

#### 4. Shirley

- (1) I was born in 1944 in Nottingham, and I grew up with a brother until I was ten and then he left to join the Air Force, which upset me because we were very close. I was always a very sickly child until I was about ten, and then they took my adenoids out and I've never looked back since! And I went to a grammar school, called Mundella, which was by the Trent River, and I did all the sort of usual things that children do. I seemed to walk about a lot and spend a lot of time in the garden. My mother was always ill a lot as far back as I can remember. She had bad nerves, so whether there was any physical cause, I don't know. But after I did get diabetes, my cousin, young cousin, got it and died of it, and then my father developed it after me, after he retired, but he got the type 2. I think he sat around eating too many sweets after he retired, so whether I would have got it in later life if I hadn't had the fall I don't know, because that's what brought my diabetes on when I was twenty nine.

Why did your cousin die of it?

I think I'd had it about ten years or so, she was only eighteen and she'd just got engaged. It was all very tragic really. She got it and went into hospital with some kind of stomach bug, and for some reason or other they didn't discover that she'd got diabetes and she died within forty eight hours. And her mother was absolutely distraught because, because she couldn't eat properly, she'd been taking Lucozade in, which you know has got a lot of sugar content, to build her up, and she kept saying "oh, I've killed my own daughter", you know, and she was inconsolable for a long time. I don't know anybody else in the family who's got it, but then we're not a very big family, so it could be lurking there! But as far as I know, I'm the only one in the family still going now with it.

What did you do after you left school?

I went straight into the Civil Service, I'm afraid to say, 'cause my father was a Civil Servant and I didn't know what I wanted to do, so I just joined the Civil Service, which is what you did then. I said I wanted to go in the Home Office or something really posh like that, and they sent me in the Inland Revenue! And I've been there for forty three and a half years. So it's been quite good to me actually, because it's helped me with looking after my parents when they were both ill. I gave up for a time and went back part-time, and also they're very good on looking after you

- (2) when you're ill, you know. You can have time off because it's such a big organisation, and until recently they let you have time off to go to the clinics and things. They don't any more, they've tightened up on that. But it's been a good job to me, and I suppose it's ideal, really, for someone who's got diabetes in a sort of fragile way like me, because if I was like a road builder or something it might present a few more problems.

Now let's go back to the time of your diagnosis. How did that come about?

It came about, I was going on the bus and it drew up very sharply, and I tumbled right from top to bottom of the stairs - knocked the breath out of me. And the next day, I was very bruised but I thought I'd got away with it; I thought I'd just hurt myself like that, but then I gradually started to feel ill. I was terribly thirsty, very tired, and after about six months I decided something was the matter with me and I went to the doctor, and that's what it was. But funnily enough, it never occurred to me that's what it was until then. I became obsessed with being thirsty and I thought I was going mental or something! And because I was so hungry and I was eating about two or three cooked meals a day, and the weight was dropping off me, and I thought "this is wonderful", you know! And then I started to feel so ill and I got terrible stomach cramps and kept having blackouts in the street, and that's when I decided I should do something about it. But with no family background, you see, it wasn't the first thing that occurred to me really, and I hate doctors anyway, so. I remember going up to him and saying "well it might be just catarrh that's making me thirsty"! You know, I hadn't a clue that's what it was.

What year are we talking about, and did you know other people with diabetes?

The only person I knew who'd got it was the sister of a friend of mine, and she was an older lady, and all I thought was that she couldn't eat cakes and sweets and things. I had no idea of the full implications of it, and it's only dawned on me really over the years, because I don't think even when I was diagnosed I really understood. They told me I should feel shaky and dizzy and that, but they never really explained about things that subsequently happened to me, and so I think I was in a bit of a cloud cuckoo land really. I know I hated the insulin. I hated the way it made you feel, and I didn't like having to... because we had the glass and steel syringes then, which were quite difficult, quite heavy to use, so I didn't like having to do that, but apart from that it was no big problem I suppose, really!

- (3) The GP I saw referred me to Selly Oak Hospital because he was a locum and he'd got a friend who worked there, and I went along and saw the consultant in September 1973. The consultant's name was Dr Blatchford, wonderful man, and he said that I had to go in as an emergency patient, 'cause they did in those days, and I had to go home and get my clothes and that and go back the next day. And I was in for a fortnight, and initially they put me on a very high dose of insulin, I kept falling about all over the place, but after about a fortnight they said I could go home, and then I just was left then to get on with it really. So I came home with a lot of little metal needles and these syringes, and I got myself a saucepan to boil the syringes up in. And in the hospital they tried, they didn't let you actually go out, but they tried to give you things to do, like helping to give the flowers out and doing the washing up and, you know, things like that, just to keep you active so that you got some idea of balancing your movement as well as your insulin. And I was put in a critical ward, which was quite an experience, because of people coming in with heart attacks

and suicides and, you know, acute asthma cases and things. But it was very interesting, you got to know all of the different cases. But even back then, I can remember, because they talk about the shortage of nurses now, and I remember being very ill in the middle of one night, and it was a two storey building, like an out-building, and I was wandering all over the place in this kind of daze looking for a nurse to help me. And eventually this nurse was coming down the stairs from the ward above, and she picked me up and sorted me out, so things were bad, night nursing anyway, even back then.

