44. Ian Vokins

(1) Tell me about your background.

Well, I was born in 1942, and I lived for the first few years in a small village in Berkshire, called Steventon. When I was five, we moved to the next village across, called Milton, and my... I spent my early years there, until I started work when I was fifteen. My father, originally, was a gardener, before I was born, and then he became a chauffeur and a driver for the RAF, as a civilian, through the war, actually, then. And my mother was in service before I was born, and then she worked for a petroleum company - Esso. And I have a brother, who's six years younger than me. Had a similar upbringing, and he developed diabetes when he was in his late twenties.

Was there any history of diabetes in your family?

No, not at all. Both sides of the family were investigated and we couldn't find any trace in either side.

Tell me about your early years, before you were diagnosed with diabetes.

Well, I had a fairly normal upbringing. We didn't have much money - it was just after the war. I can remember going to the shops with my mother, and getting the coupon book out and - the ration book rather - and having the bits cut out to buy various things. I hated school with a vengeance - all three parts of school: the primary school and the junior school and the secondary modern school. I was bullied by pupils right the way through, for some reason, best known to them. And I think it was because I was tall and I was a good target, because I wa'n't very strong, ever, so... And never seemed to get on with the teachers that well either, so I struggled at school. But I was a - what they call - a late starter; I started learning after I left school, and I left school at fifteen.

(2) You say you weren't very well off. Did you have enough to eat?

Yes, we always ate very well. My mother was an exceptionally good cook, and we always managed to get, you know, good food, because that was the most important thing. Most people didn't have a lot of money in those days, and everything got repaired rather than throw it away and buy new ones, like you do today. Then we all learnt - and I learnt - to repair things from my father, so that was the sort of way things were then.

What sort of things did you repair?

Everything. Whatever broke, we wouldn't throw it away, unless it was unrepairable. I mean, we didn't have things like toasters and televisions then, so... but I just can't recall anything at the moment, but everything got repaired.

You always lived in villages as you grew up. Were they close communities?

I guess they were fairly close. Everybody knew everybody else, and there was a village hall where we could go down and watch the latest film. They would... they used to take films round all the villages and show them in the village halls,

and everybody would turn out and pay their half crown - or whatever it was - to see the films. But my childhood, I can... mostly I can remember spending most of my childhood over the local fields, and fishing in streams and things. It sounds a bit Huckleberry Finn, but really, that's what it was like. It was... I knew, you know, at the age of nine, I knew all the names of all the birds, all the trees, all the... I could tell you what tree a leaf came off and things like that, because it was just passed on from... Often wondered, since, how that information came, but it must have been older brothers passed it to their younger brothers, and then across. So, everybody seemed to have an interest in rural life, really.

(3) And how did your diagnosis with diabetes come about?

Well, it happened in July 1954. I can distinctly remember an aunt of mine coming to tea and noting that I was drinking excessive amounts of anything I could get hold of. And my mother took me to the doctor's on... at the first opportunity, and I was diagnosed within an hour or two, and in hospital the next day.

Did you need to go into hospital next day - were you really ill?

I wasn't feeling very good, but I wasn't really ill either, but I was sent into the Radcliffe Infirmary, as I said, the next day. I was admitted to the Leopold Ward in the Radcliffe Infirmary, and I was in there for three or four weeks. I think the insulin that I was put on was called Insulin Zinc Suspension, and I was on approximately eighty units; that was just one injection a day. A few weeks or months later, I was admitted to the children's ward in the Churchill Hospital. I guess I was having problems with control, and I remember having to eat large quantities of potatoes, and nothing - not even a trace - of sugar. I was...

(4) And I wasn't making any progress at all with the control, and they were upping my insulin dose every two or three days. And then my doctor was changed, and I can remember a Dr Smallpiece coming on the scene, who was a lady doctor, and she took over and allowed me to have a slightly more liberal diet. Remembering that this was 1954, and I was only twelve years old, it was quite a strain for me to have to eat all these potatoes and, you know, bread with hardly any butter on, and stuff like that. And she allowed me to have a scrape of marmalade, I remember, or jam on bread, and stuff like that; but only small amounts. But there was a definite response to my control, and after being in there for actually eleven weeks, on a hundred plus units a day, they allowed me to go home. I think they were glad to get rid of me, actually, 'cause we used to have some fun in there. I remember that being quite a highlight in my life, being in the children's ward in the Churchill Hospital. I remember having a crush on one of the nurses!

