

### 13. Grace

- (1) Well, I was born in Birmingham in 1931. I have an older brother and a younger sister. My father, at that time, was a printer; worked for his father's firm in Birmingham. My mum was a stay-at-home mum then. And we attended Church schools, but my brother went to a boarding school, so there really was just my sister and I at home. My dad joined the army in 1939 and was sent to France immediately, and when he came home, he, I suppose, has what's now called post stress or whatever it's called, and couldn't face going back into a factory, so he applied to join the Forestry Commission. And we all moved to Suffolk in, it must have been 1946, '46 '47 we went to Suffolk, and lived in quite an isolated situation in Suffolk. I was able to leave school, I must have been fifteen – fourteen, fifteen, because in them days you left school early. What did I do? I went to work in a shop. I had a job as a counter assistant, then I worked as a cashier, and it must have been then that I was taken ill, although it was a long time before it was diagnosed. I was ill for quite a long time.

Have you any idea how long?

I think it must have been about nine months, and nowadays that absolutely wouldn't happen, and I puzzle why it happened then. And I think it was because my mother... we'd lost a little girl when I was just a year old from leukaemia, my sister, and whether it was because my mother couldn't face the fact of another sick child. And the ramifications

- (2) of illness then were quite serious, because we lived a long way both from the doctor, and an extra long way from the hospital, and I suspect she perhaps couldn't face the fact that maybe I was ill.

What were your symptoms?

Loss of weight, though always hungry and eating a lot, and terrible, terrible thirst, oh constantly thirsty. And it wasn't until one night after dinner, I was feeling so ill that I started to cry, and my dad must have said "this has gone on long enough, she must see a doctor", and that was when I was taken to see the local doctor. And he diagnosed immediately diabetes, just from the urine sample. And I was sent, must have been almost immediately, within a day, to the West Suffolk General Hospital. Well, they knew I was diabetic when I went, so it wasn't a case of them diagnosing, it was a case of them treating then.

What are your memories of the hospital?

Of being afraid, I'd never been in hospital before. It was then an old hospital and it was army huts, long huts, with I suspect about, oh, twenty or thirty patients in a ward, which I quite like. I still do like a ward to be in, because I like to see the different people. I'm not fond of private rooms. Of being afraid of everything, although looking back, they were all very kind and nice, but the uniforms and the matron - terrified. And of always being hungry, because I was, of course, put on a diet immediately. And the way they found how much insulin

to give me - I don't know whether they do it today, I can't imagine that they do - but I would be given, before each meal, a large glass of glucose, which they must have measured what that would show up somehow, and then insulin, and gradually the glucose was lessened and lessened till I wasn't having any, and I suppose that way they calculated how much insulin I needed.

- (3) Was it difficult to drink whole glasses of glucose when you'd never done so before?

It's not a very nice tasting thing, but because I was so afraid, I wouldn't have dared say "I don't like this", and so I drank it. But the thing was, because I was given glucose, my mother assumed that I could have glucose, and she would bring glucose tablets in for me. I don't recall them ever making any enquiries about diabetes or reading a book.

You mean your parents?

My parents, yes. But because, as I say, I was given this glucose, my mum assumed that I could have it, and would bring these little packets of glucose tablets in for me! But I'm sure I didn't have that many, so it probably didn't make a great deal of difference to anything that was going on. It's just now, looking back, and thinking "why didn't they ask?". But you see, in those days, doctors... you didn't ask doctors, they were kind of a local god. You didn't argue or enquire - I don't think he would have put up with it. He was used to saying what would happen, not interested in what you thought. I never, in those days, especially to my parents, or me as well, not say "I don't want to do this" or "why am I doing it?". You accepted what the doctor said went.

But didn't any of the hospital staff offer any information to you or your parents?

I don't recall that they did. I was given a diet sheet to go home with. I was told that if I didn't learn to inject myself, I couldn't go home, and not question anything.

How did you test your blood sugars?

Well, I didn't. There weren't the possibilities of doing it. There wasn't even an easy way to test urine in those days. No tests at all. There was something called, oh, and I can't even remember the name of it, it was a liquid that you boiled. And you had to boil something for four minutes, you had to boil the urine, you added this

- (4) liquid to the urine, you had to boil it for four minutes to get a result. That was the only test, and I can only remember kind of doing it once in the whole of that time. I don't know how they really treated a diabetic in those days, because you only went for a blood test every three months, something like that, and no way in between of knowing what was going on with your body.