Can you remember what kind of training you got to do injections?

I can't actually, I mean, I don't think I did the standard thing with the orange. I suppose they must have just showed me and I did it, you know, I don't remember them... The injections really weren't a big thing as far as I was concerned. I was more worried about the effect the insulin was having on me, but I never worried about the injections. The only thing that bothered me was knocking the air bubbles out of the syringe because, I still get air bubbles even in the plastic ones now. But it used to be quite a job, I thought, and I was terrified of getting the wrong dose, you know. But no, that's all the training, if you can call it that, that I remember having. They sent me home with a packet of glucose to put in water if I felt funny, which was absolutely disgusting stuff, so I just bought sugar lumps from then on, and that's what I still use now. They've tried giving me glucose tablets, but I don't

(4) like those either. Sugar suits me well enough.

What about testing for sugar levels?

Back in those days you had to do it in your wee, and as I wore glasses that can be a bit of a, because, you know, you have to sort of bend down and position it in the stream, and your glasses fall down the end of your nose, and you're trying to hold your glasses up! And it was a bit hit and miss, because you were given a selection of about four or five colours to choose, and quite often you'd think "is it that colour or is it that one?", you know, and you wondered if you'd made the right call sometimes. But that's all the testing there was then. And then they introduced something years later, a similar thing only it was blood, but you still had your strips and you still had to decide, and then, of course, recently they've brought in these little machines, which are wonderful because they give you the answer straight away. I think they've brought in a lot of wonderful things, because you had to... I think I saved, to get the blood out of my finger, I saved an old needle off the end of one syringe and I used that, I just used to stab my finger with it. But now you have this little thing that you press and a little thing shoots out, and does it for you.

What about diet, what training did you get when you were in hospital?

Well actually, I was looking for the little diet sheet they gave me and I can't find it, I must have lost it, but it was a card, and it was in three sections - green,

black and red. And you were absolutely forbidden to eat anything on the red one, you know, obvious things like biscuits and cakes and that, and the green one was like leafy vegetables and meat and that sort of thing, and the black one was, the consultant used to allocate you so many units a day, I think mine was ten, and each unit was worth ten grams of carbohydrate, so you could have one apple and two biscuits, and I think you could have five strawberries or something like that, you know, and about one and a half Weetabix, it was ever so precise. And you had to split it through the day, so many units per meal, and you had to stick to that, you know. I didn't see the, or did I see the dietician, I can't remember now straight away. There was a sweet little lady who used to be the dietician. I think, probably, I saw her maybe in the hospital once, and I sort of asked, you know, how much out of the ten I could go, and they said "only one", you know, the most, you know, you had to be really strict. I believe it's a bit more kind of, you know, you're let a bit more

- (5) flexibility now about what you do, but it was very rigid then. And, of course, living in a family made it a bit difficult, because I can remember when we used to have a rice pudding - my mother used to make me one in a little tiny dish like that, with one tablespoon full of rice and a Hermesetas sweetener, it was a little tiny pudding. And one time I fancied having a jam roly-poly, so I worked out I could do it with this tablespoon full of flour, and I did it and wrapped it up in a hanky and put some diabetic jam on, but when it came out of the saucepan it was only about one inch square, it was sitting in the middle of the thing! So I decided it wasn't really worth all the effort, you know. But you just sort of, because there weren't all the diabetic things and that now, I'm very into diabetic jellies at the moment because they're nice, but all that sort of thing, and even if you could get it, it was done with saccharin so it tasted a bit tinny, you know. The puddings they did you in hospital were horrible because they all tasted of saccharin as well. So gradually, over the years, I don't use sweetener hardly at all now. I remember speaking to a lady in a restaurant once whose brother had diabetes, and she told me that he ate rhubarb without any sweetening in, and I thought "oh no", but I do it myself now! Over the years, you just gradually find that you can't take the sweetness, and so eating the sugar is quite nasty for me because it leaves a nasty taste in my mouth, you know, but I suppose it's good really, because these sweeteners aren't all good for you, are they? But as I say, that's what happens to you. You gradually find your diet adjusts, and you think at the beginning you'll never get used to it, but you do, it just becomes a way of life. And I'm lucky living on my own, because I don't have to sit amongst people. Christmases used to be a nightmare at first, because my family used to love cakes and sweets and puddings and all that sort of thing, and I had to be sitting there saying "it's all right, I don't mind really"! And you have to, you know, not make it uncomfortable for other people but, you know, you just have to manage as best you can really.

How did your parents react to you having diabetes?