What were children's wards like in those days?

I remember them being fun. There was a Scout leader that used to come, and we had - although it was girls and boys in this ward - there was, I guess it was called,

a Scout evening, where we would play games, and had to have these - whatever Scouts have round their necks: woggles and toggles, or whatever they are. And that was quite good fun at the time. But we made our own entertainment. I remember getting friendly with a couple of the young lads in there, and we used to have quite a time.

Can you remember, back in the Radcliffe, being taught to inject yourself?

Yes, I can - yeah. That was using an orange. I remember them giving me an orange and a syringe, and saying "pinch it up". And if ever you've tried to pinch an orange up, it's not that easy, but that was how we were taught to do it. And I think they

(5) also used a pillowcase as well... a pillow as well to do it, but I can distinctly remember the orange!

Did you find it difficult?

No, not at all, no. I accepted, after the initial shock - you know, at that age, and I'd never heard of diabetes before, and I don't think my parents knew that much about it either, so it was quite a shock to everybody, so... - but once we'd accepted it, after, you know, quite a short time, everything seemed to slot into place with the managing the diet and the insulin.

How did you test for sugar levels?

Well, we didn't actually... 'cause, in those days, blood testing could only be done in hospitals and laboratories. It was done... I can remember in the hospital, we used to use various... it was a urine test, but we didn't even have tablets in the hospital. We used to mix some ammonia and something else in a test-tube with urine, and boil it over a Bunsen burner. And mine used to go orange nearly every time, I remember, which means plus two percent. And then they brought in a thing called Clinitest, which was a tablet you dropped in so many drops of water, and that gave you a similar result.

And what did they teach you about diet?

Well, first of all it was fairly strict - you know, don't eat... I could eat as much meat, fish, eggs or cheese - I can remember that being on the diet sheet. Meat, fish, eggs or cheese were free, but the carbohydrate intake was extremely strict. And I remember being given a set of scales by the

(6) almoner, and they only went up to eight ounces. And I used to have to weigh the bread and my cereal and just about everything on these scales.

How did you manage when you came out of hospital the first time?

I can't remember too much what happened in that first period, because something must have gone wrong for me to have to go back in for such a long time. But it's all a bit hazy, that first period.

What about when you came out of the Churchill?

Well, then I was... When I was diagnosed, it was after finishing at primary... junior school, sorry, so when I came out of hospital I was in the senior, the secondary modern school. And I remember they treated me like a bit... well, I'm not sure whether I would say special or more like an alien, really, because I used to have to have - I had school dinners, I remember - and every day, for three years, I had dried apricots, that had been hydrated, but I couldn't have anything on them. But that's what I had every day for about three years!

How did your fellow pupils react to your having diabetes?

I don't remember anybody... well, I can remember one person, in the beginning - it was not the friend of mine, it was his mother - asked me if it was catching. I seem to remember that, but I don't remember any other reaction, really, from people, that I was that different, if you like.

Did anyone else in the school have diabetes?

No. Actually, yes. I remember a girl, and she - I never did find out what it meant - but she said she had drinking diabetes. Now, I don't know what that... apparently it was different to diabetes mellitus. I really don't know what that meant, but I can remember her saying that.

(7) How did the teachers react to your having diabetes?

I don't remember any special treatment from teachers, really, to be honest. And I always made an effort not to use my diabetes as an excuse not to do anything. And I tried to take part in sport, although I was pretty useless at team games, like football and that; didn't seem to have the stamina for that.

Did you tell everyone you'd got diabetes?

Yes, I did - not because any other reason than I was always a bit apprehensive about having a hypo in front of anybody else; that was the only reason. And I was always told, when I was young, to let people know that I was a diabetic, for that reason.

And did you have any hypos while people were around?

Yes, once or twice, yes - a full hypo when I went unconscious; that's... if that's what you mean by hypo. When people ask me how many hypos I've had in the last six months or whatever, I always hesitate, because to my mind there are various degrees of hypoglycaemia. You can just have a... feel a bit unsteady; you can start... your sight goes a little bit hazy; then a bit later you get confused; then the lights go on and off; and then finally you lose consciousness. Now, what's a hypo? Is it the beginning of that or the end of that?

Did you have any hypos, where you were completely unconscious, in front of your fellow pupils?

