

18. Patrick Grogan

(1) Tell me about your background.

Right, well I was born in Bexley in Kent in 1935. Dad worked in... he worked in the ordnance factory at Woolwich, mostly throughout the war, because he actually was a heating engineer. And anyway, he... after the war, he volunteered, while he was... to go into the RAF, but he wasn't taken in to the RAF because he was considered to be too old. So then they said they'll put him in the army, and they put him in Remy. Then he was discharged in 1947. And I think it was in 1945 my mother had my youngest sister - she's ten years younger than me - and then my mother stayed at home, as did most of the mothers at that time. So, because of that, during this period of time, all throughout the war, we stayed in that area, except for I think it was about a fortnight, whilst the air raid shelter was moved from down the garden up nearer to the house because it flooded. And I remember that quite well, because I used to make little paper things to float on the water, and there was a spring in the garden. Then we came into Birmingham when Dad decided to change his job from working... he went back into the... Yes, that's right. He went back into the Royal Arsenal, but then changed into the Royal Dockyard, where he did - I don't know what he was doing exactly, but plumbing work, sort of heating work, and that. And he decided that he wanted to move up into Birmingham, where they came from. And I'd already got another sister as well, and she's four years younger than me. So we then came into Birmingham,

(2) and we lived on the east side of Birmingham; that's Alum Rock.

What year did you move to Birmingham?

I think it was 1950. It wouldn't be... yeah, it would be 1950, because I've got a photograph which is dated 1951, so, of the family, so therefore we'd know that's when it was, you know.

And when were you diagnosed with diabetes?

At the age of thirteen, when... I didn't feel terribly well. It was a Tuesday morning - I remember it because I asked my mother, I said "I think I've got the 'flu coming on", and anyway, she said "well, in that case, you'd better stay away from school". And I stayed away, and I gradually... I didn't feel right anyway; I don't know what it was. But anyway, I didn't feel right that day, and sort of the following morning I began to drink a lot; and when I say drink a lot - by the end of the day I was drinking probably a glassful of water every five minutes, or maybe three minutes in some cases after a bit. And my mother, when my father came home, she said "you'll have to get him to the doctor's, you know, because there's something really wrong". And having done that we went to the GP, and this doctor - he was an elderly man, he was about probably coming on to his sixties, I should say - and he must have told my father what was wrong with me. And anyway, I went back... I went to bed anyway, and I was in bed from overnight, and I was told I couldn't eat anything - only cabbage, and that's

all, because the rationing was still on then. And if you think about it, they sort of cut everything out. And I lost - between that time that he saw me and the following Monday, which was the earliest date they could take me into the hospital to go and get some treatment, I lost half a stone, which was

- (3) not very pleasant. And anyway, I managed to get up on the Monday morning to go to the hospital, which was an hour and a half's bus ride away and three different buses. I went to King's College Hospital in Denmark Hill, and I saw a Dr Lawrence, and Dr Lawrence was the leading specialist at the time in diabetes. And when I went to have a blood test in my arm - it was the right arm - I mean, to take some blood out of, I passed out, and all I can remember is a voice shouting "get him up to the ward!". And there was these two - they must have been hospital porters, I presume. Now I was very lucky, because it was either the eleventh of August or the twelfth of August, that Monday. So having done that, they rushed me up there, and I remember they ran with me down the corridor on a trolley, and this nurse put me into bed. The next thing was about half an hour later, they came and they said "right, we're going to give you this injection". And she gave me this injection in my arm, and said "right, in a few minutes we'll give you a dinner", and I thought "ooh, great". And in the meantime, after feeling... I was lying down, and then about twenty minutes later or so I began to feel all right, and I sat up in the bed and I was right as nine pence in about half an hour. And they gave me a dinner, which was the first real food I'd had for a few days. And the following... oh, then my father came and saw me after I'd eaten my dinner, and they must have explained to him what was going on, and what I'd got to do and all this sort of thing. And then he told me, he said "oh, I'll bring your Mum up tonight to see you", and he went home.
- (4) And the nurse, I think it was the following day, turned round and said "you'll have to have insulin for the rest of your life". And then, I think it was either the second day or the third day, she turned round and said "oh, well, as you've got to have it for the rest of your life, you might as well learn how to do it - here you are, put that into yourself". There was no sort of preparation like there is today, where they teach you how to inject an orange or whatever it is - none of that. It was just a case of "there it is. Do it". And, of course, the choice is stark - it was either do it or die, so you do it! And that's exactly what I did. And then I was allowed to get up and walk around the ward. It was only... it was a side ward, a small side ward with only two beds, and I occupied the one and then somebody else came, and they occupied the other one for a period of time. The thing that struck me most was that there was a young baby there, eighteen months old, who'd got the same problem, and they were treating that child. And after a bit you realise that you weren't the only one with that problem. So when they discharged me, it was about three, maybe four weeks later, I then had to go to the hospital every two weeks, every Monday, on a Monday. Yeah, that was right, every Monday on a

two weeks. And I kept doing that until I left school, which was at the age of fifteen then.

Have you got any other memories of RD Lawrence?

Well, yes, he was a big tall man. He'd only got one eye. I always remember that, because I don't know what happened to his eye, but I do know that he'd only got the one eye. And he'd got quite a powerful voice as well, and this one Christmas they had a children's party, and I remember him saying to one of the, I think it was a staff nurse or something like that, "oh, there's an awful lot of carbohydrates around here", you know, and I

- (5) heard him say it! And it always struck me as quite a funny remark, you know. But nevertheless, he obviously knew what he was doing, and he was quite a brilliant man, you know.

Apart from being taught how to do injections, or rather not being taught how to do injections, what other education did you get about testing sugars, or diet?