Well, my dad never said anything about anything, but my mother was a very strange reaction really, because, as I say, from a child she'd always been ill, we'd had the doctor up to the house I don't know how many times, and yet when I went home and told her, her first reaction was "your grandmother would have been ashamed of you", and I didn't know quite why. It was although I was a leper or something, you know. And it really hurt me, because I thought "well she's having the doctor all the time", you know, but I don't know why she thought that, I don't know if there's any particular stigma attached to being diabetic, do you? But it wasn't easy that was. Gradually, over time, she did get used to cooking for me and that, but I don't think she really, really accepted it, and even now my family, I don't think they really understand what it's like, and I don't bother trying to tell them, you know, I just try and manage as best I can and not make a big issue out of it.

(6) How did people react at work?

In the main, there wasn't a big reaction really. I think people were sympathetic, but they didn't really know what it was all about. I remember getting a card when I was in hospital from one of them, and it said "while you're ill in hospital" with a big question mark after it, and one of the nurses was quite indignant because she said "don't they realise how serious it is", you know, but I think it was pretty typical that, like me beforehand, I thought you just couldn't eat sweets and things, I didn't realise the physical implications of it. I did try to keep it very much to myself really. I didn't talk about it much, and I tried to hide it if I wasn't feeling very well because that's just the way I am, and I still do that now. And I've only had one occasion recently when I was so ill that I couldn't hide it, and then they were all getting very upset and wondering what to do, and they were saying "what shall I do, you're worrying us", you know, and I was saying "it's all right, just leave me alone, just leave me alone". So it's obviously better really, because people don't know what to do, and so the more you can hide it the better in my experience. A few years ago, I did work with a lady whose mother had got it, and she was very good, 'cause if she could see I wasn't very well she seemed to be able to pick up, and she would just go and get me a nice hot cup of tea and then leave me on my own. And that was a big help, because the tea was very comforting, and because I knew she knew I wasn't very well and if I needed help she'd notice. But there doesn't seem to be anybody like that now, because the only other people in the office who've got personal experience, it's older relatives and they don't have these hypos, if anything they have a lot of high blood sugars, so they've got not experience really of coping with it either.

Can you talk to me about the history of your hypos?

Well, at the beginning they followed the standard pattern of just feeling very shaky and light headed, and, you know, as though you haven't got the strength to go on, you know, and you can't make sense, you can't think clearly. If anybody asked you to add two and two together you'd have a job, you know. And I went on fine like that until, because initially everyone was on pork insulin and I was

on that for years and years, and then they introduced this human synthetic stuff, which they put me on obviously, and I was on it for some time, some months I think. And then all of a sudden, in the middle of the night, I suddenly came awake, and I was thrashing about in the bed like somebody having a fit. And this all went on for about an

- (7) hour, because that clock up there was striking, I could tell how long it had been for. And from then on, these have been the bad hypos that have led me to, you know, have these convulsions. And then I had one down here once in an afternoon, and I actually knocked myself unconscious. And when I woke up, the television was on the floor, things broken in the front room and everything - I must have rampaged all through the downstairs. And I always dread those, because even if I don't convulse, I can wake up and I have this kind of, I call it my bendy feelings, I don't know how else to describe it. But you feel a compulsion to sit up and move, and you nearly always want desperately to go to the loo, but as soon as you try to move your arms and your legs, they don't seem to belong to you and they go in all the wrong directions, and they feel as though they're made out of bendy rubber, and when you try to stand up, you fall over. That isn't the worst though, the worst is the feeling inside your head, you feel really weird, and a part of you knows what's happening to you but a part of you, it could be the first time and you're really frightened. I don't know if that makes sense, but fortunately my sugars are a bit more stable now. I have these, I still get them a lot in the daytime, but touch wood I haven't had one in the night which has made me go like that for some months now, which I'm very grateful for. But whether that was the result of this new, well I think it must have been the new insulin, because they put me back on the pork. I kept going to the hospital for about eighteen months and they couldn't seem to decide what was causing it, and then I went once and the doctor said to me "how did I feel about going back on the pork?", and I said "oh I'll try anything", you know, "I'm desperate", and he said "because we've been getting reports from all over the country that this insulin doesn't suit everybody, and people are having bad reactions". And a friend of mine told me later that she'd read in the paper that eleven people had died as a cause of being on this insulin, so I suppose I was lucky to get away with it really, wasn't I? But after that, I went back on the pork and things dramatically improved then. So whether some people, I know they've always told me that I'm very sensitive, because I think compared with other people I only take quite a small dose, and I've only got to have one extra thing on the thing and, you know, I can be all over the place, so I suppose some people are just more sensitive to all kinds of medication, aren't they, than

- (8) others, and that seems to have been my big bugbear.

Can you remember what quantities of insulin you've had over the years?