Not while I was at school, no. I had one hypo when I was fourteen. I'd been playing basketball, and I remember going back to the school on a bus, and then getting my bike and having to cycle four and a half miles home. And I hadn't

had enough to eat and had quite a serious hypo, where I fell off my bike and kept getting on, and fell off again. And then somebody found me half way across a bridal path, luckily. And I got... they - it was some youngsters, actually, and they told their parents - and they took me back to their house and brought me round, and then eventually took me home. But that one I remember. But I haven't, in my... I've only had about eight - can I use the word - 'full' hypos in my life, really.

How did the parents of these children know how to bring you round?

Well, actually, that's a good question. They found a purse of sugar knobs in my pockets, because that's what I used to carry with me, and so that's how they knew. I was just lucky that they realised that's what they were for.

(8) Did you have any changes in treatment of your insulin while you were at school?

Yes. I can't remember the dates, but I was on protamine zinc insulin afterwards - after the Lente - with soluble, so that was a mix; but still only once a day.

Can you remember if the change made any difference to you?

Yes, I think it did, Yes, I did... I was on protamine zinc for quite a long time. One thing I might put in now is - it's quite interesting - is the way that I used to inject in those days. I used to have glass syringes, in the first instance, that sometimes... And the insulin, being so lumpy and full of bits of protein and stuff, used to block the needles up. Used to have to have quite large-sized needles to stop them blocking up, but they still blocked. And sometimes the glass syringes used to explode on me, and I wouldn't know how much had gone in. Then they brought out metal and glass ones, which weren't really a lot better, but at least the needle didn't used to shoot off, 'cause they had a screw fitting on them; well, a locked fitting. And then eventually... And I used to have to boil the syringes and keep them in methylated spirits in a dish. And it was quite a performance, and it really was difficult when I was away from home or doing anything away, sort of thing.

Did you go away from home at all while you were a... during your school days?

Not much during my school days, really - only on holiday and that. But when I left school, then things changed quite considerably.

Did your diabetes affect your choice of what to do after you left school?

No, not at all, no. I actually left school at fifteen, and I went to be a pre... what we call a pre-apprentice, at an RAF civilian maintenance unit. But after passing the entrance exam and eight months later, they closed the unit, as they did on a lot of these units. That time after the war they were sort of cutting back. But I managed to get an apprenticeship at Atomic Energy Authority at Harwell, and did my first year at Winfrith in Dorset, living in a hostel with forty other apprentices. And this was the first time away from home. But I didn't have any real problems. Looking back on it, it's quite surprising, because I still

had to boil my syringe and keep it in methylated spirits and do everything, but I didn't have anybody to fall back on. And I was the only diabetic there, so... But I didn't really have any problems, and used to take part in everything that was going on.

Can you remember how your fellow workers reacted to your diabetes?

I don't really remember any reaction, to be honest. I wasn't treated any differently to anybody else, and I used to take part in all the activities that were going on and sport. We did actually have a gymnasium at the centre, and... which we had to do every day, and I didn't have any problems with that.

(9) What sort of social life did you have in your teens?

Well, quite a good social life, really. I enjoyed life for the first time, since leaving school, and, you know, my life - it seemed to open up. And I didn't have any problems doing anything that any other teenager would do. I enjoyed dancing, and going out with the boys, and meeting girls, and had a motorbike and everything. I wasn't treated any different, by my colleagues, as anybody else, really.

What about smoking and drinking?

Yes, I smoked and had a drink. But I never ever drank - I always say this to people -that I've never had more than two pints in one evening, or in twenty four hours, in my life. And normally it's half a pint of lager, and I can make that last for about four hours. I've never been a great one for drinking, and I probably don't drink any more now than I did then, you know; very rarely have a drink now.

Was that because of your diabetes?

I think so, because my brother lives on Guinness mostly, and I've never really... I've often thought about that. And I think the fact was that he became a diabetic... he was a, you know, a normal teenager, not being a diabetic, and he drank with the lads, and so he got into the habit of drinking, whereas I was twelve years old when I was diagnosed, so I'd never got into drinking at all, so it didn't affect me so much. And I've never really enjoyed beer too much anyway, so it wasn't a hardship.

Had medical staff advised you not to drink or smoke?

Yes, they always advised me not to smoke - well, and not to drink, you know - but I... I don't know... I didn't take any notice of them about smoking, because in those days, that was the thing to do. Nearly

(10) everybody smoked when they... I mean, I smoked before... I can remember smoking when I was nine years old: going down to the local shop with the other lads and getting a bottle of Tizer and five Woodbines. And we thought it was great then, but... it's an act of stupidity nowadays, but there you go.