Well, you were told... Everything had got to be weighed, literally had to be weighed. And they gave you a small plate. It was like a stainless steel plate, which was used to put on... if you get a slice of bread, and you can imagine this plate was about two thirds of the length of a piece of bread, and you had to cut the top of the bread off so that the amount of carbohydrate in the bread was equal. And this was a thin sliced bread, by the way, which you can hardly get today. And you were told "cut it off", so that that would be the exact amount. Now, they gave you... what they did, they gave you a book telling you all the different values of the different foods, so that you eventually learnt what you could eat and what you couldn't eat. But, because of the fact that it was a rationed - everything was rationed in those days - they used to allow diabetic patients extra meat and extra cheese, but obviously you didn't get sugar; they took that off the list of things that you could have. So when you went shopping, because everything was rationed, you have to go and you'd have to give the coupons in. I've still got a ration book, by the way, somewhere in the house, so I can remember all these things, like tea was rationed, soap, meat, bacon, margarine or butter, whichever you... if you could get butter, but you couldn't get it very often. And you couldn't get, unlike today, you can't get

- (6) fresh fruit then, or you couldn't get... it was limited, so you only got... you could get an orange probably, if you were lucky, at Christmas, but you couldn't get it all the year round, and that was it. It was... they got rid of... Well, I remember when my sister first had a banana. I had to tell her that you had to take the skin off the banana to eat it! 'Cause she didn't know what a banana was, and because she'd never seen one before. And gradually things did get better. There was more food began to get into the shops, and they gradually eased off the rationing of the foods and things like that. One of the first things that I can ever remember was going, when I was quite... I must have been about five, five or six, no, five I think, because it was right at the beginning of the war, they had...

some sweets came into a shop, which was about a mile and a half away, and the word got round that this shop had sweets. It was in a place called Sidcup, Halfway Street, and everybody from miles around went down to this shop to see if they could get any sweets, because... There was queues were formed all over the place. And that was last time that I remember getting any sweets, and that was... After that they stopped.

- (7) You were diagnosed in 1948 when you were thirteen, so was everything taught to you as a responsible thirteen year old, or was it taught to your parents?

It was a bit of both. They expected you to learn as rapidly as possible the different food values, and they taught your parents as well. They had to, because fortunately my parents realised that they'd got to know these things. And my mother was rather strict, and everything... she religiously weighed everything. Now, it's quite funny, because later on in life, I think when my Mum was about fifty six, she actually developed diabetes, and she was fortunate that she went straight to the doctor. And the doctor said to her "well, how did you know you've got diabetes?", and she said "because my son's got it", and he said "oh". And that way, she'd learnt to recognise the signs. Now, it's obviously genetic in my particular family, because my sister - the oldest sister - developed it later on in life when she was, I think, early fifties; something like that, because I know she's had it for some time now. So it's obviously there within the family. And I know that an aunt on my father's side has also developed it in later life, so it just happens to be a bit unfortunate that it's come into both families when they merged together. But okay, this is one of those things that happens. It could be that because the diets long ago were different to what they are today. They're probably better for you, because you didn't eat so much. There were no ready made meals then - none. No freezers - you couldn't go into a shop and buy something out of a freezer, because there were no such things. And

- (8) everything that you got, you either grew it yourself, or you would buy it when it was in season. So, for example, apples - you could only get them when they were in season. They'd be English apples; no foreign apples at all. Plums, when they were in season. Strawberries would be more or less a rarity, but they would come in for about maybe three or four weeks, and then that was it, the season had finished. And it was always like that, and you just got used to it, because winter vegetables were available, and you would eke out the things like that. Everything that you had, it was always the same. You decided how much you were going to get and you'd have to make it last, because that was the way of life then. And all the neighbours were the same; they all had just a certain amount of food or whatever. But some people were better at managing some things than others, for example, my mother, because we lived in a hard water area, we had great difficulty in making the soap ration last. Now a lady up the road, she managed to have... she made her soap go a bit further, so what happened was that my mother used to swap tea for the soap you see, because tea

was rationed. And it worked fine; everybody did things like that, they swapped various things. Of course, your clothing was rationed as well in those days, but there you are. All the clothing had utility marks on. That was a mark to say that it was up to a certain standard, and that was it.

Just backtracking to the story of your diagnosis. It sounded very, very sudden. Had you felt ill at all before that day?

Well, it was very sudden. I'd had, previous to that, I'd had all the normal sort of childhood illnesses that you had then, such as whooping cough, chicken pox, measles, and then I had rubella. Now I had rubella about six months

- (9) after I'd had measles, ordinary measles, and I'm convinced to this day that somehow or other it sort of weakened my immune system to such a degree that it brought on this other problem that I've now got, you see. So no, I can't say that I really felt ill; it just came on almost over night.

And do you think that your parents or you had heard of diabetes before that?

I hadn't heard of it, but I don't know about my parents, whether they'd actually heard of it. They might have done, because I know they'd got a big medical book, and it's possible that they looked it up to see what there was about it, and maybe that was it; I don't know.

When you were in hospital, how were you taught to monitor your sugar levels?