Oh, I'm afraid I can't, no. At the moment, I think it'll be somewhere round

about, round the twenty, twenty five mark, certainly not more than thirty I don't think, whereas speaking to some people at work, they have fifty six at a go, you know, which does seem off the planet to me. And when I first started, I just had one that lasted all day, and then they changed it to two a day, and then three, and now I'm on four, because you can get better control that way obviously. I think I'm on about thirty now I think, because they put me back on the human now because my control was slipping on the pork, so I seem to be on a bit more of that one. I didn't want to go on that at all, I resisted it for ages, but the nurse persuaded me in the end, and I'm still wrestling with that at the moment.

How long have you been on human insulin?

Just a few months now, a couple of months I think. The pork I was on for years. I was quite happy and comfortable with that, but they sort of keep putting this little bit of pressure because they know it's better for you, and I think it's been developed a lot more. Presumably there was just the one kind when I first went on it, but they've got these charts now that show you all the different kinds and the different lengths of time that they last, and when they peak and go down again, so I think they've probably refined it a lot more now, so hopefully it'll be a success this time.

(9) How often have you had hypos over the years?

I've always had, I think, more than usual. Whenever I've been to the doctor's, I've always been able to report quite a few instances, but it seems to have got worse over the last few years, and even now, with the new human insulin I'm taking, I'm still getting them most mornings. And the last two Sundays, I've had to turn back - I've set out for Church and felt so ill I've had to come back again, so I'm going to ring the nurse this week and see if I can adjust it again. At the moment it seems to be mostly mornings. A few weeks ago it was mornings and afternoons, and occasionally, say about once a week, I'd get one in the middle of the night, but as I'm a bad sleeper anyway, I usually wake up and then I realise that I'm having a hypo then, and I just come downstairs and make a cup of tea and go back to bed again. So at the moment, as I say, touch wood they're not any big problem because I know they're coming, it's when you don't know they're coming that they're a problem. And I've been getting through a lot of Tate & Lyle sugar, I'm thinking of taking shares in the company! But, they're all right, I don't think people at work, well I think if they do see me eating sugar, they know better than to ask if they can do anything, because they know they can't, and I just get over it. But the biggest problem is if somebody comes to me with a question and I'm in the middle of one, and I'm trying to make sense and talk to them. I'm silly really, I should say "I'm sorry, can you go away", but I don't like to draw attention to myself, because I'm always afraid they think I'm looking for sympathy or something, and that's the last thing I want, so I always try and just carry on as well as I can. And I seem to be doing all right, because nobody ever notices, because I've said to somebody once "didn't you notice I wasn't making any sense", and she said "no", so I've come to the conclusion that I must talk silly all the time! But I just manage like that. It's a nuisance if

you're out, because you do feel tired and you want to sit down, but there again you just plod on really, you just walk slower. I've been out on walks sometimes, I remember one terrible time I was coming home from somewhere, and I can remember literally ricocheting off the walls. I was coming down Woodlands Road and I was sort of bouncing off the walls, and I managed to get, goodness knows how I got home, I don't remember. And I was out once, and a neighbour of mine was out jogging, and he'd got an aunt who'd got diabetes, and he could see me sort of, I can remember these two women looking at me as though I was drunk, they probably thought I was drunk, and then he saw me and he put his arm through mine and helped me to

- (10) come home, which was really nice. But I suppose maybe people if, because I think if you're a man especially, sometimes the police assume you're drunk because you're incoherent and falling about the place. But it's surprising how you can cope really. I've never actually collapsed, I've always managed to be able to cope somehow. I don't know if it's willpower, it can't be willpower because it's a physical thing isn't it? But I never really understand why I don't get carted off to hospital, because if you are having a hypo and you're physically incapable of getting any sugar, you'd think you'd go into a coma, wouldn't you? But I never have. Even that time I was unconscious for hours, I just came round from it and I felt terrible, but I wasn't in a coma, and I'd obviously got concussion because I'd got a bruise on my head, and I was violently sick when I came round, so I don't think I'd been in a coma. And I asked the doctor once why I didn't, and he didn't know. So I don't know if there's a certain number of people who just don't go into them, because apparently your liver produces sugar, doesn't it, so maybe I've got a very efficient liver - I don't know! But it's very useful, because being on my own, it was difficult when my parents were alive, especially my mother, because I used to have to get up in the night to her and put her on the commode and that sort of thing, and I do remember sometimes feeling so bad, I was sort of leaning against the bed and wondering how I was going to manage it, but there again I just did it. I don't know how I did it. I think God was good to me - He does help me to cope somehow. I just did it.

Is it a worry to you living on your own?

Not at all, no. I wouldn't like it if I was with anybody, I don't think, because, as I say, I don't like it to impact on anybody else, I don't like to worry anybody else. I must say, when I'm having these bad ones, when I feel weird, it would be nice to have a friendly hand to hold then, but you can't just have a friendly hand for half an hour and then, you know, I mean, I cope anyway. But because it's better really, because if you're feeling really grotty and all you want to do is curl up in a ball, you can do that if you're on your own, whereas, like if I'm at my brother's or something, I have to put a brave smile on and pretend everything's all right. So overall, I think it's better being on your own. But I suppose if you've always been used to having somebody there, you'd probably prefer that



don't you?