How long were you in hospital?

The first time when I went in? I think probably about three weeks, don't know exactly, but I think in the region of three weeks, but always hungry, never getting enough to eat. And I remember meeting the... they used to bring round hot milk at ten in the morning and in the evening, and I remember meeting the ward maid some time later and chatting to her. And I said "oh, you always gave me a large mug", which she did, and she said "yes, I always felt sorry for you because you were always so hungry", so I always got a large mug of milk!

What else can you remember about the diet?

The diet; well, it was high on protein and low on carbohydrate. I remember that as being very difficult for me, but there was no bread, no potatoes – well, very little. And the diet sheet that I was given when I went home, the only thing that I remember on it was the first meal that my mother fixed for me; it said three hard boiled eggs and a half a slice of bread. And I would find that very difficult to eat today. The eggs fine, if you can have bread with it, but eggs on their own I couldn't eat. And I said to mum "three eggs", which in those days was quite difficult, because we didn't have that many eggs in the ration - it was still rationed you see, you got one egg a week. And she said "well if that's what it says, that's what it says", that's what I had to have. But I felt guilty eating those eggs, because it meant someone else wasn't getting theirs. It certainly wasn't very easy for my mother, and not for me either, because I couldn't have what I wanted to have.

There weren't extra rations for you then?

There was extra fat, yes,

- (5) you got extra fat, which is quite different to what you'd be given today, you know. The whole diet has topsy-turvyed, hasn't it? You can have carbohydrate today, encouraged to have a baked potato, you know. I would have loved that then, but. And there weren't calorie-free, there weren't no drinks, sugar-free drinks or anything, so you couldn't have orange squash and you weren't allowed orange juice or anything like that, so. I don't recall it as being a terrible hardship because my memory has faded, but it must have been difficult for my mother to provide what I was supposed to have.

Can you remember learning to inject yourself?

Yes I can, and I never found that a great difficulty. I must have done it quite easily, because I don't recall that it stopped me from going home when they said I could, so I got over that, and I don't have any great memories of trauma or anything associated with it.

Were you given a deliberate hypo while you were in hospital?

A deliberate what, dear?

A deliberate hypo. Were you allowed to go into a hypo?

No, no, that never happened. At one time during, and I don't know how long after diagnosis, not long after diagnosis, I did have a hypo and the doctor came. My dad would have had to cycle into town, which was four miles - we lived in the middle of a wood - fetched the doctor out, and he treated me to where I was certainly conscious, and then left. And then I went into another one, almost - it must not have been very long afterwards, so it would have meant my dad cycling into town again, and they sent an ambulance and took me into the West Suffolk. And I remember waking up in bed there, but I can't remember whether... I must have been given glucose or something, but I don't have any great memories of it, just the fright of waking up and not knowing where I was. And that was the only time that that ever happened in my whole life - ending up in hospital.

Can you remember how your family reacted?

My mother reacted by saying that she felt terrible saying it, but she was glad it

- (6) was me and not my sister, and that was because my sister was a goer. I was very quiet, enjoyed the radio and books and that. My sister was the opposite - she loved dancing and going out, although she was two years younger than me, so she was quite young. But because I was accepting, didn't make a fuss, I always remember my mum saying "I'm glad it's you", especially when I lost my vision. I don't know how she would have managed - my sister, but.

How did the rest of the family react?

I don't know, I absolutely do not know. I don't think it made a great deal of difference to anyone, except my dad, who had the job of visiting me on a Sunday. Because in those days, hospital visiting was just twice a week, and my mum could take a bus on a Wednesday, and it was two hours in the afternoon. My dad, bless him now thinking about it, he had to cycle, and it was like twenty miles from home to the hospital. And he would come, and my mum would pack a lunch for him, and he'd stop half way, eat his lunch. But he wouldn't leave me without a visitor.

How did people at work react to your having diabetes?

I don't think they reacted at all actually. The lady that I worked for, that was my boss, her fiancé had actually died with it, but you see you're talking the late 1920s. She was quite elderly then, and she always treated me very nicely because of that. But I don't think it made... it certainly didn't make any great difference to my life or how people treated me; I've got no memory of that at all - of being any different. Most people are kind anyway.

- (7) You mentioned losing your sight. When was that?

