise. Those are a collection of people who could perfectly well join a gym and get a grip and stop drinking too much beer. However, if you take somebody else who's got say Type 2 diabetes, who's middle aged from South Asia, speaking English as a second language, the idea that this lady is going to get into a gym or start going jogging round the block, in a South Asian community, is just dream on. Because it's not going to happen.

Not everybody can do everything. And so what you do with people who can't do everything, is to say 'well let's concentrate on the things that you can do'. South Asian ladies for instance are very unlikely to be smoking. Hoorah. That's going to be a bonus, and so that's one risk that we don't need to start thinking about. What can you do about diet? Well you can do something about diet, but you need someone who's culturally sensitive to the ways in which you might change your diet. Changing a south Asian diet is going to be very different from changing a Caucasian diet from someone who's a three generation East Ender.

Beyond culture, is the whole issue about how people psychologically cope with disease. And that goes from people who are in complete denial about the fact that they've got anything wrong with them at all, right the way through to people who, instead of managing their diabetes in order to live their lives, live their lives in order to manage diabetes. Now that actually is a major catastrophe. And you can just imagine that if you spend every waking moment managing your diabetes, you've got no time for family and friends and anything else. And every time you go out, people think I wish you weren't here, because you're fooling around saying 'Oh I can't eat this little bit of fat. And 'I've got to have this much carbohydrate, I need to weigh everything.' So you can go one way or the other.

Teenagers with Type 1 diabetes for instance are often in entirely the opposite direction of saying 'actually I'm going to carry on with my life regardless of the fact that I've got diabetes'. So they don't even bother to spend ten minutes a day, which they need to, thinking about their diabetes. And so their diabetes just goes completely haywire. So that by the time that they're 25, then there's a huge raft of problems associated with the complications, because over those critical teenage years, they haven't concentrated on glycaemic control, blood pressure control, all of those things. And you wouldn't expect teenagers to be able to do that. So teenagers need a very different raft of support. You have to be sensitive to people's psychological needs. to what stage of development they are, to what options they've got in their life.

Illness and disease is something that comes out of your mind as well as you're body. And that's why the word 'disease' is about a description of you being ill at ease with one thing or another. And if you take diabetes as an exemplar of this, there are people who are more diseased by diabetes than others. Some people manage just to say, okay that's something I need to spend three minutes a day on, and I can survive that, no problem, it doesn't affect my life. Other people who are pole-axed by having the diagnosis of diabetes.

Diabetes is a multi dimensional disease. And when I say that we're treating many things, it does mean literally that you are treating many things. And therefore you're needing to take many tablets and many medications. And this seems sometimes completely counter intuitive. So you turn up with a little bit of sugar in your urine to your doctor, and then half an hour later he's told you that he wants to give you this tablet to control your blood lipids. He wants to give you this tablet to control your blood sugar. He's giving you two tablets to control your blood pressure. He's giving you aspirin because you're of such and such an age. He's giving you a diet. He's told you to do this exercise. And you just think 'well this is ridiculous, it can't be true. Half an hour ago, I was feeling perfectly okay, except someone put a dipstick in my urine, and now I seem to be on half a dozen tablets. And so people can get really turned off with this.

People often say 'well look, if I start taking these tablets, am I taking them for the rest of my life?' The answer is 'well you don't have to take them for the rest of your life, but as long as you take them, you're more protected than if you didn't take them.'

Patients sometimes blame themselves for deterioration in their health. They say 'Look I've tried everything, and yet my weight goes up. I've done everything that you've suggested, and yet my blood sugar is higher than it used to be, what's going on?' And there is a real necessity for health care professionals to be engaging with patients, to say 'actually what's going on is not simply that you're not following advice'. One of the problems about weight increase is that most of us increase weight, regardless of what we do, as time goes on. This is a problem of the human condition. In Type 2 diabetes, the blood sugar is likely to go up because Beta cells once they start to fail, continue to fail. So that on average, people are needing to be on insulin after about six years after diagnosis of Type 2 diabetes.

Now lots of people self flagellate and say 'oh goodness, it's because I haven't followed the diet, and if only I'd have been careful and hadn't had those biscuits then I wouldn't be on insulin now'. And that's not true. So we need to encourage people to say 'look lifestyle is important', but actually some of the things in life you cannot change. You can't change the remorseless rolling on of time.

Patients' experiences are very different for diabetes these days compared with forty years ago. There used to be a very much dictated form of how you would look after your diabetes. In other words the whole business of 'me doctor, you patient, I'll tell you what to do, you get on and do it'. And this rather sort of paternalistic view, it's not necessarily totally bad and some patients have done extremely well on the basis of saying 'well actually I am a patient and I do need to be told what to do. Tell me what to do, and I'll do it'. But it doesn't gel well with modern ways of doctor patient relationships. And there's a whole collection of frightfully politically correct words like 'empowerment' and so on. Which says 'no, you as the patient need to be looking after your diabetes, and I as a physician will simply be advising you, or maybe even just listening to what it is that you're doing and not giving you much advice'.

Now there is absolutely no doubt that if you've got diabetes you have to take responsibility for your own care. Because if you come to see me, you might see me occasionally, but you certainly won't be seeing me every day. And diabetes is something you need to be thinking about every day. You need to be thinking about what are you going to do about your diet? What are you going to do about your exercise? What are you going to do about taking your medications? Are you going to monitor your own blood sugar? Those are sort of things that actually need to take a bit of your life every day. But, generally speaking you find that the attitudes of the health care professionals, they include diabetes specialists, nurses, dieticians, podiatrists, as well as the doctors and clinic nurses, is all very much more in the direction of saying 'well look, we can give you advice.' 'We will give you any advice that you want'. 'We will help you in your daily life. But ultimately it's up to you to do this for yourself'.

There's much more information that patients have available to them. The use of for instance the internet, people feeling that they've got a right to know about their medical conditions, means that much more numeric information is conveyed to patients. People are much more likely to know what their blood pressure is. Much more likely to know what their blood lipid levels are. Much more likely to be taking a personal interest in their own blood sugar.

I think that the more numerical patients are, the better. I don't think it's essential. But I now try and hand out patients lists of saying 'Look, this is your haemoglobin A1C, which is a measure of your blood sugar, this is your blood pressure. This what we're giving you. These are the trends with time. This is what we're trying to achieve. This is what you're weight's been doing'. So that people can then start going home and saying 'I can see that my weight is doing this and this and this. And that my blood pressure is doing this, and maybe I should do this'. And actually that sort of information feedback is much better than simply going along to a doctor, and him saying 'I'm going to increase your insulin'.