Well, the truth is that, at that time, there was no home monitoring kits or anything like that. All you could do was to monitor urine samples, and that was it. And that involved having a little test tube, heating it over the... putting, I think it was eight drops of urine into this test tube with this, I think it was... something, you had to drop something into the test tube, I can't remember exactly what it was now. Anyway, you dropped it in and you boiled it up for one minute, and then you compared the colour to a colour chart, and that would tell you roughly whether you were right or wrong. Subsequently though, I went into - while I was living in Birmingham - I'd be somewhere in my mid twenties when I was asked to go into the General Hospital, where I had then become a patient. And I went there over the weekend to help this doctor look at my blood sugar levels and my urine output etcetera. And he compared all that, and discovered that there was no point in taking urine samples off me because I've got a low threshold, and it always gave a positive reading, even though

- (10) my blood sugar level might be quite low. And so, as soon as I found that out, I literally gave up doing any urine testing, because it was a waste of time. And so for a number of years, I could only tell by the way I felt whether I was right or wrong. Because you couldn't... the only blood test that you could get came from the hospitals, and they usually took quite a long time to do those tests. If you went into the hospital and you got an appointment, say the appointment was at say one thirty in the afternoon, it wasn't uncommon to not come out of the hospital until, say, five o'clock. There'd be great queues. I can remember what the hall looks like in the

old General Hospital in Birmingham, which is now the children's hospital. It was full of patients; there'd be lines of people sitting on the chairs all waiting to go and see the doctors, and well, that was it. You had to accept it because there was nothing you could do about that.

When you were in King's, what were you prescribed in the way of insulin? How often did you have to take it?

Twice a day. No, I can't remember what it was... oh, one was a zinc protamine, I remember that. That was the longer acting of the two insulins that I had. Exactly... no, I can't remember the first one, but anyway. And I've always had two injections a day ever since, so... You get used to it. You know that you've got to have it, so you govern your life according to maybe the time that you do the insulin, or... But I have a theory about this, that you don't let the diabetes rule you. I had an aunt, who was my mother's sister. She was diabetic, and she used to regiment herself really tightly. Now, I found that that was a waste of time.

- (11) I didn't believe in it, and I actually think that what you've got to do is to realise what you're eating and assess how much there is within it, within the product that you're eating. So when you look at it - nowadays most of the products have got an analysis on them and you can read what's on them - see if you think it's the right thing for you. If it's got lots of sugar in it, you'd probably say "no, I won't have that", or if you do, you'd take a limited amount, so that you know exactly what to do with it. I don't believe that you need to go eating special diabetic foods, because you don't. They're a waste of time and they're a waste of money, and they're a bit of a con trick. And it's much the same with a lot of the dietary foods, which you'll see in the shops, saying "this is good for you", and the probability is it's no better than anything else. So you just eat a little less of whatever there is.

Now let's go back to you coming out of hospital after, you said, three or four weeks in hospital. How did your family react to what had happened?

Well, they just had to... they had to adjust to the idea that I'd got to have a more strict regime, you know. I think it was a bit of a shock, you know, but they got used to it. And they realised that I'd got to do this sort of thing and keep to this very limited diet, because at that time it was a limited diet, because, unlike today where you can go out and you can buy whatever you like from wherever you like, there were no supermarkets as there are today. In fact, I can remember... yes, in about 1948, '49, one of the first Tesco's stores opened near us. And it was only a small shop, probably like, well, if you take two ordinary shops and put them together - that would be as big as it would be, and that was it. And most people in those days

- (12) used to shop at the nearest... there was Co-op shops, and then there was things like the Home and Colonial Stores - they were the forerunners of

Safeways, by the way. So those sort of shops were the shops, and there was a few departmental stores, but not many. Large stores didn't really exist.

Did your mother find it difficult fitting your diet in with the needs of the rest of the family?

I don't think so, because what she did, she adjusted the... I think what she did, she looked at what the rest were eating, and then sort of gave me more or less the same, but slightly less, if you know what I mean. So she didn't have this great problem in getting used to it. But she was, well, very strict in the amount that I could have, you know - "You mustn't eat this" and "you mustn't eat that".

Can you remember the reactions of your neighbours and friends to your diagnosis?

Well, some of them, I think, were a bit... I think some of them were a bit surprised and didn't fully understand what it was about. But when I was at school, I remember - I'd be about fourteen, yeah, be fourteen then - one of the teachers, who taught generally, I suppose you'd call it biology and that sort of thing, he asked me if I would mind if he taught the rest of the class about diabetes. And I said "no", because I thought then it might be better for me if they understood it rather than them not understanding it. And so he took this lesson on how the pancreas worked etcetera and what it did, you know, so much the same as he'd done with explaining how the heart works etcetera. But you didn't get, in those days, you didn't get sex lessons, there was none of that. That wouldn't... I don't suppose that there would be one child in the whole school who actually knew anything about sex at all.

(13) How did you manage your diabetes at school?

Well, I suppose my blood sugars used to run somewhat higher than perhaps was desirable, but... Most of the people, because they only got checked at their hospital appointments - the hospital appointments were more frequent than they are nowadays; I only go once every, what, year? And... or the last time I went it was fifteen months, I think, before I was checked. And you can... nowadays, where you can check your own, but then when you were at school... My father wrote a letter to the school telling them what was wrong with me, and that if I were seen eating something in the school lessons, they'd just take no notice, you see. But normally I didn't require anything, and I would come home for my lunch or I would take something with me, so this didn't make a great deal... it wasn't really a problem.

What about sport?

Well, I just took part in the things that everybody else was doing, so it didn't really make any great difference, you know. It's just one of those things - you did what you wanted to do, and I've... The way I look at it is, you do what you want to do, not what some of these people will tell you - "ah, you mustn't do this and you mustn't do that" - because it's a load of rubbish.

Who did say “you mustn’t do this and you mustn’t do that”?

Well, you get this from a lot of people, generally sort of more from GPs rather than anything else. I’m sorry to say this, but over a period of time, certain GPs didn’t quite understand. I’m not being critical of them, because it’s not their fault; they didn’t get enough education about what diabetes is all about. Most of my GPs, in fact, were excellent - they were brilliant with me, but every now and again they might say something, and you have to sort of say “ah, no, that’s not quite right”, and you have to tell them. And I found myself telling them

- (14) how it could be controlled and how you do it, and yes, they actually learnt from the patients.