Did you have much contact with the medical profession as you were growing up?

In the sense of my diabetes - I guess, yes. I used to go regularly for my diabetic clinic appointment - probably never had any more than three month stretch at a time. And then, in later years, it got to six months, and that's about what it is now. I think it went a year once, but only once.

What did you do about medical treatment after you left home?

If you mean when I went to my basic training for Harwell, I had a... I used to go to a clinic down in Weymouth, and I didn't have any special problems down there. I've always been... I mean, in those days, again, I was using the urine tests. And I believe my, what they call, renal threshold is very low, so my tests always appeared to be high blood sugar, but, in actual fact, I don't think it was as high as it was thought at the time.

When were you told your renal threshold was very low?

I can't remember exactly, but probably in the mid sixties or seventies, or early seventies.

(11) Talk about what happened after you came back from your training.

Well, I can remem... the first thing I remember about that would be when I was about seventeen and I got a motorbike, which I was very proud of. And I passed my test on it and it was a wonderful time. And then, one day - I'd had it about eight months, I suppose - and my father came home from work and told me that a friend of his had run into six cars, in his car, on the way home, and ended up going in the wrong direction. And it turned out he was a diabetic and hadn't had his midday meal or something, and he obviously had a hypo, and he was in big trouble. So, I had to go and declare to my insurance that I was a diabetic. We weren't aware, at the time, that you had to declare it. And when I went in the next day and told the broker that I was diabetic, and he made a phone call, and that was the end of my motorcycle times, from midnight that night. So, I wasn't very happy about that. But eventually we managed to get insurance for me to drive a car, so I was off again, then; that was the following year.

Was it difficult to find an insurance company?

It was, at first, and one of the... there was... somebody recommended it in the diabetic magazine, I think, but they were very expensive, and... But then, after a few years, other insurances seemed to open up. And you can... after that - I don't really know what happened - but my brother, who's now fifty five, or fifty six even, he still rides a motorbike, and, you know, with fully insured and everything, so he's never had a problem with it. And I've never had a problem since. Any insurance company now seems to take diabetics on without any loading or anything.

(12) What did you do after you'd finished your apprenticeship?

Well, I went to work at an atomic energy establishment at Culham, after I'd finished my apprenticeship, and I carried on working there for a few years. When I was twenty four, I got married. And we had... although... I was going to say we had children, but before that - I'd like to say - we discussed, before we got married, whether we should have children, in fact, because I was very concerned that I was going to start breeding diabetics, and I wasn't prepared to do that. But I didn't think it was fair on my future wife that we should get married without getting this sorted out first, so we made an appointment to see... or actually, we... my clinic appointment - she came with me. And we talked to, I remember, Dr Cook at the Radcliffe Infirmary. And he advised me that there was a slightly - or advised us, rather - there was a slightly higher risk, but not considerably; certainly not two to one. And so that satisfied my future wife and myself, and so we got married. And in two years we had our first child, and in another two years we had our second child. And they're now thirty three and thirty five, and they're fine; regarding diabetes anyway. My eldest daughter has got Crohn's disease, but I don't think that's related.

When you say you weren't prepared to breed diabetics, was diabetes so awful then?

I guess it was, really. I've always had this fear of popping off, as it were, too soon. I've got to the stage, now, where I think, if it happens now, I've had a good innings. But, I guess that's a sort of negative way of thinking, but it's always been in the back of my mind, you know: "am I going to make twenty five?", "am I going to make thirty?". And I'm sixty two and still kicking, so I'm quite pleased, really.

Who had led you to believe that you might die young?

I don't think anybody did. I think it's something I just secretly worried about on my own, you know.

Did you ever ask a doctor or a nurse?

Yes, I did, yeah, and very early on. And - I think I was about fourteen or fifteen - and the doctor said if I looked after myself, I should reach seventy odd without any trouble, but I don't know that I believed him, really.

(13) What jobs did you do as your children were growing up?

I can remember in '71, when my youngest one was born, I was working for Oxford University in the engineering department, in the cryogenics laboratory. I was there for about six years and enjoyed that. And then I got a job at the Nuffield Orthopaedic Hospital as a research technician, which was funded partly by the university and partly by the NHS, mainly creating new tools for the surgeons there, and helping with new designs for orthotics, etcetera.

And can you remember how you managed your diabetes while you were at work?

