

48. Edward Walsh

(1) Tell me about your background.

Well, I was born in August 1944, on the same day as my mother and father's wedding anniversary, funnily enough - nineteenth of August. We lived in a place called Winnersh, which is halfway between Wokingham and Reading, and I lived there for twenty five years, till I got married. My father was a baker, and... locally, did baking. He was up at four o'clock in the morning baking the bread ready for everyone, and then came home usually about four o'clock in the afternoon. It was normal childhood, really; I enjoyed it, no big problems, very countrified, as it was then. We lived in this little bungalow with a huge garden, and rode around. Very active, really, and I suppose I've been very active for most of my life, doing a lot of sport. Educationally, I didn't like school, and I left when I was fifteen to do an engineering apprenticeship, and I enjoyed that. I enjoyed then the educational side, and I then went on to college and got an HNC in Mechanical Engineering, ONC and going on to HNC in Electronics. And that's how I pursued my career, really, as an electromechanical engineer.

You said you were always very active. Can you talk about those activities from the earliest age?

Yes. The two main ones, at that time, were football and cricket, and I played football every weekend; Saturday, Sunday. I played with my brother during the day, and this really started, I suppose, just before I left school, and then on through my apprenticeship, right on. And then I started other sports - tennis, I liked badminton and squash. Played those really for the... I suppose right up until around, oh, '97, which was when I had my hip operation, and then, from then on, I couldn't do it. But sport was really a big part of my life for a long time. And running, although I didn't like running too much; it was just a means to an end.

Did you play at a competitive level?

Yes. I played in the Reading and District league at football; that was the main one. And then cricket, later on as well, in the sort of Reading and District leagues. And then when I came over to Charlgrove, to here, I played for the local pub club down the road - The Lamb - for a while. And then really to do with... it was more sport associated with the firms that I worked at, 'cause they all had sports and social clubs. So, that's how I got into sport.

And what about diet? Can you describe you childhood diet, beginning in the 1940s?

Right. I don't remember an awful lot of it. Some of it I do, but I used to always go into Reading, at the time, and this was just after the war - must have been around about 1947, I suppose. And my grandma - I'd go in with my grandmother and my mother into Reading, and we'd have... she'd treat me to some grapes, and a pig's trotter, funnily enough, and I always remember those. But sweets and sugar and all that sort of thing was on ration, so, in my

early years, we certainly didn't have many sweets or any cakes or things like that, although we did manage to get cakes later, 'cause my father was, as I say, a baker, so we were privileged there. And so, I was careful with my diet and...

- (2) But I always had a weight problem, from when I was... I suppose once I'd reached about twenty. Before then I was thin as a rake, and my mother used to worry about it, really, that I was too thin. But later on it... I was then had a weight problem, and I had a weight problem, really, for the rest of my life. And I've tried to keep a diet. I haven't had sugar or... I mean, tea and coffee were the first things to go, and that was back in, oh, round about 1968, '69; somewhere about that time. And so from then on, no sugar. I gave up smoking as well round about 1968. I didn't used to smoke a lot. It was just, as all kids did - we smoked. But then, at one time, I decided "ugh" - it was enough; I'd had enough. And it was a waste of money, really, and I didn't really enjoy it, so I just decided to give up smoking. And that was it, I gave up smoking. My wife carried on for another year, but I found it very easy to give up smoking. I didn't have any withdrawal symptoms or anything, so I gave up on that day and never smoked again.

You say you gave up sugar in tea and coffee. How much sugar would you have had during your childhood?

In the early days, not a tremendous amount, 'cause, as I say, sugar was on ration till I think it was about '52. After that, I'd have probably around two spoonfuls of sugar in tea and coffee whilst I was at home with my mother and father, and that's how it was, really, right up until I'd left home and got into married life. And it seemed to suit me and I put weight on, and then I decided to try and get rid of it, and so I did. I really dieted for the rest of my life, I suppose, on and off over the time. I'm not always successful, but we try.

When did you get married?

In March 1968, and I sort of changed career, then, as well, and I went in the civil service. And I worked at a place where we could have lunch at midday - and, if I'm honest, that's when I prefer it. And then the

- (3) evening meal, I tend to have a very light evening meal, or that's the way I like it. And unfortunately it isn't always the way that we can do it, so.

You said that you began to put on weight because married life suited you. I mean, can you just try and remember why you began to put on weight in your twenties?

I don't know, really. Some of it is because before I was married I'd play football every day: lunch hours, evenings, weekends, Saturday, Sunday, training twice a week - Tuesdays and Thursdays. So, there was a lot of sport - an immense amount of sport. When I got married, we were concentrating on trying to buy a house and all things like that - more sedentary, I would say. And so that's when I think the weight started to go on. And, as I say, I changed my career then,

and I went to work for the civil service that had some quite good facilities, and I was able, then, to get back into - about '69 - back into some more sport and running at lunchtimes and evenings. Didn't always suit my married life, but it was easier, then, to control the weight. But, as you get older, you can't quite play so much sport and at the same level, so it got harder and gradually harder. And then diabetes came along, which was... oh, that was 1994 that I was first diagnosed.

We'll come to that, but can you describe your diet after you got married?