But you weren’t told by hospital staff not to do things?

No, not generally speaking. They would leave you to do whatever you wanted to do, you know. They didn’t generally turn round and say “you can’t do this or you can’t do that”. They would... all they would do is to sort of... they might occasionally refer you to a dietician if they needed to, but in general they didn’t do that. And I found that the dieticians in the hospitals generally deal with new patients and not with existing patients, because most existing patients have learnt what they’re supposed to do, and if they haven’t learnt, then they jolly well should have done.

You were diagnosed at the beginning of what we would now call your teens, often a chaotic time full of drinking, smoking or whatever. How did you find this strict regime in your teens?

Well, I never took any notice, because I didn’t smoke and I didn’t go out drinking, so, because my parents didn’t drink and they didn’t smoke either, so it really didn’t bother me, you know. I just sort of thought “oh well”, you know. It’s one of those things - you either put up with it or not bother. And I found that it was best to ignore it, you know, and not broadcast the fact that you’ve got something wrong with you. I can’t stand people who carry on about saying “I’ve got this wrong with me or I’ve got that wrong with me”. If they have, why don’t they just deal with it and not make everybody else’s life a misery by going on and saying “I’ve got a bad heart”? And they broadcast it all over the place that they’ve got a bad heart or something, you know. There’s no point in doing that. You just have to get on with life and say “okay, well, so you’ve got to be a bit more careful than you might otherwise be, but...”.

Did you let people know that you’d got diabetes when you were applying for work after school?

Oh yes, I always told every employer, because a) you would need time off to go to a clinic to

- (15) get checked over, and b) it was important that they did know, because at one time I worked for a company, a machine tool company - I was building machine tools - and during that period when I was there - that was in the



early '70s - I did in fact collapse on a couple of occasions. But fortunately they'd got a surgery - there was a nurse there. And anyway, they just treated you and got you round, you know, so. So long as the nurse knew what was wrong with you, you'd be okay, you know, so.

Did your diabetes affect your choice of work when you left school?

I don't know if it did or not. I think it did, yes. Overall, yes it has, because I'm no good at it with a job which is... where I don't move around. Overall, I chose to do maintenance work throughout my life, and by doing that I was free to move around and do a job which was sufficiently physically active to keep me in sort of reasonably good health, without having to... I don't see the point of sitting at a desk. I did, at one time, operate what's known as a CNC miller, which is a machine which is computer numerically controlled. And you have to write out programmes for this, and spend quite a lot of time looking at drawings and working out how to make the machine work. But when the machine was working, that... you weren't doing anything after that. You were just sitting there doing nothing, and that used to irritate me a great deal. All right, that was in a tool room, but that's not the point. I found that that was somewhat boring, not being able to move around. And I found that when I was doing other jobs that I'd previously done, I could move round the factory where I was working, and I could chat to people and do the things which I wanted to do, which I felt that that was a much better system.

(16) What did you do immediately after you left school?

Well, I went in to do watch repairing, and it was all right, but when my father decided that we're gonna move up into Birmingham, 'course that job finished, and we moved. And then I looked around Birmingham, and I got another job with another man in the jewellery quarter doing watch repairing, and I stayed there for a while. But eventually I realised that my eyesight wasn't quite up to doing things like that, so I moved out of that trade into... I went, actually, into instrument making. And then... it was all right, but again I was tied down and I didn't really enjoy it, so I - jobs were more easy to get then - so I managed to find a job which was doing maintenance work. And it suited me down to the ground, because I like that, and it was... And I carried on doing maintenance work ever since, and right up until, more or less until I retired, you know.

And when did you get married?

1968, so I'd be thirty-three, or something like that; or thirty odd anyway!

How did your wife, or previous girlfriends perhaps, react to your diabetes?

Well, some people would understand, and other people... My wife understands, you know, but the first... I remember the first time that I had a hypo, my wife was... she panicked a bit. And then, after a bit, she realised... I don't know, I think she sort of found out what to do, and after that she just takes it in her stride; it doesn't bother her now. In fact, she's more able to tell if my blood sugar's going down than I am. She just looks at me and says, you know, "you

better get something to eat". And the reason for that is that over a long period of time, the sensitivity to insulins decreases.

- (17) And I had... when I had human insulin, I couldn't tolerate it at all. In fact, there was one morning when I got up, and I'd just done my insulin, and I'd only walked two steps across the landing - now my blood sugar must have been low at the time, but I didn't realise it - and I just went flat out onto the floor. She heard me hit the floor, and she tried to get me round but couldn't, so she called the paramedics. The paramedics couldn't get me round either, and they rushed me to Selly Oak Hospital, which is the hospital which I'm under, and they spent about probably an hour before they got me round. And they were, I believe, they were quite worried at one time, and then... Funnily enough, I was only in my pyjamas at that time, but I was whipped off to the hospital with just my pyjamas on and nothing else. So then, when they'd fixed me and I was okay, they said "right, you can go home now", you know, and so I had to get a taxi to go home. But it's one of those things. I couldn't tolerate human insulin because I got no warning at all. And as a result I asked to go back onto animal insulins, because, I understand, I was told by a doctor that I know, he said "yes, there is a difference". The animal insulin has got... the chain of molecules has got a little tail on it, if you like, to put it like that. And he said "that is the difference between this so-called human insulin and the animal insulins - there isn't this tail on this human insulin". Now the human insulin is a synthetic insulin, it's not indeed human at all; it's made from *E. coli* and it's a by-product. And the company that sort of rules the roost, if you might put it
- (18) like that, did threaten at one time to take away animal insulins, which are made from a powder, and they're... they add a liquid and that, and a preservative in them, to reconstitute them. Whereas, the ones which they call human insulin, whilst they suit most people, there is a group of people whom they obviously don't suit. And there has been cases recorded which people have actually died, because - usually young people, by the way, who've not got much experience of diabetes and how to control it - and usually they've died of hypos, usually in their sleep.