I can't remember exactly the year, but at some stage, around then, I was put on two injections a day, which I didn't like very much the idea of, but it certainly

helped with my control. I've always been... tended to be on the high side - somewhere between eight and ten on the Richter scale, or whatever scale it is. But I did... I've always been rather a stressful sort of person, I guess. Most people say a worrier. I don't like the word stress, really - it's a modern sort of thing, but I've always sort of worried a lot. In recent years I've managed to control that quite well, but back in... when the children were young, I got myself in quite a state, I remember, in a period. I don't quite know why, but I guess it was a conglomeration of things that got me in this state. And my GP, at the time, recommended I saw a psychiatrist, rather than put me on Valium and those sort of things, so I did. I actually had a course of treatment with a lady in the Littlemore Hospital in Oxford, and I just used to go and see her once a week, for, I think, probably about six or seven weeks. And she introduced me to Zen Buddhism, which was quite fantastic, and I responded well to that, and I did do it for some considerable time.

What did you have to do?

Well, you just shut your eyes, and it's a bit like self-hypnosis, really. You have to count and think about your... you have to focus your mind on your breathing and counting. There were various things you can do, but that was what I did, and it... you're not exactly... you feel as if you're asleep, but you're not - you're very focussed. And it relaxes you completely, and it helped me considerably. And I managed to control the sort of worrying aspect, and so, these days, I'm a lot more laid back, as it were.

What effect did Zen Buddhism have on your diabetes, if any?

Well,

(14) the fact that it was quite successful in what it was trying to do - to calm me down - and I think probably had quite a significant effect on my diabetes, because you get into this vicious circle - because if you're worried or concerned or stressed, your blood sugar levels tend to go up, and that makes you worry a bit more. And so you're chasing your tail all the time, with that.

And when your sugar levels go up, does that affect your behaviour?

Yes, I think it does. Again, in recent years, I manage to control it more, but when I was young, I used to sort of be a bit of a pig to live with, because I would fly off the handle quite easily. And it is related to, not just high blood sugars, but low blood sugars as well. If you... it's much more noticeable, in fact, with low blood sugar. I'm just talking about the early stages of hypo - you're very quick to react to anything and usually a bit negative. But the high blood sugars is more because you can't really be bothered or you can't focus so easily. Your mind becomes a bit muddled and you can't be bothered with people, and it makes you sort of irritable, more than anything else, really.

Do you think, if you're diabetic, you're more likely to attribute changes in your behaviour to physical causes?

Yes, I hesitate to go along with that, but, I think to a certain extent, I don't... I hate the idea of using my diabetic condition as a crutch or an excuse. But I do generally think that there is a case for that, when you've got a bit out of control, one way or the other.

How did your wife cope with you having diabetes?

Well, she coped very well. She had a good model to go on, because she knew my mother for, like, two or three years before we got married, so she knew what she was in for. And she had to... she tried to sort of model it on my mother, who was absolutely superb. She knew exactly how I was and knew exactly how to react to me - when to leave me alone and when to help. And my wife sort of took note of all this, and she does very well. But it is very difficult, and I've heard her say quite often, you know, to other people, that it's not easy.

When should you be left alone and when should you be helped?

I don't know - I really don't know. It's the way you help, really. You don't want to be fussed. You just want a calm, general agreement. You don't want conflict; you don't... if you get into an argument, it escalates in seconds, so you don't... that's not a good idea. So, you just want calm, really.

(15) Was your mother always calm, even when you were first diagnosed?

Yes, she was. She seemed to be a natural. She knew exactly how... what condition I was in. If I was high or low, she just knew how to behave to keep me from getting frustrated and worse, and the key word is calm. She just calmed the situation by, you know, not telling me I was doing something wrong or I should behave myself, or anything else - just be calm.

You've talked about what qualities you needed in your mother and in your wife. What qualities do you need in doctors and nurses?