Yes, I... again, it was a meal, a good breakfast, a meal at lunchtime, because they had a canteen and we had a meal at lunchtime, so we were able to sit down and have a meal, and then when I came in at night it was a light tea. So, that was... But gradually, I think, over the years, it's changed, and really can't put a date to when it actually changed, but it gradually it changed. I get up and I still have a breakfast, but it's - because I get up early - and

- (4) it's usually tea and toast and that's it, and it got that way. And then, because we only had half an hour lunches and things like that, lunches even changed. We were grabbing sandwiches, and then I was having a full meal in the evening. And from that... and that really goes on, or went on, for quite a time. And that was the subtle change. It just subtly changed over the seventies and eighties, really.

Was there a tendency to put on weight in your family?

Yes. My mother was quite a big woman. To be quite honest, I didn't know my mother being slim; she was always quite a large woman. Small but large, and she battled for years with trying to lose weight, not very successfully. My father was similar, although he wasn't a large man. He was a... because of his bakery and his... I always thought he was quite fit. Never went to the doctor - didn't like doctors, never went to the hospital - he said he'd never go in a hospital. So, that was quite a surprise when he first was diagnosed with diabetes.

How old was he?

That I... I can't remember how old he was, but he was in his fifties, and I'd said late fifties. He... in fact, we don't know how long he had diabetes before, because he had double vision. One day the double vision came on, and so to cure it he put a patch over his eye, and he carried on working like that. And I suppose it was my auntie that nagged him and nagged him to go and get it sorted out. And he went to the doctor and they sent him to hospital, which he said he'd never go in, and they diagnosed him with diabetes. And he was in there for a week while they, in those days, it seemed they sort of settled him down. But he didn't... he had tablets and he used to have to test his urine as well, which... and he did that, which then cured his double vision - he was able to take the patch off his eye. And he then lived with diabetes like that. I don't know what sort of diabetes care he had, because it wasn't...

- (5) it didn't seem to be as good, certainly as it is these days, and that was

only, what, in, oh, 19... - when did we move here? '77, 1977 - so it was about that sort of period that he was diagnosed with diabetes. He then died in 1980 of a heart attack, and that was out of the blue. It just... we got a call one day and said that he had died just crossing the room, and he... It was a quick way to go, so probably that would be the way he wanted to go, 'cause he wasn't in hospital or anything else, so it... but...

How old was he when he died?

Sixty four. His treatment... Mum looked after him quite well. I don't know whether it was at a clinic or... because he went into the hospital, and, as I say, it was for about a week that he went in to stabilise him and get his treatment sorted out. But he was a very secretive man. He didn't like anybody knowing anything, so, you know, it was very, very difficult for any of us to know what was going on. But Mum used to look after him really quite well. She used to make him - of course he didn't have sugar or anything like that or cakes - but she used to make him jellies with gelatine and fruit juice, so there's no sweeteners in it. It took a bit of getting used to, but he used to like it. But I never remember him having sweets. I don't remember him having sweets when we were younger. He used to like an ice-cream now and again, but that was about it, so I wouldn't have said that his diet was any different from anybody else's diet.

Do you remember if he had difficulty in changing his diet after the diagnosis?

No, I don't think he did, because it wasn't a huge... it didn't seem to be a huge change to him. Not like Mum, which was a lot diff... she was always a picker, so every time she got anything ready for us, she used to pick, and so she had a problem in that way. But certainly my father, it... again, it just... because he was so secretive... But, of course, I'd left home in 1968, so I didn't see the home life, so I can't really comment on that in great depth, apart from, as I say, when we used to go round... And we used to see them most weekends, or some time or other. And when my daughter was born in 1972, they were so over the moon, and they used to take her for walks and everything round what we used to call the bluebell woods at Woodley. And so, that that I saw of them, they certainly... my father didn't eat between meals or anything like that, so it was all at mealtime. And at that period, then, he wasn't overweight - not that I remember him being overweight, so he was... as I say, I always imagined him being quite a fit man, so it was quite a surprise, really.

You say he was secretive. Was he embarrassed about having diabetes?

Yes, I think he was. In fact, I think Dad was embarrassed about being ill at all. He didn't like... it was almost, I think, seen as a weakness, so he wouldn't give in to anything, really. And he never... well, all the time I can remember, right up until he was diagnosed with the diabetes, that was the only time he had off work. He didn't have time off work, even with colds or anything like that. He just went to work and he worked; that's the way it was seen to him.

(6) So, now tell me about your own diagnosis with diabetes.

Right. I was diagnosed early 1994. I suppose it goes back a little bit before that, actually. That was the date that I was actually given that I was a diabetic, but before that I was diagnosed with hypertension; that's high blood pressure. And that came about because the firm I was working for had insured me as a... I forget what they call it, but anyway, they insured me, but I had to have a medical. And I went for a medical, and this must have been, ooh, 1985 or 6, somewhere around there. And so, I went for the medical, and they found out that I had high blood pressure and sent me to my own doctor, who then started to control my blood pressure. And this went on for the next years, really. And then, before '94 - must have been probably two, a couple of years before that - I used to get up in the night to go to the loo quite a lot; maybe four times a night. And, to be quite honest, I didn't think anything of it. It's one of those things that just kept creeping up, you know - you wake up at night, go to the loo, then it's twice, and this is over a period of say two years or three years. Anyway, it was time to have another session with the doctor for my blood pressure, and he said "oh, while we're here, we'll do a urine sample. Can you do a urine sample?", so I said "yes, fine". Did a urine sample, never thought any more about it, until I got a call from the doctor to go and see him, and hadn't a clue why. So, it was quite a surprise when he told me I had diabetes, because I just didn't feel it, apart from the going to the loo at night, which I then learnt that it was a symptom, but I was ignorant of the symptoms. Even though my father had diabetes, he didn't talk about it, so I didn't know. And I didn't even think about the diabetes, and I didn't even think that I would get it. It was something my father got, but I didn't think I'd get it, so it was quite a shock. I felt a bit upset as well, at the time, because it was...