Can you remember what age you were when you changed onto human insulin and had this crisis?

I don't know about what age I was, but I do know that it would be somewhere in the eighties, because I certainly couldn't... I found it very difficult to control. With this human insulin, it was... I couldn't sense any difference in myself at all, and then you'd suddenly feel... you'd suddenly start to... well, it's difficult to explain. Sometimes, with some people, you get all sorts of different feelings, like you might feel sweating for no particular reason, or you might get double vision - things like that, or you just may just feel unsteady on your feet. This sort of thing happens, and, but it just affects different people in different ways. My sister tells me that if she gets low blood sugars, she feels hungry. Now, I

have to admit that it doesn't necessarily apply to me, but I do know, with the present insulin that I'm on, that

(19) I do get some sort of warning. I get... I feel shaky and I don't feel right, and therefore I know that there's something wrong. And what I usually do then is to either go and eat something, or go and take a blood test and find out what level the blood sugars are at. Now, I've had blood sugar levels go down as low as 1.8, which is extremely low and extremely dangerous, and it's this loss of sensitivity which causes the danger to you. Now, I never go out without first of all eating before I go out, because that way I know that I shall be safe. If I walk down the road to wherever I want to go - I go to the shops or somewhere - I'm not going to collapse in the middle of some thoroughfare. So, I can go out for the day, like I went out the other day to London for a lobby. And I was perfectly okay, because I'd done my insulin before I got on the coach to go, I'd eaten before I got on the coach, I'd take some food with me while I'm on the coach, and I eat while I'm on the coach. And on the return journey, I knew that I could do my insulin on the coach, and then eat again. So, it really is a case of doing what you want, and not sort of letting it govern you; you can't do that - you can't let it govern you.

(20) How did the staff at Selly Oak react to you wanting to change off human insulin?

Oh great, they didn't mind at all. The doctor that I asked turned round and said "yes, that's perfectly okay". And I told him the reason why, and he said "right", and he wrote me a prescription out. And it was only for a small amount, and then he wrote a letter to my own GP saying that I'd been prescribed a different insulin, and that was it; there was no problem at all. Usually the staff in the hospitals have specialist nurses, and they are usually... if you've got a problem and you want to get some advice, you can go to them, and they'll give you the advice, and they will tell you what to do, you know, and how to do it. And I was in there for some reason or other, I don't know what it was now, and they said about where did I inject, and I was injecting into my thighs. And I said "well, no one's ever told me anything different", and I said "but it's caused them to swell up", and that is excessive fat tissue, and the insulin then doesn't disperse in the way that it should. So, when I mentioned this to the nursing specialist, she turned round and said could she have a look, and I said "yes", and she said "oh, have you not changed the sites?", and I said "well, no-one's ever told me to change the site", and she said "well, anyway", she said, "you should change the site". And she suggested that I put it in my stomach and that, and so they calculated out how much less insulin I'd got to take. And I did that, and it worked fine. And

(21) much to my surprise, the insulin was working much better and I was taking a lot less, so I was quite pleased over that, and I thought "that's great", you know.

What sort of age were you then?

Ooh, probably fifty, I should think.

So, for perhaps nearly forty years - am I doing my maths right? - you'd injected in the same site, and nobody had told you to change? So how much contact had you had with the medical profession in those forty years?

Well, I suppose I went on a regular basis to the hospitals, but when you go to your GP, really they hadn't got real responsibility for your care, because it's only in more recent times that they've altered the system. Nowadays, the PCT is doing more of the actual day to day running of the system.

Can you spell out what PCT is?

Yes, wait a minute... it's the Primary Care Trust. The Primary Care Trust is responsible for allocating the money which goes to each GP within your area, and they also give money to the hospitals within their area as well. It's quite a complicated system, but... because each of the hospitals is looking for money. But a certain amount of the money comes direct through grants from government, and then the rest of it they get by doing various other things, like getting a certain amount from the local authority for care of the elderly, and there's lots of other ways in which they try to get money. Now, the system is changing, where they're being awarded so many stars according to how good they're rated. And each hospital, they're suggesting that they all are turned into - each hospital has got a trust running the hospital - and each hospital is going to be turned into what they call foundation hospitals. Now these foundation hospitals will be receiving money from the government, but they've also got to... they will get paid according to how many patients they treat. Interestingly enough, I've just discovered that the acute beds in Birmingham are to be cut across Birmingham and the West Midlands by thirteen hundred beds, however some of the intermediate beds will be increased, so maybe the balance might be all right in the end, but it's questionable. The cost of running these foundation hospitals - they're not going to be owned by the NHS, they're going to be owned by private consortiums - and the money, they will have to pay back a rental for the hospital, the use of the hospital. This is quite interesting

(22) in my opinion, because over a period of time it's been discovered that all these new foundation hospitals are beginning to run into problems. They've all been built over budget. Now, Birmingham has... in south Birmingham they are proposing to build this new hospital, the new Queen Elizabeth Hospital, and when they do do that... They started off some years ago at a figure of one hundred and ninety two million for this hospital. The latest figure that I've heard is six hundred million, and I'm prepared to bet that it will go up even more, because none of the hospitals which have been built like this have kept to budget.

How did it work in the past, during those forty years when you were always injecting in the same site?

Well, the hospitals previously were all... My blood sugar levels kept reasonably okay, but it was... it's hard to tell, because for a long period of time I had no means of telling how good the blood sugar control was, until I bought a blood glucose meter.