(11) Has your diet changed over the years?

Yes, it's changed a lot. Of course, when I was with my family, I had to fit in with their meals and everything, so I found, generally speaking, I was just eating less of the same thing that they ate. The biggest change came to me a few years ago. My next door neighbour's son-in-law had a job where he ended up with a lot of spare fruit and vegetables on a Sunday, and she used to give me this enormous bag and I used to have to try and use it all in the week. And I've really got into fresh fruit and vegetables now, and I really feel a lot better for it. And I also, I eat a lot of the sugar free stuff that you can buy in the shops now, because you could only get diabetic stuff then, which was very expensive and not all that nice. I like sugar free jelly and the tins of fruit in the fruit juice. I think that's the only things I really have. I use sweetening powder if I absolutely need to, but I use that less and less now. And people buy me the diabetic biscuits and things like that, but I'm afraid they get crumpled up for the birds because... and they're such a waste of money, it's a shame. And people buy me diabetic chocolate, which is bad for you, so the nurses say. It gives you as bad sugar as eating ordinary sugary stuff, so that sort of gets binned quite a bit. Somebody at Christmas bought me some chocolate covered brazil nuts, so I soaked all the chocolate off and the squirrels had a lovely time with the brazil nuts! I feel awful really, but it just doesn't ring any bells for me at all. Sometimes I have one or two chocolates. They're useful if you're having a hypo, because although they're diabetic, as I say, they do seem to make your sugar levels go up for some reason. So sometimes I might... I had a couple of boxes given me at Christmas and I used them up when I was having a hypo to make me feel a bit better then! But apart from that, and I'm really into sort of things like wholemeal bread, and I've noticed I don't eat as much meat now either, and I just feel really well, apart from having the hypos. And it doesn't seem fair because I've got high cholesterol and high blood pressure, and I've tried doing all these things and it doesn't make a scrap of difference. But I think if you're a diabetic, it's just one of the things you have to... But according to the optician, my eyes are in good nick, which surprised them after I've had it for so long. So maybe that's a good side effect, because I think some people don't like keeping to the diet and I'm one of those people who like a routine, so now I'm into it I'd find it hard to come off it now. I think if they were to say tomorrow that I wasn't diabetic anymore, I'd probably

(12) stick to the same diet, because it's what I'm used to, you know.

Have you stuck to the same kind of rigidity of blacks and so on that you had to begin with?

I'm ashamed to say I probably have really, at the back of my mind. I mean, back then I did literally weigh things, and now I sort of use my eyes, you know, but, you know, I'm afraid I'm very boring. It's more or less the same skeleton outline as I've always had, 'cause it suits me. But I think I'm a bit of a pain

when I go out with me friends, you know, because I stick to my diet then. I do slip off it occasionally, but I'm not even tempted, you know, I'm not interested in trying new things and that. I'm a really, really boring person! You know, it's all right for me, but I do understand some people find it hard. When I was first diagnosed, I knew a girl, she was very, very thin, and I remember I had to go back in a few months later, just for the day for some reason, and she was there. I didn't know it was her because she'd put so much weight on, and apparently, she said, she just couldn't stick to it, she couldn't accept it, and they kept having her back in. So I often wonder what happened to her, whether she was alright. And there's a chap at work downstairs, he also can't stick to his diet, and he has to keep going into hospital with all sorts of horrible things, but he can't seem to stick to it either. There are some people that just, I don't know whether their mind refuses to accept it or what, but, I don't know what happens to them, because I'm always terrified of going blind or losing my feet or something, and I think that's another thing that keeps me on the straight and narrow as well, especially living on your own. You've got to be able to look after yourself, haven't you?

What complications have you had over the years?

I don't think I've really had any at all, as far as I can remember. The only thing I've noticed recently, when they put the tuning fork on your foot at the hospital, I have got a little place on one of my feet where I can't feel it. And I think I've got something called diabetic eczema in my ear once, which I've never heard of, but that's what the doctor said it was - it was absolutely driving me mad itching. I think probably itchings sometimes get on my chest, maybe that's connected with diabetes, I don't know. But I've always been really, really lucky, because they always say that you don't heal up from cuts and things, and you get lots more illnesses, colds and things, but that doesn't seem to be the case for me. Sometimes I wonder if I've really got diabetes at all, because I don't seem to fit the pattern,

- (13) but then if my insulin goes a bit haywire and my sugars shoot up, then you realise you really have. But saying that, I've never really spoken at any great length to any other diabetics so I don't know what their experience is, it could be the same as mine. I remember when I was in hospital once, a young nurse came up and spoke to me, and she said that she was something called a brittle diabetic, which I've never heard anybody else use that phrase, and she said it meant that she kept suddenly going into hypos all the time. So I don't know if there is any connection with the way I am 'cause I've never heard anybody else use that term, and that was right back at the beginning, in the 1970s, when I first had it. Maybe they call it something else now, but, I mean, she was a nurse, so it must have been a phrase that she had been taught by the medical establishment.