- (7) well, I hadn't been ill, apart from high blood pressure, but I just thought "oh, that's one of those things. Most men suffer with high blood pressure some time or other". But the diabetes was quite a shock, and I was, I suppose, disappointed, really. I'd led what I'd call a fairly healthy life, certainly for the last... all through the eighties. I'd been playing sport, I'd been really quite active, and had a sensible diet - I thought was sensible. Not to say I didn't have the odd biscuits, cake, that sort of thing, but I didn't feel a lot, so it was quite a... And I remember the doctor going through it all, and saying that we'd got to keep, now, blood pressure under control, and all that sort of thing. And that became more of a fight to get the blood pressure under control. But he gave me tablets, and I think it was Glibenclamide was the first tablets that I had, and this was after... and I had to take, I think it was, one or two a day. I can't remember now, but I think it... it might have been only one, but I had this Glibenclamide tablet. And I went into Wallingford, which is just down the road, on a Saturday morning to do some shopping, and I felt really ill and shaky. And so I went back to the doctor, and actually, while I was in the doctor's surgery - this was on the Monday I managed to get back into the doctor - and while I was in the surgery I had all this symptoms again of shaking and feeling quite unwell. I now know it was the Glibenclamide, and I

didn't need Glibenclamide. I could actually control the diabetes with diet, so what I'd had in those early days, I think, was a hypo and... but didn't know it, 'cause these things weren't really explained to you very well at the doctor's surgery. And it's not... I suppose it is a criticism, but they didn't tell you all of the things that might happen to you, so you were totally unaware; didn't really know anything. And that's when I... one of the things I did do after that was sign up to "Balance", the diabetes magazine. And so I read a bit about it and found out a bit more about it, 'cause in those days it didn't go to the clinic. I didn't test my blood either - that wasn't even told to me. So, the first years... and I think

- (8) it was okay, the first years. It was just whenever I went to the doctor, I had a blood test, and as long as the blood test was okay, I was doing okay.

And after that shaky spell, you gave up tablets?

Yes, the... I was taken off the tablets and then controlled it with diet. Now, this went on, I suppose... it's difficult to remember all the dates, but I had a detached retina in September 1995, and I know then that I was still controlling it all with diet; there were no tablets. Whether the detached retina had anything to do with diabetes or not, I really don't know. There was no reason that I should have a detached retina - it just came on. There was no blows to the head or anything like that, which boxers often get. At the hospital they just said I was unlucky and it just happened. And everything seemed to happen from then on. I had to gradually go back on tablets. I had a lot of tablets for the high blood pressure - different ones. Atenolol was the first one, and I can't remember all the others at the moment, but Atenolol was the first, but then there's about three other ones that I had. And at the same time, playing the sport - I used to be wicket keeper - and I was finding it very, very difficult to stoop and kneel, and the... it was my hip. At first I thought it was my knee, but it was my hip. I'd got arthritis in my hip, which I didn't know at the time. But I kept on playing and thinking, "oh, it was the sport and I was just getting old for the sport", so... But it didn't go away, and it got to the stage where I was falling out of my car to get out of the car, because I couldn't swing my hip in and out. And finally I had a hip replacement in August 1997, and that's really when the sport stopped. I couldn't really go out and play football or cricket. I don't know whether you ever could, but I just didn't feel that I could actually put that sort of strain on

- (9) my hip, because when I do anything like that, it's all or nothing - I can't take it gingerly or anything like that. So, most of my exercise, now, is walking and gardening, which is what I do. But that was August 1997, I had a hip replacement. And I was, I think, still controlling mainly with diet at that time. But then, from '97, it got a little bit more difficult to control it, and that's when I then started Metformin and all the other tablets, gradually increasing them until I was on, oh, eight hundred and fifty grams three times a day of Metformin and Glibenclamide. And I can't remember what the dosage of that was, but I was up to the maximum

dosage. And in that time, as well, I had, in April 1999, an angioplasty. I had a little problem with my heart. I was at work and I had pains, and I didn't really think... I thought it was just indigestion and carried on until I came home. And I went round to my brother's, who lives in the village as well, and... to fix his son's stereo, which I did, and I came home. And there was the pain there again, and I thought "oh", and I said to my wife it didn't really feel right. And then it developed, really, into a bit more severe pain, and then I got pains down the arm and pains up the side of my head, and this was about eleven o'clock at night. She tried to get hold of the doctor, but couldn't, and in the end rang for an ambulance. And the ambulance came and then I went into hospital for observation. And that was strange, 'cause I was in there for about a week, and then they discharged me. I didn't really know... one of the nurses... one of the people said they thought I had angina. But it was ever so strange - they