When was that?

Probably ten years ago now, I suppose. And, of course, one of the problems was that when they first brought blood glucose meters out for the public to buy, they were expensive. And the first ones, if I remember rightly, came out at about anything from about eighty pound, hundred pound a piece. Now, my income wasn't that good, so I left it until they came to a more reasonable price. When I bought my first meter it was about thirty pound or so. Of course, you can get the VAT back on that by claiming exemption, so you don't have to pay the VAT on that. Now you can get a blood glucose meter for ten pound, so they're more affordable, they're much better and more cheaply made. They're just as accurate,

- (23) and in fact, because they're easier to use, it's probable that most people can obtain one for themselves. In general, the hospitals do not give a blood glucose meter, except in certain cases. Now, if they find that a patient is on a low income and unable to afford it, and they consider that that patient should have one, they are able to give the patient a blood glucose meter. And they will do that, because it's in their interests that the patient keeps good control of the diabetes, because the complications from diabetes are serious. You can lose your eyesight, you can get strokes or heart attacks; all these things are there, and it's much better if you can keep it within reason. The more you can keep it normal, in what they would describe as a normal level, which is, for a normal person it's between the level of about five to seven, and that is quite a close tolerance. If it falls below five, you're going toward being hypo, and if you go the other way and it's too high, and it runs too high for too long, it will certainly damage your general health; it depends on how bad it is, you know. I did know of a case where one lad refused to do insulin, and as a result - he was only in his thirties - he was going blind. Now that was... to me, that was absolutely stupid, but then that was up to him, wasn't it?

You said that as soon as you started using a fresh injection site, the insulin dispersed better and, you know, everything improved. So why do you think you or the medical profession had allowed yourself to go so long using one site?

I think it was just that they didn't realise that... they'd no reason to ask me whether I was moving it around or not. I was... you see, you start at the top of the leg and work down, and then alternate the legs, so... I suppose it didn't occur to them - why should it? I mean, it wasn't the sort of question that they would normally ask

- (24) people, and the probability is that they thought that somebody else had already told you how to move the sites around. For example, you could do

it in your arms or in your stomach; wherever, so long as there's sufficient flesh on you to enable you to do it, you know, so. And since the needles are only comparatively short and small... I suppose, if you were a doctor, you wouldn't necessarily sort of say to every patient "ah, do you move the site around?", because if the patient comes to see you and the blood sugar levels are reasonable, and they've been reasonable over the previous, say, three months, you've no reason then to suppose that the patient is not doing the right thing.

Who have you found most helpful with your diabetes: GP, hospital consultant, nurse, podiatrist?

Oh, undoubtedly the consultants are usually the best. It's very rarely that I've gone to the clinic and sort of said "I didn't like that particular doctor that was on". Occasionally I found there was only one doctor which I didn't particularly like. But most of the doctors, or a good many of them, actually had diabetes themselves, so perhaps that helped them to understand what was happening to you, and I believe that that was probably a good thing.

But it was a nurse who advised you to inject on a different site. How do you find the nurses?

Most of them I find are excellent, because... I've never had any complaint about any of the nurses in the hospitals, or indeed even in the doctor's surgery, now that they've put nurses into the surgeries, which is a comparatively new thing. They're all... they're training the nurses more frequently than they used to. All of them get training about diabetes, they get training about people with heart problems, renal failure. All this sort of thing is taken into account, so therefore the

(25) system has improved enormously; there's no doubt about that. Waiting times - when you go for an appointment now, you're likely to be seen within... if not bang on time for your appointment, certainly within a very short time of that appointment being given to you. So the system is greatly improved.

How is it that you know so much about the National Health Service?

Well, one of the reasons I know such a lot about the health service is because I'm a member of NHS Concern, which is, if you like, a group... whilst it's political, it's non-political; it's not tied up with any political party. What we do is, we monitor what's going on in our local hospitals and what's going on within the community. And I'm also a member of the West Midlands Pensioners Convention, and as a result of that, I represent the West Midlands Pensioners Convention on BACUP, which is an organisation which the City Council and the... Various organisations have come together to give advice to the City Council as to the needs of the elderly, and this includes members from social services, or rather social care as it's now known, and other... The medical staff come to the meetings as well, so you get to know these people who are within

the organisations, and you know what they're doing - this includes mental health - and everything else that there is. Because, throughout life, most people, or by far the greatest number - about eighty percent of the population, will go through some form of mental health crisis. It's not unusual. Really, there isn't any stigma to it, if you think about it, because they now call it stress and all sorts of things like that. But

(26) it happens, 'cause most people find that there is a point in life when things get on top of them.

Has that happened to you?

Well, no... I don't know really. Some things are a bit more stressful than others, but no, not all the time. I think it's one of those things. I happen to be very laid back, and I let things roll over me and I don't take any notice. I don't make... if somebody upsets me, sort of thing, I don't carry that on because I just accept it. And okay, they've got a difference of opinion with me, and I shall just leave it at that and say "okay, we'll agree to differ". And I think that's the best way of dealing with things, because most people do have differences. They see things from a different angle, maybe because they're... some people don't care. Now I go out doing... I also go out doing charity house to house collections, like last week I went out doing house to house for asthmatic people. I believe you've got to put something into society before you can draw out of it. And there's one thing that I always tell people, that is "when you came into this world, you needed somebody to help you. When you go out, you're going to need somebody to help you. And while you're here, you're certainly going to need somebody else to help you".

How has your life with diabetes changed over the years?

Well, I think it's got easier if anything, because nowadays the regime isn't as strict as it was. There's more choice of food, which I've already mentioned. You can buy almost anything that you want, so by selecting the right sort of foods, you can keep reasonably healthy throughout your life. There's no reason why you shouldn't; not the way I look at it anyway.