Do you feel that you're a brittle diabetic then?

Well I sometimes wonder, I mean, as I say, no one's ever suggested it, they just

say that I'm sensitive to the insulin, but maybe that means the same thing. But I do find that that's a problem with doctors, that, especially when you go to the clinic and you don't see the consultant, it's a different face nearly every time you go, and you get the impression they're just filling in their stint. And if you do ask them a question, they don't seem to know the answer, or you could ask two separate ones the same question and get two different answers. So over the years, I don't really trust doctors. I'm sure they do their best, but probably we expect too much from them, you know, and it is quite a specialised subject, I think. They've got these nurses' groups now that you get put onto if you're having a bit of trouble and they seem to know the subject a lot better, and I suppose the consultants probably do as well. But I seem to remember I mentioned to you once, going to see the doctor at the clinic and he told me off for putting my insulin up when I had bronchitis, which I thought a perfectly sensible thing to do, and he said I was wrong, that I caused this bouncing effect. Anyway, so I cut it down, 'cause I thought doctors were gods in those days and he had to be right, and I ended up suffering from terrible dehydration, which meant all the stuff on my chest thickened up, and when I tried to cough it up it stuck in my throat and choked me, and that went on for months. It was terribly frightening, and in the end I went back to Dr Blatchford and he knew straight away what the problem was. I could have hugged and kissed him, you know, 'cause I never thought I was ever going to get better. But, I mean, this was quite an older man, he must have had a lot of experience, that told me, and yet he caused me to have all that trouble.

(14) So what did Dr Blatchford advise?

Well he bunged my insulin up straight away and he got the pharmacy at the hospital to prescribe me this special linctus with ipecacuanha in, it was wonderful stuff. It was only liquorice water and ipecacuanha, but it was wonderful stuff - I wish you could get it now in the chemist, and from that time on I did start to get better. But I think you've got to be careful not to put too much faith in doctors about your diabetes, unless they're specialists, because it seems to be, there's a lot more to know about it than your General Practitioner realises, and I suppose this is why they always send you back to the hospital if you've got a problem. But sometimes you fall between two stools, because you're not quite sure if you're a medical problem or a diabetic problem, you know.

So when you're talking about "don't trust doctors", you're meaning GPs really?

I suppose so, or even these ones that just come and you never see them again at the hospital. Once or twice you do recognise a face and you have a bit more faith in them, but I think they've just got to do their stint, you know, of being a diabetic doctor for an afternoon or something. Maybe I'm wrong, but I'd rather trust my own judgement now, after thirty years experience, because you know what works for you. So maybe it's right for somebody else, but if it doesn't work for you, it doesn't work, does it?

Do you see the same consultant regularly now or not?

No, I don't remember the last time I saw the consultant, I'm not even sure what he's called now. The last time I saw one, I think it was Dr Page, I've seen his name up there somewhere, but I don't know whether he comes to the clinic very much. No, you just see a doctor when you go now.

What have been your experiences of the National Health Service over the years?

I have to say that I think I've been fairly lucky really, with my GP anyway, and general medical matters, I think Birmingham's pretty good. They've always got me in to see somebody fairly quickly, and no, I've got no complaints at all, I must say. Other people have told me terrible stories about what's happened to them, and I can only speak as I find, and I'm pleased with what's happened to me, apart from my diabetes, you know. But I suppose that's a big subject, isn't it? And the longer you have it, the more you think you know about it. Maybe I'm a bit cocky, I think I know more about it than I do.

(15) Do you usually do what the doctors suggest?

The doctors don't often suggest things, but I think I do if I agree with it, if that makes sense, and sometimes I just sort of smile nicely and go away and do what I think. And if they put me on to the nurses, I'll go for a bit and then I'll get a bit fed up, because I sort of feel, well I can tinker about with it as much at home by myself without having to, you know, go to them all the time. So I just get a bit fed up of being interfered with, I think, which is nasty, because if I'm really frightened about something I go back to them soon enough. But over the years, experience has taught me that I can usually work it out myself. Although saying that, now I'm a bit in a muddle with my actual doses, getting them spread out over the day, so I might need to get a bit of help with that, so I'm not probably being very fair. I think you've got to use your common sense. If it makes sense to you, what they're saying... I mean when I first went on this human insulin, the nurse said you must put it up an awful lot more than you're taking, and I said "oh, I don't want to do that, because it made me so ill before", and she said "well, I can only tell you what the right thing is to do". And I didn't do it, and then gradually I crept it up a little bit and a little bit, but I didn't do it as quickly as she taught me. I crept it up a little bit my own way, and I felt more comfortable with doing it. I think you like to feel that you're in control of things yourself, 'cause that's really what diabetes is to me, it's being in control of your life and your diet and your insulin, and feeling that you know what to do and how to cope, and, you know, just making it part of your life, and you're not dependent on anybody else for how you cope with things.