- (10) discharged me, and I thought "oh, right - okay". I didn't really think there was anything wrong with me, so I came home. And I'd failed the treadmill test in the hospital - fell off the back of it, because I just couldn't keep going. And then, when they discharged me and I came home, and the grass needed mowing, so I mowed the grass and back came the pain. And so I went down to my doctor and said about the pain - "it's back" - and if I walked anywhere the pain would be back. And the firm I worked for, at the time, had me on a medical plan, so... Apparently I was going to have to go back to the hospital in about, I think then it was about sixteen weeks for another test and see a specialist. And then, as I say, I went back to the doctor and said "look, my firm had a medical plan", and then I went... they said "oh, that's good, we'll get you in straightaway". So, within a day, I was back in the hospital and within another day I had the angioplast, and it was all done so quickly, and I was really impressed with that. But, I thought, really, I didn't know when I came out of the hospital that any of these were open to me - it was just that I happened to say to the doctor there was a medical. So, if I'd had to have waited, I suppose, for the National Health to go through, then there was quite some waiting time to see a specialist and then finally to get the angioplast done later, could have been quite a few weeks. And who knows what might have happened. Fortunately, since then I haven't had any real problems, but I'd become intolerant... they were giving me aspirin as well after that, and there were some other tablets that I had to take after that, but aspirin was one of them, and I started to get an awful lot of stomach upset. They then put me onto coated aspirin and that was okay for a while - I suppose about six months - and I started to get the stomach upsets again, so I stopped taking the aspirin. I must admit it was my own decision, really, and it seemed to clear up a bit. And then it came back. And I went to see the doctor, and he said that he thought it was about really probably time that I was on insulin, and as he didn't deal with insulin at that time - and I don't think he still does - he sent me to the Oxford clinic, and I think

that that was around about early 2000. And I went on to the insulin, and I'd said about the troubles with my stomach, so that I could then drop some of the Metformin. And since dropping back to a five hundred gram Metformin, I've had no more problems with my stomach upsets.

- (11) Before we go onto how you found insulin, can you talk about your own attitude to having diabetes, because you said that your father was quite ashamed of it?

Yes. I'm not sure that I was ashamed of it, but I certainly kept it to myself. There weren't many people that knew that I had diabetes - only if I went somewhere and had to have a special diet. It wasn't really special, but because I was on diet only, you really have to watch what you're eating, so puddings and things like that were out. So, if I went to a friend's or anything, then they would know that I was diabetic and couldn't have all these goodies. But, as I say, it was one of those things that you didn't really feel comfortable with. It was something that you kept secret, and I suppose, to a certain degree, I've done that for quite a long time - even, really, up until fairly recently; I would say, oh, I suppose when I went on insulin, really. I then had to tell people at work, just in case there was something, so there were one or two people that I told at work that were what you would call friends, I suppose. But it... I didn't let it be widely known. And taking the insulin: nobody knew I took insulin, really, apart from the, as I say, one or two. And I used to then... and then, in those days - the early days - it was insulin in the morning, insulin at night, so it didn't affect work too much. As I say, that was in 2000, and that carried on. So, yes, I was conscious of it, and certainly early on, when I was first diagnosed, I didn't know how to cope with it, really. It's the first time in my life that I'd had anything major, certainly, and so there was a bit of apprehension, I suppose, about it, and so you didn't really tell anyone. And I suppose I can understand my father in thinking it was probably a little bit of a weakness as well, yes.

Can you just talk about the mechanics of changing to insulin and blood testing?

- (12) Yes, 'cause the blood testing and everything else all sort of started about that time. I remember going to the clinic in Oxford, and the girls showing us... the nurses, sorry, showing us how to take the insulin - how to inject yourself. And I remember that absolute fear of sticking the needle in myself. I didn't want to do that; I really didn't. And they said "it doesn't hurt", but even so, just the thought of putting the needle in. And you go to the clinic and they lead you right the way through it, and they give you a needle to help - an unloaded one, obviously - and they do it themselves, which I thought was marvellous. And they showed you in my tummy. They said there was two places you can really do it, mainly: in the tummy and in your thighs. It used to be in your arms apparently, but it's very difficult to do it in your own arm, so I chose my tummy. I still have a little bit of weight there, so. And I was really surprised how easy it was to do. Obviously they give you the smallest needle there is, I think, to try, but it was so easy and it didn't hurt.



When you say the nurses did it themselves, do you mean they injected themselves?

Yes. They actually put the injection - there wasn't anything in the injection - but they actually put the needle into themselves to show how... one did it in her tummy and the other did it in her thigh. And I thought that was... well, it certainly was an immense help to me, 'cause I watched their faces and they didn't flinch, so I thought "it didn't hurt them", 'cause I don't think they would have covered it up - they'd have flinched or something. So, it enabled me to do it. But that first time that I put that needle in, I thought "phew", and I did it, and it wasn't too bad. And so then, a couple of months later, you go back to the clinic, they do an assessment of how much you need to take and all the rest of it, and they guide you all the way through, which was really quite good. So, I started taking the insulin. To say it never hurts is... sometimes it does - it stings. And at first I used to bruise quite easily, but I got used to it and got able to do it, and I don't bruise so much now; I don't hurt myself so much.