Have you had any complications?

Not really, no. The only thing that I've got now is I've got a very slight beginnings of cataracts on my eyes. Now, my mother had that, so whether that is just ageing, which I suspect it is, rather than anything else. And if you keep your blood sugar levels under control, cataracts should not grow fast, but if you have got bad control then the eye will deteriorate much quicker. So, the real answer is to try and keep yourself as near normal as you can for as long as you can, and there's no reason why you shouldn't. I mean, I can still read even quite small print - because I'm short sighted - without glasses, so to me, the answer is got to be just look after yourself. And if you look after yourself, you'll be fine, you know.

Can you describe your daily regime then, which is looking after yourself?

Well, I always... I usually have the same sort of breakfast. I usually have a cereal which is, how can I put it, not a sugary cereal. In the winter we eat lots of porridge, which... and the reason for that is, not only is it cheap, but it's good for you. It keeps your ticker going okay, and it keeps the cholesterol levels lower, which is what you want, so. Well,

- (27) you know, something that is perfectly normal. I don't think that I... We eat a lot of fruit and vegetables.

When do you take your injections?

First thing in the morning, and then in the evening. And if I find that something does go wrong, like you get... maybe you get 'flu or something - you shouldn't, because I'm supposed to have a 'flu jab - then after that you should be fine. You know, there's no reason why you shouldn't remain perfectly all right. If you do get something like a very heavy cold or 'flu or some other thing, the answer is that you check your blood sugar levels. If it means increasing the amount of insulin that you have, or the frequency of the insulin, then do it.

What type of insulin are you on and what kind of injection?

I'll have to go and have a look and tell you, 'cause I can't... oh, Actrapid and Insulatard. These are both pork insulins, which are fine as far as I can see. They don't affect me. They make me, you know, they keep me okay, so as far as I'm concerned, that's it.

And what kind of... What do you use to inject?

Well, I'm just using the ordinary plastic syringes, which, unlike the old syringes, which used to be... When I first had diabetes you had a glass syringe, and then you had to replace the needles on the syringe. Now, at one time, in order to keep those syringes clean, what they suggested you did, you kept it in a case, which I'll show you in a bit. And the syringe was put into surgical spirit, which they don't do any longer, because they've realised that surgical spirit, if you keep on rubbing it on your skin, it hardens the skin. And if you get any of that spirit still left on the needle or inside the syringe or anything, it'll hurt like hell.

- (28) And so what they did then, in order to keep the syringe clean, you had to boil it -take the syringe apart and put it in a saucepan, and boil the syringe in water for about five minutes. And that would take away any sort of thing which had built up in it, or anything wasn't right, it would sterilise it again. And then you just let it cool off, and you could re-use it, you know. And the syringes used to last, or they lasted me, usually about anything between six to twelve month, and then you'd have to go and get them replaced, because they gradually, a glass syringe gradually wears away. But with these disposable syringes, you're supposed to use them once and then get rid of them. Well, that works fine, but I'm afraid that I sometimes use the syringe more than that.

How much more?



Oh, it depends. I have used the syringe the whole week if necessary. But I was told that this, you know - I don't know who told me, but somebody told me anyway - you ought not to do that. So I decided that the best thing to do was to comply with the instructions on the syringe, which is use once only and then destroy it. So I do tend to do that more frequently now. And that's it, you know; this is what I do.

Have you been offered a pen instead of a syringe?

No, I haven't been offered a pen. When I did ask about pens, unfortunately the nurses in the clinic sort of said "no, they don't do them for that type of insulin that you're on". But I've subsequently found out that isn't quite true, that it was probably lack of knowledge at that time, that they didn't realise that you can actually get a pen now. But I've been using the syringe for that long that I don't take any notice now. I just sort of say "oh well, you know, I might as well just use a syringe", 'cause it works, and

- (29) it's convenient, so I don't take any notice. A pen would be better in certain circumstances, but they're also more expensive I believe, and so it's questionable, really, whether you ought to put the health service to extra cost. And I feel that there's no need to put them to extra cost, because if you've got something that works: keep it. There's no point in repairing something that is not broken.

And then continuing with your daily routine, how do you spend the rest of the day after your morning injection?

Well, that depends. I take the dog out, and then I'll come back home. I'll probably do... I don't know, I'll probably... I might do some gardening, I might do anything; it all depends... I might go out to a meeting. I'm not too regimented, in the sense that I always do the same thing at the same time.

Do you have a lot of exercise?

Well, I walk a fair bit, yes. I can... it's not uncommon for me to walk, say, three miles a day quite easily, and I don't take any notice, 'cause I'm quite used to that. I believe that it's fairly good for you; you might as well do that. You might as well walk, 'cause there's no point in... When I go to get my pension, sometimes I'll walk down to the post office, which is about half a mile away, so it's half a mile there and half a mile back. But I'm so used to it that I don't take any notice, you know; it's easy to do.

In your life, has your diabetes stopped you from doing anything you wanted to do?

No, not really. No, it hasn't, because I... The only thing that diabetes will stop you doing is, you can't drive public vehicles, you can't drive a train and you can't be an airline pilot. But other than that, unless you've got ambitions to be one of those sort of persons, in which case it'll probably irritate you to death and you won't be very pleased. But really, they only do that for common sense, because

if you're an airline pilot and you suddenly had a hypo, it wouldn't be too good if you crashed the plane, would it? So, they're only common sense rules. And I think that no, it's not stopped me doing whatever I want, you know. If I want to do it, I'll do it, you know.

How do you see the future?