You said that you'd got irritated from time to time with people tinkering around. Can you think of any examples?

Well a couple of years ago, I did have to keep going to the diabetic nurses because it went a bit out of sync again. I kept going back for months and they'd just move it a little bit and send me away, and then they'd move it a little bit. Nothing ever got any better, and I kept thinking "what's the point of keeping going back, nothing's changing, they just keep moving it, and I could do that

at home”, you know. So I got a bit fed up once ’cause they kept me waiting, and I said “oh, I’m going home”, and she said “do you want to make another appointment?”, I said “no, thank you, I’ll sort it out myself”. And I went away and I did, and I don’t think it took me any longer than if I’d kept going back to (16) them all the time.

How did you sort it out yourself?

Well I just kept moving the insulin doses around until I got it more or less balanced again. I’m probably a very difficult patient to deal with, but it’s just that I like things to be done fast. I don’t like having a lot to do with doctors and nurses really, and if I can’t see why I’ve got to go to them, then I’d much rather just manage on my own, because it’s just a pain to keep going back to them all the time. And I know the nurse that I used to see back then, she used to make me feel like a rather naughty five year old child, so I think that probably had a lot to do with me not enjoying it very much, you know. Some nurses can be a bit like that, can’t they?

Have you noticed any changes in the National Health Service over the years?

Yes, I suppose they have to... they’re more friendly. I’ve noticed the GPs are more kind of, they treat you as an equal more and you can have a bit of a joke with them, whereas before you always called them “Doctor so and so”, didn’t you, and you were very respectful. But now you tend to feel as though what you think is as good as what they think, as far as discussing things goes, and you can ask them questions. And also, the way the hospitals are run and that, they seem to have got their appointments... ’cause when I first used to go for the follow-up appointments at hospital, you’d be there three or four hours, and now you can reckon to be seen within an hour at the very most, so they do seem to have sorted that out a bit. Can’t think of anything else really.

Have you noticed many changes in social attitudes to diabetes?

I’m not sure about attitudes. I think people are more conscious of it as being a very prevalent disease nowadays, but mostly, of course, it’s older people who are just on diet or tablets, so I don’t think they always appreciate what having a full blown hypo is like. I don’t know always, as well, whether people appreciate keeping to a diet. I know one or two of my friends, they say to me when I say “oh I can’t have that ’cause of my diet”, they say “oh, well I’ve got a friend who’s a diabetic and she eats this, that and the other”. And I don’t know if there’s a whole swathe of diabetics out there who are just not keeping to their diets or what, but I think there does seem to be a fairly casual attitude towards it, and that may be good. I don’t know if I’m too kind of uptight about it, but as I say, it’s not a subject I discuss with people generally speaking. If it’s people I don’t know very well, I’ll just say “I’m a diabetic, I don’t eat that”, and they say “oh” or something and just pass on, so it’s not a big issue really.

(17) One thing I have noticed is that when you go to, in my case, wedding receptions, that I’ve been asked beforehand if I’d like anything different to

the set menu, and that the things provided by the hotels have been very good, and, you know, made me feel I've had a nice meal, even although I'm not having what other people are having. So I think in that respect, probably, catering facilities are better and there's more choice now, as there probably is in sort of vegetarian areas as well. I think the catering industry is getting on to it much better than it used to do, 'cause right back at the beginning you either had what they'd got or go without, you know, and even if... I can remember asking for a piece of fruit sometimes instead of a pudding, and the terrible calamity and the flashing about in the kitchen trying to find you a banana or something, and they seem to be much more clued up to that sort of thing now.

Talk a bit more about changes in food available.

At the beginning, it was pretty dire. Everything seemed to be sweetened with saccharin, which always left a nasty taste, and the chocolate, diabetic chocolate used to look like that stuff you got left on the grocer's shelf and went all a funny colour on the top, and it tasted awful. But because it was all you had, you used to eat it and say it was nice. And there weren't all these lovely sugar-free sweets and jellies and tinned fruit in fruit juice, and that sort of thing. It was all from the diabetic counter, and it was all vile really, and it was all very expensive, but you had it because you were so desperate for a change from what you'd already got. Then, I should think about twenty, twenty five years ago, the supermarkets seemed to gradually start introducing sugar free and salt free things, and I cottoned on to the fact that there wasn't much available at the Boots counter any more and you could go into Sainsbury's and get nice things from there. And there's a wonderful range now, of tinned fruits and jellies. I don't tend to go in for the diabetic biscuits and things, 'cause that's just horrible and it's a waste of anybody's money buying it, I think. Years ago, Cadbury's used to do a wonderful milk chocolate bar, it was absolutely delicious, and then it suddenly disappeared, so I wrote to them, this was back in the 1980s I suppose, and asked them what had happened to it, and they wrote back and said they were very sorry, but the production costs far out... because they had to apparently cleanse this thing that they made it in, and it just wasn't worth all their time and trouble and money to do it, so they just removed it from the shelves. And I started to notice that there were German ones, the Germans seemed to be much better at this sort of thing than us, and they were quite nice, they were filled bars, I think the firm was called Hollicks or something, can't remember 'cause they don't have them any more, but they were very nice. They used to do an absolutely lovely marzipan one which was lovely, and then I went through a phase of eating nuts instead, but they're very fattening aren't they, and now I'm onto fruit instead. So you sort of refine your taste over the years. I think diabetics nowadays are a lot luckier in the little extra treat things they can get for themselves, because there's such a broad range of stuff that's produced. I think it's for slimmers probably, but the diabetics reap the benefits of that, and there's better sweeteners as well, which you don't seem to need as much of to sweeten things with.