- (13) I think the... taking the sample out my fingers is probably the worst thing now - that really does hurt. And because I've got arthritis in my hands, some of my fingers you only have to touch and they hurt, so I'm really restricted to probably four fingers that I use now, so they get a hammering, but they're all right. But I think that's the one thing that I'd like to see some more improvement on is blood sampling. It is still the worst bit.

Did you do any blood testing before you went onto insulin?

Do you know, I can't remember - I really can't remember. The two seemed to go together, but I think I must have done some blood sampling before I went on the insulin because of the increase in dosage of tablets. So, yes, I think I did, but I can't remember when. It's just... now, it's testing and insulin; or it was then. That really is until I went... I had a job in French Guiana, and that was a real eye-opener, really. I'd got myself all prepared. It was for a three month contract working on the European Space Agency, and, as I say, it was for a three month. So, I went out there well prepared. I'd had all my injections that I needed for various...

- (14) prevent various diseases. So, I'd got my insulin pack all up and enough for probably about three months, but because it was French Guiana, they said that it was a French territory, they had very good medical out there anyway, so I needn't have worried too much. But I took it all out with me, and I was testing, so. But what I did find is that gradually - it was incredible - I didn't need insulin, and I didn't need half the tablets that I'd taken with me. I lost a fair amount of weight out there, and this I put down to the lifestyle, really. The lifestyle was a complete change from what it is in this country. Out there I had a good breakfast, and it was really a good breakfast - much more than I have here, and it was bacon, eggs, fruit, fruit juice for breakfast. It wasn't the same bacon as we get in this country, or the same sausages that we get in this country. And I don't really know exactly what it was, but it was a bit like Parma ham or

something like that, but it was all grilled, or might even have been fried for all I know! But we had a very good breakfast. This was about quarter past seven in the morning, so not much different from now at home, but, of course, it was cooked for you, so you didn't have that problem, and then off to work. And then we had a break, and it was about an hour and a half's break, because it was the French way, really. And we had a meal - and a really good meal - between twelve and half past twelve, I suppose.

Tell me what you had.

Oh, it was all sorts. There was steak - they really looked after you well - there was steak, there was fish. You could vary it all through the week - it was something different each week, cooked in a French style. There was often, as well, local fish and things like that were available. But it was a big meal. And I found

- (15) that suited me. And then, in the evening, I'd probably have a yoghurt - something like that, or fruit; I didn't need anything else. And able to go for a walk. It got dark at seven o'clock, so you weren't out for long, because they have... the day there is twelve hours day, twelve hours night. But walk along the beach, and that's how I lived, really. And occasionally went out in the evening to socialise and have a meal. But, as I say, I found I didn't need the insulin, I didn't need my tablets, and I'd lost weight. And yet I felt that I ate more - it was really strange. And, of course, there was a lot of heat - it was hot out there, so... but... And the walking around as well, because it was a site, and I was looking after a site, I had quite a walk around between various facilities, really, but it wasn't that strenuous. And a lot of things then disappeared that I suffer with now - even my hands seemed to get that much better. Certainly my hip, I didn't even notice that, although I didn't notice it for quite some time. So, it was just immense - it was amazing, the difference. And, as I say, I was out there for approximately three months, and I came back and my wife didn't believe that I wasn't having the insulin. And I said "I've got to carry on like this, I've got to carry on", and we made a conscious effort to try and live that lifestyle. But back in this country, it's so, so difficult, because you then start working. I work for a smaller firm - they don't have the facilities, so you can't get a meal at lunchtime.

We ought to give the dates that you were in French Guiana.

Oh, right. Yeah, I was in French Guiana from January 2002 till April 2002, so that was the sort of... the period. And I came back from that feeling a different person, I must admit, and I'd have done it again, but,

- (16) of course, you're away from your family and so you're missing your family. And living out in French Guiana is okay, but it's not like living in the UK - not quite safe, so you didn't go out in the evenings, so there was no evening socialising or anything... or very little - there was some. But the climate was incredible, and, as I say, the eating was so different. It

reminded me more of how we used to live when I was younger and the meals of when I was younger, 'cause Mum didn't go out to work, and everything was prepared and everything was done, and we ate... well, we had school meals. That was the big thing in those days as well, and so you had a school meal, and you came home and had perhaps, you know, a light tea - bread and jam or an egg, or something like that. It felt much more like that, I must admit. And, as I say, I came back thinking "yes, that's what I want to do and that's how I want to... 'cause I can then not have insulin, not have tablets and I feel better". And I then went onto the Proactive... I think it was Proactive research at the clinic, and you're really well looked after then, but I couldn't keep that lifestyle up. I went and worked for a small firm that you couldn't have a meal at lunchtime, so I was buying meals and microwaving them and all sorts of things like that, but it just didn't happen. And since then we've slipped back. I've gone back on insulin quite heav... I feel quite heavily. I don't know, because I think that's one of the things: that you don't know what's heavy, what isn't. There's still a certain lack of knowledge and understanding, and it's probably a lot to do with me, 'cause I don't go through the clinic and ask a lot of questions. I just go there for... and it must be hard for them as well, really, 'cause they don't get much feedback from me, I suppose, apart from I did tell them when I came back from Kourou how I felt. And it lasted, I suppose, about three or four months, and then I was

- (17) back on insulin. I put weight on, even though I tried desperately hard not to. And I'm convinced that if I could live that lifestyle, even now - I might be kidding myself - but I think I could actually kick the insulin again.