Yes, well, when I was in the hospital in 1947 and diagnosed, the young houseman sent me to have my eyes examined because I'd complained about blurry vision, so, you know, that was one thing that was bothering me. And he sent me to the eye doctor at the West Suffolk, and I snuck a look at my records, and it

said cataracts. But the specialist that was in charge of the diabetes unit there told this young, Dr Farnham his name was, told him off. She said “we never send a newly diagnosed patient to get their eyes tested”, I suppose because the vision would change so much during treatment that it was pretty useless, except that the surgeon diagnosed cataracts. So I kind of... I kept it to myself, but I knew what I’d read. And it was very fast acting, because within, oh, a couple of months I would think, I knew that I was gradually losing my vision. And the eye surgeon at that time was a Dr Cory, and he said that he would do a treatment that they called needling in one eye; says down on here it was bilateral surgery, but it wasn’t. He would do that needling to give me some vision, because it would be so many years until they could do the regular surgery that they did in those days for cataracts - you had to wait until they ripened, which can take some years. So, bless his heart, he took me into the hospital and did this needling. And it was a process that... there were several weeks, even a month, between treatments, it was done several times to disperse the cataract, and so I was in hospital for a fairly long time. He told my mother it could take up to six months, but I don’t in fact think it took quite that long, but I was in hospital that whole of the time, in the eye ward, which I loved, you know! I met such nice people, and I remember them to this day. But again, I went through the period of being absolutely terrified, and I was the whole of the time really, of having this surgery, because you didn’t get an anaesthetic or anything. They gave me a liquid that was supposed to relax me – it tasted vile, and now I can’t even remember what it was called, but that was what you got. And then you got eye drops on the day, and I was always afraid that they wouldn’t work enough; lived in fear. There again, you get through it. It wasn’t pleasant, but there you go. But I do remember the other patients in the ward who had the regular cataract treatment. I was fairly lucky, but they had to sit up – lay down on the day of the op, then they had to sit up and not hardly move for quite a few days after that. It was quite unpleasant, I would have thought. We weren’t allowed pepper on the ward, I remember that, in case anybody sneezed! But there again, you get through it.

What was the result of your treatment?

That I had good vision in my right eye.

(8) What was your vision like before you went into hospital for this needling?

Well, it was bad. I was registered as blind, and I remember a lady coming to the house, and I couldn’t read... I could see very little, thinking about it. My sister used to read to me. Yes, not good at all. I relied on the radio for any kind of entertainment.

How did you manage at work?

Well, by that time I would have given up work. Yes, absolutely - I didn’t go to work then. I must have given up work as my vision faded, got worse, to where I couldn’t... because I absolutely couldn’t see anything by the end. And I think that’s why the surgeon took pity on me, to think that I would be that way, you

know. At that age, you see, when I should have been having a nice time and enjoying life, I didn't, except that, you see, I was such a quiet person, that to me it was a bit of a relief that I didn't have to keep up with my sister. She was doing all the things that you would expect teenagers to do, and I was very shy, and so I had an excuse not to do these things that I didn't really want to do, but was expected to do. So, I know my mother praised me, but it wasn't deserved, 'cause a part of me was quiet and liked that quietness that I was allowed to have.

Now, you gave the impression that it was a very short time after your diagnosis, but you're now talking about quite a long time without sight.

I am, aren't I, yes, but I can't tell you exactly how long, just that the eye surgeon said "well, we'll have to try this", and it worked, because the sight that I then had lasted me for, oh, until 1964, when I had the other eye operated on. But the feeling was, in those days, that the vision that I had in my right eye was not guaranteed to last, so they would save the other eye until I lost the vision again in my right eye, and I would still have an eye

- (9) that was good, that was the reason; I don't think it holds water today, but that was it then. And he arranged for me to have contact lenses, so I had, you know, twenty-twenty vision in that eye. He did a very good job, for those days.

And how was your other eye?

Well, I didn't have vision in the other eye, and I didn't have vision in the other eye until 1964, when I then was in the States and had the surgery done then.

You'd better explain how you came to go to the States.

Yes, well I met my husband, who was an American airman, in 1951, and we married in '52, in February '52, and in October of that year we went back to America. We went to live in Texas, and where are we then? Lived in Texas, then Georgia, and in 1955 we were sent back to England. I was then pregnant with my first child in '55.