Well, I think, after you've been a diabetic for a few years, one of the things that the doctor ought to have is a little bit of respect for the fact that you do know quite a little bit about diabetes after some time. And you don't know all the answers, but if you're treated - like I have been on occasion - like a complete novice, then it's difficult to have respect back, because you know that they're saying the wrong things. Basically, you need to... from a doctor, I always think you should have reassurance. It's very important for a diabetic - or to me anyway - to have reassurance. You always want to know the worst, but when it comes down to it, you don't, really. So, I would hesitate to - even if a diabetic says "tell me what you honestly believe to be my prognosis" - don't tell 'em. I've had... I can remember four doctors, who I've... The first one was Dr Smallpiece, which I mentioned when I was first diagnosed, who I've got a lot to be thankful for, because she seemed to drag me out of a very deep place. And then Dr Cook, who was, I remember, being rather a large gentleman, but extremely competent and very well-respected, and he was always very reassuring. I think the best one was Dr Hockaday - I liked him very much. He treated me like an equal, used to ask my opinion on quite a lot of things, and was always very much in control. I

had a lot of respect for him. I think I've been with Dr Matthews' clinic since 1995, but don't know Dr Matthews very well - I think

(16) I've only seen him twice.

What about nurses?

The diabetic nurses, they've just introduced - or they've introduced, I think, for a few years now, diabetic nurses - but I've got a nurse assigned to me. It's very difficult to get hold of her though. She seems to have got enough work for ten nurses. I don't know what's wrong, but it's very difficult to see her or get any help. It started out as a brilliant idea, but I don't think it's working terribly well, to be honest.

What contact with nurses did you have before the introduction of diabetic specialist nurses?

I didn't have any contact, really - only, just, you know, nurses in hospitals. I don't really know what...

Have you taken part in any medical studies of diabetes?

Yes. I'm not exactly sure when, but I think it was probably in the late seventies, I took part in a study with an opthalmist at the Radcliffe Infirmary. I used to go in once a fortnight, and I remember having to... he gave me boxes of pills to take, and then I had to look through and focus on these lights in this box and tell me when they went out of range and stuff. It was looking at my peripheral vision, I think. And he told me that there was - these tablets that I was taking, or capsules - I don't know what they were - but he said that fifty percent of them were placebos, to make the research valid, so... But I was a bit worried about taking the tablets anyway, so I didn't actually take any, but I didn't tell him. So, I told him when we finished the project, so I'd be able to be counted as placebos anyway. And in the early eighties I agreed to take part in a research project with an Australian doctor and his wife, who was also a doctor. They put me on an insulin regime, which made me feel quite dreadful - fluctuating test results, feeling heady and very tense. I was in touch with them by phone two or three times a week, but they insisted on me continuing. I lost two stone in weight - down to less than ten stone - and at six foot one and a half, that's pretty skin and bone. Out of desperation, I managed to get an appointment with the consultant Dr Hockaday, who was absolutely mortified, and immediately changed me back to my former regime. I remember putting weight on immediately, and back to almost twelve stone in a few weeks.

But, while you were losing weight, were you telling these Australian doctors that you were losing weight?

Yes, that's when I was contacting them by phone. They told me to keep in touch with them, but they just told me... you know, I told them I was losing weight, and I really did feel dreadful. I didn't know what I was doing most of the time.

But you didn't feel you could take yourself off the regime?

I didn't have any chance to do anything - that's all the insulin I had.

Can you remember what it was?

No, I can't.

(17) That was in the early 1980s, I think you said. Can you talk me through the rest of your career after that?

Yes, after 1980 I went to work for a packaging company called Metal Box, and that was very interesting. Again, research and development, with all kinds of packaging machines. And I eventually got onto a project where I had to go to... my first trip was to Holland, to look at a machine. And I remember that vividly, because I had about eight hours notice to go, and I'd never flown before and had to go to London airport and catch this plane. The ticket was waiting for me, I'd never even been to London airport before, so that was quite a traumatic experience. Plus the fact that the machine I was going to sort out in Holland was something I'd only ever worked on a prototype, so I didn't even know what it looked like. So, the fact that nobody spoke English, and... it was quite a job. But I can't remember any problems with... from a diabetic point of view. I did my injection. I managed, through sign language and one thing and another, to get the local restaurant to give me some potatoes and some fish, and I lived on potatoes and fish for a week, because I didn't know how to ask for anything else, so. And then I started having to go to the States on a fairly regular basis, for somewhere between two and eight weeks at a time. Again, I managed... Something I should say now, really, that I have noticed that whenever I go anywhere - be it in a car or on a plane or anywhere - I always have trouble for the first few days. I guess it must be - using that horrible word - stress, again. I can't think of any other reason why my blood sugar level goes through the roof, and I'm talking somewhere between thirteen and eighteen millimoles, for, as I say, the first few days. Then it seems to