How often do you go to the clinic while you're on this study?

While I was on the study it was every two... roughly every two months. It varied a little bit, but it was every two months. And they look at your feet, and they gave me heart... they looked at your heart, monitored it, monitored your blood pressure and everything else, which is still a fight for me, even now - the last time I went to the clinic it was. But that was every two months, and it really is encouragement, really, when you're on that. I've now gone back to the clinic every six months, and I've just been to my first one. And you're there for a little while, and yes they give you some encouragement, because diabetes has to be treated by the person, there's no doubt about that. But now, it's not the same as being on the Proactive. It's quick, it's... well, for instance, they don't look at your feet - they might do the next time, I don't know. They did take my blood pressure and I gave them a water sample, but that was with the nurse, and then when you go and see the... I'll have to wait and see what the next ones are, but it's not quite as good, I have to say. As I say, some of that might be my problem, in that I don't seem to talk to them very well. I can't... and this goes back, I suppose, to upbringing, and a bit like my father, I don't readily talk about my illness. Really, this is the first time I've done that. I've kept it really to myself, even... like now, the last time I went to the clinic, and

I know my blood sugars are going up a little, but the problem is that... is my injections at lunchtime. I've missed them out, and the reason being - I've tried to think, 'cause it's...

- (18) you'd think it was so easy to take an injection. You know you've got to do it, so I thought "why don't...?"... And the reason being, I suppose: I've got probably three worlds. And, like most men, I think this happens, is that you've got your home life, which is at breakfast time and at evening time, so you've got your home. You go to work, and as soon as I get in the car and go to work, I'm thinking work. And I'm so involved in it that everything else - my home life, my diabetes - I don't have diabetes. It all goes and it's just concentrating on work. You don't really think... you don't even really think about yourself; it's just total work. And so, I get so involved in it, I forget to take my insulin, and I don't even measure it. I measure in the morning. Every morning, religiously, I measure and I take my insulin and I take all my tablets, 'cause it's all there and I'm locked into that diabetes world then. But, as I say, when I go out the door, it's totally gone. And I suppose it's probably... it's harder for me to understand - you know, it is very, very difficult. I can understand people saying that they do get wrapped up in another world and it just disappears. So, I've had to change a little bit now, and I've had to tell a couple of the people at work that I have to inject and that I need reminding at lunchtime. And there's one woman there that's really very good, and she's put it on her computer screen to remind me at half past twelve to have my lunch and take my insulin, because it was so easy just to grab a sandwich, carry on with your work. And even down to drinking, because I don't drink enough - I know I don't drink enough. I make myself a cup of coffee when I get to work in the morning, and that cup of coffee probably gets reheated in the microwave two or three times during the day. So, I have one cup of coffee during the day, and that is it, often. Now I'm trying to make that better with the help of some other people. You do need the help sometimes, because otherwise you just get wrapped up in your own world and that's it. And, as I say, there's the three worlds: my home world, my work world and my diabetes world, and really you've got to bring them all together, and that's been difficult. The one thing about in Kourou, those worlds did come together, probably because you're on your own, so everything has to be... you're in a different world - you don't have your home world there, you've just got work, and I didn't have to take my insulin, so you can't really tell. But the other thing I did do out there, because it was so hot, you were forced to drink a lot more.

- (19) You mentioned the encouragement you got while you were taking part in that study. What encouragement was it?

I think the encouragement was that they were there. You were seen, you were listened to, although it was sometimes difficult to explain everything that was going on, because you're... especially me, anyway, because I am conscious. I

know I've had a lot of things go wrong, but they all seemed to sort of happen in... as soon as I got to fifty and everything seemed to... But I don't... I tend not to dwell on it, but the encouragement that you need is to... Because it can be such a routine, such a... it becomes almost "oh, diabetes", you need to be encouraged to say it is worthwhile doing. And it has to be you doing - nobody can do it for you. I mean, as they say, they can give you encouragement, they can do all the... that, and I think that's the important bit, and I think that's... I get a certain amount from reading the Balance, the magazine. You don't get it from your own doctor, because I don't see him that often now, so you don't get it from there. You need it from your wife, but your wife isn't with you all the time, which is then why I think talking to people at work has been... you know, it's only happened the last couple of weeks, so... They didn't even know that I was taking insulin. They knew I had diabetes, but it didn't sort of affect my work or anything like that, but now that they're encouraging me to do it, I'm hoping - and we'll see over the next few months what happens. But you've got that encouragement every two months working on the Proactive, and the nurses on that really seemed to be good and switched on. I have to say, I'm not so sure about the 'run of the mill' ordinary clinic, which is every six months.

- (20) Can you describe, then, your recent visit, which was an ordinary visit - not to do with a study?