Before we come onto your pregnancy, did you have any contact with the medical profession in those years in the States?

Very little really, very little. I remember going to a doctor, and my insulin was changed. I was quite ill. I was taken into a hospital there because I was ill, I remember, and my insulin was changed, but it was an American Air Force hospital, and in those days, wives and children were only very second class – their main duty was the airman and not the family. You got care but it was not... you never felt like you were number one, because you knew you weren't. And the Air Force was better than the army – if you were an army wife, you were given very short shrift. But I remember going in because I was not well, and then changing my insulin, and I don't think that I,

- (10) I wasn't pregnant then.

Did you have any fears about becoming pregnant, as a diabetic?

I don't think that I did. I knew it would be - there would be difficulties, I was aware of that, but I don't think I was afraid of it. No, I wasn't afraid, just aware that there would be probably problems to overcome. And I had a nice doctor, and I was seven months pregnant when we came back to England, and that was when the trouble started. I'd only been back maybe a week or so and haemorrhaged, and had to go in to Laken... I happened to be visiting my parents 'cause we'd just got here, and my husband had gone to Bushey Park where he was going to be stationed, left me with my mum and dad, and I haemorrhaged and was taken to Lakenheath Hospital, and was in two or three weeks, bed rest, hoping to delay the birth. And it worked for that longer time, but then the baby was born, and he was only three pound four ounces. In these days it would have been enough, you know, that's a fairly large baby isn't it in today's. He lived for four days, but his lungs were not strong enough, so I was still in the hospital when he died. That is not pleasant, memories of either the treatment or the birth or anything. It was what you would hope to not have, you know.

How much support did hospitals give in those days to people who lost babies?

None at all, you didn't even get support because you were pregnant. I remember the labour as being horrific; just being left alone the whole night, and being told to shut up, "you're making too much noise". Yeah, and horrible nurse.

- (11) No, it was most unpleasant and nasty really. But you were treated as they didn't want you there really, you were a nuisance. You know, they were there for the men, to take care of the men, and I don't think they wanted women involved. You know, it seems awful now. I've heard lots of other people say the same thing about their treatment, and you certainly hope it wouldn't happen today, but it was not a pleasant time.

So this was an RAF hospital at Lakenheath?

No, it was an American Air Force hospital, and no support at all. It just happened, and you had to put up with it and get on with it, which you did, you got on with it. And then my mother and father had moved by the time I came out of the hospital. They were in the process of moving house when I came home, and by the time I came out of the hospital, they had moved to a house in Windsor. And it was a large house, so my husband and I had part of it, moved in with my mum and dad. And in January of 1957 I lost another baby - became pregnant again, and went through almost the whole of that pregnancy, and after an x-ray... I had good care, not grumbling about the care, and a lovely doctor, but having gone in for just an appointment, he did an x-ray and found that the baby's head was not formed properly. So they brought the birth forward - I can't remember the name of what you call it now, where they give you something to bring on contractions, I can't remember... induced, that's the name, induced the birth, and the baby was born, and true, it's head hadn't formed properly. And I can't say I didn't get good care; the doctor was extremely nice, good

doctors, but there again, there wasn't any great support from anybody. It was just something that happened and you got on with it, which you did.

(12) Which hospital was this?

This was at an Air Force hospital at Ruislip, where I went for my pregnancy care. Great doctors and nurses. And then, I'd been in touch with a lady who we lodged with at Greenham Common. How did I get from Windsor to Greenham? Oh, before I went to the States we had moved to Greenham Common, that was when they were building the Air Force base there, and we lodged with a couple - had rooms in their house. And when I lost the second baby, she wrote to me and said she was expecting a baby and couldn't keep it. She had separated from her husband and this baby had belonged to someone else, but she couldn't keep it, would we consider taking the baby. She'd arranged for it to go into Church of England home, but she would be happy for us to have the baby. And we were very pleased to think that maybe we could, and we looked into all the legal aspects of it. And when my daughter was born on the Saturday morning, this was 1957, she telephoned us and told us that we'd got a daughter. We went to see her the next day, and brought her home when she was two weeks old, so we had our daughter. At the time she also had a son, who was then a year old. She said "I'll never part with him", he was a darling little boy, and we would have taken him given the opportunity, but she said "I'll never part with Stuart". But when Stuart was four, she decided she couldn't keep him any more, and she called us and said "will you take him", and we did, so we had a son and a daughter then. And it turned out, we learned many years later, only this year in fact, that that was a pattern with her. She'd have the babies, she had seven, and only kept one of them, over the years. So my daughter and son were the first two that she had and didn't keep. Anyway, that was our blessing that we had Elvena and Stuart. And then in 1960, I can't tell you a lot about treatments, I'm sure I was going to the hospital but I can't remember doing it, but I would have done. In 1960 I was pregnant again, and that was an accident, we certainly didn't plan it. I was five months pregnant when we then went back to the States again with the children, and Robert was born in March of '61, and I did have marvellous treatment. I had a great doctor, well taken care of, and I think, you know, that points to Robert even being born alive.