(18) settle down. But I did notice that when I went to the States, that was a bit of a job to get over, but whether it's the different food or what, I don't know. But apart from that, I managed quite well with my injections and food, because one of the biggest problems was eating on time, especially when you're living out of a suitcase. And you're working on machines in factories, and you can't just put it down to go and eat when you feel like it or when you have to. So, that was sometimes a bit of a problem, but didn't get into too much trouble when I was an hour or two late for a meal. So, managed that all right. Then, in '92, the project I was working on got sold to an American company, and so did I, because part of the deal was that some expertise went with this machine, still in its development stage. So, I was asked if I'd like to go to California to work on it, and take my family with me, so. I wasn't very keen at first, but my wife liked the idea, so we packed up everything we had and off we went to California for a couple of years, which we enjoyed immensely. So, I wasn't living... it wasn't like when I was going over there on my own, living out of a suitcase.

I had my wife and youngest daughter with me, and so, from a diabetic point of view, there wasn't any more strain, really, than working... living at home here.

Did you have any contact with the medical profession in California?

Yes, I did, yes. I used to go to a clinic over there. Slightly different system, but, as far as I was concerned, he was excellent and did everything that I needed. I remember going through a phase where I had high cholesterol, and he sorted that out for me.

And what did you do after you came back from California?

Well, when I came back from California, I was on the dole for about six months. And then, I was just thinking that I must do something, even if it's a change of profession, and within a week of thinking that, the phone rang and I was asked to go back to Metal Box, which is just down the road from me, and do another project on - or take part in a project - on the same thing that I was doing beforehand: aseptic packaging. And I spent another five years there, so that took me up to about 1997. Then that project came to an end, and I was only on contract, so that was the end for me, again. And I applied for a job at Rutherford Appleton Laboratory at Harwell in Oxfordshire, and got a job running a small workshop in the space science department, which was quite interesting. Managed the job very well, and enjoyed it very much, but in 1992 I became sixty, and civil servants get retired at sixty, so...

(19) I should have said 2002 I became sixty, and I got retired from Rutherford then. So, since then, I've been just doing odd jobs for people, which I quite enjoy. I get a very small pension, and my wife still works, so I'm going to try and keep her going till she's seventy odd, if I can. And we manage quite well, really. We're not big spenders, so we jog along quite happily with me doing a bit of gardening and a bit of decorating and woodwork for people. And I've just currently doing a... I've been asked to do a job connected with space science at Birmingham University, so I'm currently doing eight weeks there, to assist with the construction of a unit.

And have you had any complications associated with diabetes over those years?

Well, I guess things are starting to fall off now. My eyes don't seem so good now. They said, a little while ago, that they're cloudy, but it's not cataracts, so I don't really know what that means. But I do know that I need more and more light to see things properly. My feet are... my feet are in good condition, so the podiatrist keeps telling me, but I can't really feel my toes and the balls of my feet; that's... feeling's gone in those. And I've just had... well, no, I don't think that's... I was going to say about my ears, but - I've had a severe infection in my ears - but not really associated with diabetes, except for the fact that I don't seem to respond to antibiotics very well, so that took a long time to clear up.

What about blood pressure?

Yes. I believe they've changed the sort of limit on blood pressure now, so when I was just inside it before, I'm now just outside it, so they've put me on a small dose of something beginning with R.

(20) What would you say were the chief improvements in the treatment of diabetes, since you were first diagnosed?

I think the most major one is being able to test your blood very, very quickly and frequently, and I find, especially nowadays, that I have to test quite often. In fact, I test four or five times every day, especially before meals, and that just keeps me on an even keel, because I don't get such good warnings now - not in the early stages, anyway, but... The other significant thing - improvement - is the syringes through the years. I mentioned earlier that started out with glass syringes and very large needles, and then came the insulin syringe, which they managed to get on the National Health. About two years after they let all the drug addicts have them for nothing, they allowed diabetics to have them for nothing, which was quite an improvement. Then, in 2002, I think, I went onto the pen, which was even better. Very easy to do, extremely small needle - don't even know it's an injection, really. And now I've been put onto - in the last six months or so - I've been put onto four injections a day. I can't remember exactly what they're called, but there's a quick acting one before breakfast, lunch and dinner, and then a basal type that I have every night. And I'm on a much lower dose now. I guess half of it's because the insulin's a lot more pure than it was in the early days, but I'm on about a third of - or less than a third - of what I was on thirty years ago.

Does having four injections a day mean that you can eat what you like?