Right, yes, well, it was at eleven o'clock, quarter past eleven last Tuesday, a week gone. And I arrived there, a nurse came and did my weight and my blood pressure and took a urine sample - well, I gave her a urine sample. And my weight had gone down a little bit from what the last one was, which was quite encouraging. And then - and my blood pressure was up a bit - but then I went out and then waited for the... I don't know who, really, to be quite honest - the diabetic specialist. And they greet you and it's all quite nice, but I was in there about five minutes, if that, and that was it. And I can't really remember what we talked about much, apart from... oh, they said how can they help me? Well, that was a difficult question - how can they... I don't know what they can do to help me, so it was a bit of a... and in the end I said "well, nothing, really. It's down to me, I suppose - I have to do whatever's necessary". The one bit that probably helped, and it was to - thinking about it now - was to perhaps talk about it a bit more, and get an alarm clock to remind me to have my injection at work. But that was it. And I had to ask what my Hb1c reading was, and although my weight had gone down, the Hb1c had gone up slightly to what it was. So, we talked about the insulin, and I showed them my readings over the last months or so, and some were a bit high and some were... so it was pretty average. But I felt something lacking. I don't know - as I say, they didn't ask about anything else, they didn't prompt,

- (21) and I'm one of those people that need prompting. If they don't say anything, I certainly won't say anything. I don't volunteer a lot of information, I must admit, and I think, as I said, that's history - that's my upbringing. And perhaps other people are different, I don't know, 'cause you don't

actually have... the only person I get to talk to about my diabetes now is my brother-in-law, because he has just been diagnosed with diabetes late in life. And, of course, he now wants to know what's going on, so I talk to him about it, but I'm no expert and I don't know everything. But you don't really get the feeling that... oh, it's very difficult. You need, as I say, this encouragement, which is... may just be telling you what's happening and going over things again. What I found really good was when I first went to the clinic, for instance, you were told about your circulatory system and how it might be affected. And if you don't smoke and you can give up fats and all that sort of thing, you can open up your arteries, which, in hindsight, would have been a good thing for me to have had a little bit earlier, but you get that at the start. But, as I say, I've been on the Proactive, and they go through everything with you as well, even down to... ah, that's the other thing: eye sight. You know, "are you being checked?", and I happened to be checked - I've just been checked at Boots as well. But when you go to the clinic, all that just doesn't quite seem to happen. You do feel a bit on the treadmill. I have to say, you feel a bit - oh, you're just going through the routine. And that takes you half an hour - you come out the end of it, go home, and you think "why did we do that?". You know, there's no - and I should have asked, I probably should have asked - but I have to go to the nurse, our local nurse, to give blood samples, usually about three weeks before going to the... I don't know anything about those blood samples. I don't know... because some of them, I think, are for whether you've got fats in your blood stream or anything like that. All those sorts of things, you don't get to know. They

- (22) don't discuss that with you. They didn't discuss... they don't discuss anything, really, with you. I suppose they're trying to leave it to the patients to come, but some younger patients might be used to this, but I certainly wasn't. I didn't know how to deal with doctors until all this sort of cropped up. The only time I was in hospital when my younger days was I broke a foot playing football, so I had my foot up in a plaster, and that was the sum total of my involvement with doctors and hospitals in an early age. So, I don't know how to deal with doctors and nurses, and... But on the Proactive, it just got... it was so much easier; it really was easy. As I say, we'll have to wait and see with the nurse in the normal Health Service of the type of support you get.

Did nobody ask after your eyes at this latest visit?

No. And, as I say, apart from the Proactive one, they did look at my feet, so there was no problem, but I've never even been told about a chiropodist or anything like that, so... And I have had some problems with my feet, and I don't think it's anything to do with the diabetes actually, but who knows. They're okay now - I've sorted it out myself, which is probably a good thing, but...

But you've never been offered any chiropody?

No, none at all, which I found strange, because my brother-in-law, who's just been diagnosed - he did. So, it does seem to be which health area you're in as to what type of care you get, and that's not a... it's just it needs to be... it doesn't matter where you are, you should get the same treatment. And, as I say, the foot one is a big one. But, as I say, being on the Proactive, they looked at my feet, so there was no problem, but that is the only time that they did. You just seem to get... I know somebody

- (23) else is paying for it, so there is a difference in what's available, but it just... I don't know. It just seems you're not quite getting what you should get on with the National Health.

Can you describe a typical day in your life now, comparing it with a day in French Guiana?

Oh, right, yeah. Well, if I say now, I have my breakfast at around seven o'clock in the morning, and it's usually toast and a cup of tea. I've recently tried having some fruit as well in the morning, and that's it. Then I set off for work round about quarter past seven, and I get to work then. I drive about twenty two miles getting to work. As I say, make myself a cup of coffee that lasts all day, and then my work takes over, and I'm then doing electromechanical... I do a bit of designing, a bit of manufacturing, a bit of testing, help customers with their problems. We do oilfield instrumentation and down-the-well instrumentation, so I help them with their problems. And that's my full day from then, from eight o'clock. Supposed to have a half hour lunch, which we don't always... in fact very often don't take, 'cause I get so wrapped up in my work - I enjoy it. And so I then finish about half past four. It may well be later than that, and often is, so I may work up till six o'clock. Then I come home and have my main meal, which is something we've got to really try and sort out, because if I have a main meal any time later than seven o'clock, I don't feel well in the evening, so somehow I've got to try and sort something out. I'm not sure what yet, but I've got to try and sort something out on that. If I'm home early then we go...

- (24) we may go for a walk or I may do some gardening. And that's it, really. I do... I come in, then, in the evening. It's very sedentary, don't do very much, perhaps watch a bit of television, perhaps do some repairs on my grandson's toys and things like that, because he thinks Grandad can repair everything, which is quite nice, really.

Is it sedentary at work?