(13) Did you connect the death of your first two babies with your diabetes?

The doctor said no, it was a one in a million chance of that happening, but you do end up wondering. But they were two different things, and I suppose the first baby, the placenta separated and so I was haemorrhaging for days, and it just didn't stop. And then, I suppose, in the end it got so bad that the baby was born. And the second, where the head didn't form properly, the brain didn't form properly, I've read of that happening to other people. So whether the doctors were being comforting when they said, I don't know. I didn't really connect the two or feel guilty about it - "that wouldn't have happened if I hadn't had diabetes".



How did the third pregnancy go?

Very straightforward really. I kept it a secret from my mother because she was a great worrier, and I knew we would be leaving, so for the first five months it was a secret. And I didn't gain a lot of weight, I watched my diet very, very carefully, and it wasn't until we got to the States and were settled that I said that we were having another child. But mum was always a great, great worrier, so it wasn't worth all the hassle. I did get very good treatment. They kept a great eye on me, and I had a wonderful doctor. And he took me into hospital the month before the baby was due, so that they could keep an eye on me and that the baby didn't get too big. He said "I want the baby to be five and a half pounds", and that's exactly what he was when he was born. They induced the birth when he wanted it, and so in fact, Robert ended up being born two weeks before his due date, and no problems at all with me or the baby.

And again this was a military hospital?

It was, yes, but bit more enlightened as the time went on, because there was like, well, nearly ten years difference. Yeah, I had a wonderful doctor, and because of him

- (14) I feel like... Robert was fine, and like I say, we had good treatment. And I hadn't gained a great deal of weight, which was good. But I can't say what dose of insulin I was on or anything by that time, I just can't remember.

So now you had three children and only sight in one eye. How were you coping with life?

I did cope, life was good. I never felt that diabetes was very important. Honestly, that is the way I've always felt: that you mustn't use it as an excuse for this or that or whatever, and I never did and never have. I always felt quite lucky actually. I always felt, if you're going to have a chronic illness, that was the one to have. I always felt that, and I'm sure that isn't true for everyone, because, you see, I always feel I've been very lucky, and I have been. The eye surgeon, when I saw him a month ago, he would like a reason why I'm still here! And I couldn't give him one. And he said "you're one of five of my patients that are leading a good life really", and I said "well, I'm glad to take anything that I can get". He said "yes, but we would like to know why this is so", and I couldn't tell him why, just luck. But I think there is a gene involved somewhere, that some people are lucky and some people are not.

Why do you feel that it was better to have diabetes than some other illness.

Well, because you could live quite happily with it. I could, but you see, and like I said, because I'm lucky. I haven't had the awful things that some people have had. I haven't had kidney problems, so, you know, which really can disrupt your life and kill you. I've managed to live a happy life with no problems, and the problems that I've had have not been painful; they're liveable with, you see.

Has your diabetes affected any decisions about what you did,

(15) say in terms of employment?

No, because I was married and a mother in the time when you weren't expected to be employed. Now, if I'd had to work, maybe, but maybe not. I've got a niece now who's a diabetic in the States, and she's done everything that she wanted to do: she got a university education, she works. And I can remember writing to her at the time she was diagnosed at fifteen, and saying "Jenny, you can do anything you want to do, don't let it stop you". And it didn't stop me, but then again I didn't have great ambitions; I didn't want to climb the mountains or... And, you see, if I had, maybe it most certainly would have stopped me, but the life that I have led has been quite a protected one. My husband's always taken care of us, and the only work that I did was volunteer work, which, you know, that was fine. I was able to fill my days with that, and that's what I did, but it wasn't a demanding thing. Well, it didn't stop me doing anything that I wanted to do, and what I wanted to do I did: delivered meals on wheels, worked with old people, helped out at the school when the kids were in school. So it was quite a privileged kind of life, and not much was demanded of me physically.