- (30) Ah well, that depends on whether you're... As a pensioner, I would say that it depends really upon whether you can persuade the political... the people who are in politics to give you a better deal. And I am not just doing this for myself; I'm doing it for the people of the future, because, you see, our pensions are not good enough. And the reason they're not good enough is quite simply, they means test people if you are on a very low income. Now, if you get above, for a single person, a hundred and five pound a week and a few odd pence - it's twenty five pence, if you go above that, they will turn around and say you've got adequate to live on. Now, I personally think that just over a hundred pound a week is hardly a king's ransom, and it's not linked to earnings, which I believe is wrong. It should be linked to earnings. The reason I say it should be linked to earnings is, that as other people's standard of living rises, so should the standard for pensioners, and that isn't happening. In fact, because the link was severed in about 1980, a single person is now thirty pound a week worse off than they ought to be, and a married couple are about fifty pound a week worse off than they ought to be.

And will this affect you with diabetes?

Well, yes, because... It would do, because, you see, at one time there used to be an allowance for people who'd got diabetes, to enable you to get a better diet. But now they've decided that because of the way in which the food manufacturers make things, and that food in proportion to income is slightly lower - that the average person spends slightly less on food than they did say twenty or thirty years ago. However for pensioners, the proportion that they spend on food is still comparatively high, and the same applies for fuel as well. They spend more on fuel than does the average person who's at work, because the average wage now is over five hundred pound a week

- (31) Well, if you compare that with what they're paying out for a pensioner. And by the way, there's about... there's several billion pounds in the exchequer which is in the NI fund, and even some of our MPs didn't realise there is a national insurance fund, which I find absolutely strange. That just goes to show just how much they care about pensioners. They ought to know things like that, and they don't. And so what I'm saying is, pensioners should get certain things free, like travel. Now, in Birmingham you do get free travel, and incidentally it was because of myself that they got free travel, 'cause I triggered my father to come up with the idea of free travel for pensioners. But I was only sort of... it was about 1950..., must have been about 1958 or so, round about then - I'm going to go up

to the library and have a look and find out exactly when it was - but - I know that, because I was in the library the other day looking through some of the old stuff, and there it said that the older people's free travel pass wasn't included in the figures for transport when Birmingham owned its own bus services for 1959, so it was prior to that that the free travel came in.

And was your father a local councillor?

No, he wasn't. He was just an ordinary person, who... He belonged to the Labour Party, as I did at that time, and we put it through a system, having got the idea. I just happened to be sitting at home, and I was watching the busses go past, and I said "why are they empty? Why aren't they full of people?". And my father just turned round and said "oh, they can't be", and I said "they are", I said "they're empty". And he came and he looked, and we sat watching them for about probably twenty minutes, and more than half of them were going past empty. And I said "that can't be right, you can't... What are they doing? There's something wrong there". So, dad came up with this idea. About half an hour or so later, he said "why don't we do what they do for the blind, that's give the pensioners a pass?". And that's how it came about.

(32) What has kept you going all these years with diabetes?

What keeps me going? Well, I'm not frightened of it, you see, and I believe that, quite frankly, you'll live as long as you're supposed to live. I don't know who controls how long we live - whether it's some god or whatever, you know, whatever you like to say, or whether it's just that you're programmed to live a certain length of time and that's it. I can't answer that question. So, what keeps me going? Well, it's an interesting life, I think, because I believe that there are things to do in this society which need doing. We need to improve it, and everybody needs to improve it. And the more we take an interest in it, and the more we try to improve it, the better it'll be for everybody.

What would be your advice to someone diagnosed with diabetes now?

My advice would be to check their blood sugar levels fairly frequently, and until they got used to it, and make sure that they took the treatment that they were given, whether it be tablets or whether they were put on a diet. And exercise and eat sensibly; don't go, sort of, having a binge of something and making yourself ill. Everything should be done in moderation in my opinion.

And from your long years of experience of dealing with the medical profession, what would be your advice to doctors and nurses who are dealing with diabetics?

I don't know that I'd like to give them advice. What I would say to them is listen to the patients. Listen to what their problems are, and then see if you can help them to put them on the right track. It's no good telling people that "oh well, you're all going to be diabetic 'cause you're overweight", because the majority of people won't listen to that. They'll just turn round and say "oh, to hell with that", we're going to carry on eating our pizzas and our fish and chips

and everything else, you see, so, and not exercising. You can't make people do things they don't want to do. What you've got to do is to persuade them by example. It's rather like telling people not to smoke. For thirty years we've been telling people "don't smoke", but the children are still smoking; they're still trying it out. And if ever you've been in a ward where you've seen people dying as a result of chest infections, mostly caused by smoking, you'll never want to go there again, I'll tell you, 'cause I've seen it, and I can tell you, you won't want to do it. But the same thing applies to diabetics. You can't make a person do what they don't want to do. All you can do is give them advice, and say "well, if you don't do it, you'll die prematurely", and, okay, that's their choice, and if they want to do that, leave them alone, you know. Make them do... just say, "if you do things sensibly, you can live for quite a long time, and you'll live a perfectly reasonable life. But if you don't want to, and you want to kill yourself, well, do it, you know, carry on".

(33) Have you received a medal for having diabetes for fifty years?

No, I haven't, you see, I'm not a member of the Diabetic UK. I was at one time, but I found that the book that they gave you, which was a quarterly magazine called Balance, generally it contained the same things year in and year out. Now, there came a point in my life when things got a bit tough, so I cut it out. And I can't say that I really regret it, because I actually don't believe that you should have a medal. Why should you have a medal just because you happen to live a certain length of time? That doesn't mean that you deserve it. It's not necessary. And if you did have a medal, who on earth is going to take any notice of it anyway? So, it's like walking round the street advertising, saying "I've got this" or "I've got that", and I don't really believe in doing that sort of thing.