(18) What effect do you think being diagnosed as diabetic has had on your life?  
How has your life been different?

I know this sounds a bit Irish perhaps, but I think in a lot of ways it's made me healthier, because it's made me stick to a reasonable diet and it's taught me about going out for exercise every day, and it's sort of made me take care of myself. On the downside, it's inconvenient when I'm with other people because you have to fit in with them, and sometimes if you're not feeling very well or something, and you have to try and get round that sometimes, so it can be socially a bit awkward. But that could be partly my fault, because I'm a bit sort of rigid and I'm not very good at adapting at the last moment, but then I'm not a very sociable person anyway, so it's not made a big impact on my life. But overall, I think it's had quite a beneficial effect on my life really, because it made me pull myself into shape. But it does have its drawbacks. You have to be prepared for the unexpected and be able to cope with things that happen suddenly, like when I was going to my nephew's wedding last Christmas and the train broke down in the middle of nowhere and I couldn't have any lunch, you know, and I had to cope with that. So you have to learn coping strategies for emergencies. But then other people have to learn to cope with emergencies for different reasons, so I don't know if diabetics are any different in that respect. You just have to know what to do, don't you?

How did you cope on the train?

I'd got my sugar lumps and I'd got a packet of biscuits, and I coped alright. I was only a bit worried in case we had to walk from the train to the next station, because I knew I hadn't really got enough reserves to cope with that, because it did happen just before lunch time. But then I suppose I would have just told the engine driver and they would have made arrangements for me, so there's always an answer I suppose, but it's just owning up to the fact that you are diabetic and not keeping it a secret probably.

What advice would you give to somebody being diagnosed as diabetic now?

I would say it's a horrible shock at first, I remember I cried to start with, but you do get used to it, it's amazing how you do. And after the initial shock, when you think you can't do anything or go anywhere or eat anything, you gradually realise that you can, and there's all sorts of ways of getting round it and thinking up little ways of coping. And it just evolves over time, and it's not nearly as bad as you think it is. Just sort of take it in your stride, and don't let it faze you too much.

(19) How have you been affected by changes in technology for diabetics?

As far as testing for the blood sugars, well we started off doing urine testing to start with, obviously. It's wonderful now, these little machines, and, you know, they make it much easier. As far as the syringes are, I've recently had to start using these NovoPens, which are wonderful things, because they do give you a very precise dose without you having to even... if you were blind, I mean

you can hear the clicks and that's no problem. But because I'm developing arthritis in my hands, and they're not very strong anymore, I'm finding it rather difficult to push the end in, I find it quite hard, so I'm hoping that when I come to the end of the ones I'm using, they may allow me to go back on the plastic syringes, because they're so light and easy to use. So as long as they can keep the flexibility in the Health Service and allow you the choice, I hope they will do that. I think those are the only real technological changes, because obviously the syringes are all in sealed units now, you don't have to boil them up on the stove every day. That's a big improvement. I can't think of anything else technological that we use that we didn't do before.

How much contact have you had with other people with diabetes?

Practically none at all. I've not been one of those people - I used to hear them in the clinic, sitting talking about their symptoms to each other while they were waiting, and I never wanted to do that. I did subscribe to the BDA newspaper for a time, but I found I didn't find it very interesting, 'cause I don't find diabetes very interesting really, so I cancelled that. But the only good thing that came out of it was I did send off for this book, and it used to tell you all the things you could buy in the shops and what the carbohydrate value of them all were, you know, like fish fingers and tins of soups and things like that. But I discarded that some time ago because I think it's very out of date now, and you've got most things up in your head anyway. But it's probably a good thing, especially if you're a youngster, 'cause it used to have a youngsters club that they could all join, 'cause I think young diabetics should really perhaps go to things together, because it must be tough for them at school trying to keep up, and I don't know how they do manage really, it must be hard for them. But as far as talking to adult diabetics, I just don't. And if I've ever met one at the clinic and they've wanted to talk about it, I'm just not interested at all, except for one poor young man who told me that they'd put him on a diet of only about 500 calories a day, and he was literally trembling like an aspen leaf, and I felt so sorry for him. I did talk to him about his, and that's the only time I ever have.