I'm told I can. I'm told that I can be a lot more liberal now, but I choose not to be. I must admit that I'd - given half a chance - I'd be a chocoholic, but... I love chocolate, but I tend to use that instead of sugar when I get low. I indulge myself, when I get low, in all sorts of things that I really enjoy, but other times I don't bother with puddings and things, really.

(21) In the past, I would tend to change the amount of carbohydrate intake to balance things up, because the... that was more immediate. If I changed the insulin, as I was only on two injections a day, it seemed to have a sort of hysteresis effect, so you could never catch up with it, and it was always, you know, a sort of... well, in a way, lagging behind. So, I found it easier to change - although I was told to change the insulin - I found it more effective to change the amount I was having for that meal, if I was high at that time. But now, on four injections a day, it's much easier, as I said, to do a test before a meal, and then if I'm high I have more insulin, if I'm low I have less, if I feel hungry I can have more. So, in that way, it's much better all round for me to be on four a day.

Have you noticed changes in the National Health Service, since you were first diagnosed?

Yes. I suspect some of it is because I was very young when I was diagnosed, so I seemed to have a lot of attention and care by everybody. But, in the last few years, I found that it's... I don't know whether it's connected with the fact that as you get older, you're less important to... you know, you've had your time or what, but I just don't feel really that I'm being looked after as well as I was before. They... you know, most of the people seem to sort of say that "oh, it's wear or tear" or, you know, "that's what you should expect now" or something, but there's never any positive things coming out nowadays. Feel a bit left behind, really. I haven't got a lot of... anything really positive to say about my treatment, to be honest. I wish I could say so, but I can't.

How often do you go to a diabetic clinic?

About six months - six to nine months. In fact, I think the last two were nine months, and that wasn't because I didn't need the treatment. I was told that that was the - as the appointments were being made - that was the first time they could fit me in now.

How would you like to be treated?

I just would like to be treated how I was before, where they took an interest in my wellbeing. I just don't feel that that's what's happening now. The treatment I'm getting now, I could do with an e-mail in two minutes, rather than me take a whole day to go into the hospital, and pay an exorbitant car park charge, and then wait for about three hours, and have ten minutes with a doctor who doesn't really seem that interested, to be honest.

What about the nurses?

You mean the diabetic nurses? The nurse that I have all the time - that

(22) you tend to be put with one nurse - she's excellent in what she does, when you can get to see her, but there's a system whereby you can never speak to her. If you phone up, you get a voicemail thing, which says that she's not available at the moment, but she will call you at some point. But the last time I had this problem, I got really out of control, and I phoned her up. And the voicemail said - I was actually in quite a desperate situation, this wasn't all that long ago - and the voicemail said "I'm on holiday until such and such a date" - was, in fact, over a week's time - "if you have a urgent condition, speak to your GP". Well, I did speak to my GP, and they said "well, I really can't help you. You've got to go to the diabetic clinic, because it's out of my..." - skills, I suppose. So, I went back and got onto the desk, and asked for an appointment with the doctor. And after being quite frank with them, and about four phone calls later, I did get an appointment. And when I went, my wife came with me, and because I was not in very good state, she came in with me, or she asked if she could. And the doctor gave me a real grilling as to why I should think that I should have a special appointment, and why didn't I get in touch with a diabetic nurse? And I said that I did, and didn't seem to cut much

ice, but I did say that I don't like talking to machines. I remember saying that, because I was a bit angry at the time. But there was no... she said that somebody else would have taken it over, you know. But that wasn't true, because nobody phoned me back, and the message was "see your GP", and I did what I was told. So, I weren't very enamoured with that reaction, really, from the consultant.

How do you think your life would have been different if you hadn't had diabetes?

It's very difficult to say, actually. I can only remember two or three things, at the most, that I wished I could have done, and one would been to fly aeroplanes. Whether I would actually have been able to afford it or do it, I don't know, but that was something that I... but very little extra. I think I've led a full and active life. I've done all sorts of, you know, active things. I've played badminton and squash, I used to play regularly, and tennis, and... I never really did any sport until I was about thirty five, and I took up golf when I was fifty, and I play every week and I really enjoy it. It gives me good exercise and good reason for living, really.

What message would you have for someone newly diagnosed with diabetes?

Look after yourself is the first thing, but don't let diabetes rule your life. Try and be... well, you are as normal as anybody else, so don't use it as a crutch - it doesn't work. Just try and be as normal as you can, really.