Yes, very much so. It's computer work. I could sit at my desk all day long. I don't, 'cause... "oh", you suddenly think "oh", and I get up and warm up my cup of coffee, but it is very, very sedentary at work. It is sat at the office, and that's what you're doing: sat at the office all day long.

What would you say are the main differences that diabetes had made to your life?

Do you know, I... it hasn't. Perhaps it should have done, but it hasn't. I don't

do anything different to before I was diagnosed diabetic. The one thing, really, is that in my life, and I do miss, that I was able to do was sport. Diabetes hasn't stopped that, but my hip has stopped that, but I really do miss it. I think that's the one thing about getting older, really, is the... that side of it I do miss. And there aren't the facilities, anyway, around. If you work for a large firm - I used to work for GEC and firms like that - they do have facilities. They have sports facilities, they have exercise machines and things like that that you can use. But when you work for a smaller firm or work on your own then you don't. And I suppose the big thing with being out in Kourou is that you did actually get some exercise in.

- (25) Although the job was wonderful, thoroughly enjoyed it and I got wrapped up in it as well, but they were geared into... they had an hour's break, and you had to take that hour's break. It was... the French seemed to enforce it, and so you get that... I mean, we didn't take an hour and a half, to be quite honest, but we did go and have a meal, we did walk around, and you did take that break, which in England, nowadays, it seems to be getting less and less, I think. You know, we're working... we work hard and long, and I don't think it always does us an awful lot of good, and it's sort of built up. And I really would like to know what the difference is in other countries with diabetes, whether this is a British, an American thing, or how it compares throughout the world. I know when - I think anyway - when Asian's come to this country, they have a problem. Do they have the same problem out in their country? Is the problem in Japan? You know, there's a whole lot of other questions that we really do need to know, and it would help individually, as well, if you knew. I'm hoping, as I say, to try and - I don't know how I'm going to do it - get back to that sort of lifestyle of having a - but it is a big one - having a meal at lunchtime. I can't come home. All I know is that everywhere I've worked where you have been able to do it, I've generally, looking back over it, felt better.

What would your message be to someone newly diagnosed with diabetes?

Find out as much as you can about it, and - it's come up with my brother-in-law in that I've said to him - "keep the diet going as long as you can". The trouble with insulin is

- (26) that insulin... you can vary your insulin, which I haven't really learned how to do. I tend to be rigid with how I take it, so that's the dose I take and that's what I do. So, you don't learn... with type two diabetes, you don't really get to know how to use the insulin properly, I think - that's... which I found with the Proactive team was good. But anybody starting off, I say keep on the diet for as long as you can, on the diet and tablets, because with insulin it is so easy to slip, because you can take some more insulin, and I don't really think that's the way forward. I'd dearly love to come off the insulin - not because it hurts, not because it... anything else. It's a bit inconvenient, especially if you're going out for a day and you've got to take it with you, and it's easier to pop a tablet in than it is



anything else. But I just feel that with the insulin it would be too easy to say “ah, I’ll take some more insulin”, and really it should be the diet that’s... And the other thing, as well, is exercise. My brother-in-law’s doing it, and although he’s having trouble now, because he’s at my age, but certainly to try and get some exercise in. And I don’t like jogging - I like sport, so I think it’s sometimes... I would say to people try and play something, just to keep yourself active. I have to choose gardening and a little bit of walking, but the walking is limited because of my hip. But diet and lifestyle, I think, are the big ones; I really do.

- (27) And then we’ll record a postscript - something that came to mind after we’d switched off the microphone. Can you talk about changes in attitudes at work to diabetes?

Yes. Certainly in the past I’ve been aware of firms having not always a helpful side to the diabetes and some prejudices. And I’ve seen it. I haven’t suffered it, because I kept it quiet, so, you know, there’s... that’s another side to diabetes in keeping it quiet, especially in a male orientated and dominated area. But I noticed it in one way that a colleague became ill and was diagnosed with diabetes in the workplace while he was at work. And he was fairly open about it, but the attitude towards him was not helpful. He - and it didn’t, also... it was hard, because it didn’t give diabetes a good name, because he did lose a fair amount of work through it because he had trouble in controlling his diabetes, and he had to go into hospital and one thing and another. And, I suppose, he might have been one of those people that just leant on it a little bit too much, and therefore gave a bad name for diabetes within the work environment.

And did people at work know that you’d got diabetes too?

Probably one or two, but not very many - certainly none of the bosses or anything like that. One of the reasons, I suppose, that I kept it quiet, because I didn’t want it to interfere with my work life, and I didn’t see that it should. But there was that element of nast... yes, nastiness, especially with this person. And you sort of defended him to a certain extent, but felt that if I’d pressed that too much then I’d also be in the firing line. And perhaps you do have to stand up and be counted, but it is very difficult when you’re in that type of environment. And now - admittedly it’s, ooh, getting on for eight or nine years ago, I would think - now the firm that I work in is a smaller firm, and, to be quite honest, they’re amazing; much, much better and much clued up. But, having said that, it’s more... they’ve got more women working there, and I think women are much more open about their problems than men are. If you’re in an all male environment then you tend to keep it quiet - you don’t say anything. As soon as you switch to a female environment, even men switching into a female environment, it’s different. I’m not saying that all males suddenly open up, because you don’t, but you suddenly are able to talk about certain things and get a much more positive result.