How long were you in the States after your third child was born?

He was born in '61 and we came back to England in '68.

Any memories of medical treatment in the States between '61 and '68?

No, not really, only that I would go for the checkups that I needed. I can't give you any help there at all, because I mainly stayed healthy. I had one bout of pneumonia in 1967 when I ended up in the hospital, and my husband was away in Vietnam at the time, so I had to rely on lovely neighbours to take care of the children, which they did. That was my first bout with pneumonia, and I've had several since then, but nothing to complain of there. I must have done what I was supposed to do.

Any memories of blood testing?

Only the norm. They didn't have a diabetic clinic or anything like that, so I would have gone to a general practitioner doctor. And it must have been all right because, you know, I don't have any awful memories of being ill or anything, because I wasn't, and I must have just taken my insulin when needed. But you see, back then, there wasn't testing facilities. The only one were urine tests, but no blood tests that you could do yourself.

(16) But you talked about 1964 as being an important date in the history of your eyesight.

Yes, well, the eye was getting to a point where they felt I ought to have the surgery, but they wanted to wait until Robert was of an age when he didn't need picking up. So that was, I suppose he was three, didn't need to be taken out of a cot or anything, because I don't know whether it's the same now - I suppose it is - you're told to be very careful about lifting and bending and that. So they decided, when Robert was of an age that he was more independent,

that they would do the surgery, and they did that in the military hospital in Detroit. It was a naval hospital, which took care of all the sailors that were coming into Detroit in the port. And there again, that was a nice experience. I had a lovely doctor, and the surgery was quite straightforward as I recall, I don't remember anything untoward, and good nursing care. I can only remember the children coming to see me, and they weren't allowed on the ward, so I had to go down into the foyer of the hospital. And Robert, who was like three, I suppose, wouldn't come to me because I had a bandage - he was afraid of me, or afraid of what I looked like; he wouldn't come to me anyway. But in any event, it was quite a straightforward surgery. And I went home, took care of myself, with the aid of friends, for a month or so. And I don't remember any horrible things happening, everything must have gone straightforward. And then I had good vision in both eyes, for at least a time, till way after we were back in England. I can remember in the hospital though, one occasion, we were on the third floor of the hospital and we used lifts. And I got off one day, I must have gone down, and because I wasn't wearing my glasses, my eye was bandaged, I got off the lift on the second floor, which was the men's floor. But because the hospital was laid out in exactly the same

- (17) way as the third floor, I went along the corridor feeling, went to what I thought was my bed, and a man said "are you supposed to be here?", and he said "I think you're on the wrong floor". And I was, and that was embarrassing! But feeling, everything was exactly the same, so everything felt the same as it was on my floor. And that was my one memory of the naval hospital.

What happened to you after you returned to this country in 1968?

In '68, we came to Upper Heyford. We took a house in Banbury, but then I came under the hospital at Heyford, but of course, again, it wasn't a diabetic, it was a general doctor that I saw. And we were there till we moved into Bicester in '71, so I was under the American doctor. And the last straw - he was a strange man this doctor, a Dr Pine - and even after we moved to Bicester I stayed under him, until he had me going like every week for blood tests. And I thought he must have found something wrong with me, and it got to where I was going to the hospital every week. And then one week he said "oh, I'm afraid I've lost all your lab reports". Well they were thick lab reports, and I remember telling my neighbour, "I'm sure I've got something the doctor isn't telling me about", because it was so unusual. And then on this last occasion, when he said "I'm afraid I've lost all your lab reports, you'll have to have all that work done again", and I said to John "I'm not going back". I thought he was odd. I thought he'd fallen in love with me or something and wanted to see me every week, and I couldn't imagine what all this problem was. So then I transferred to a local doctor, never heard any more of Dr Pine, and that was when I started going to the Radcliffe Infirmary; they had a diabetic department. Was that about 1973 or something?

Am I

(18) right then, that you'd never been to a specialist diabetic clinic until 1973?

Right, yes, and I can't remember the name of the specialist who ran it. It was a doctor and his wife, but that name escapes me now, but it was at the Radcliffe Infirmary that I first had a diabetic specialist.

And how did you find that?

Well, I don't know whether I thought anything greatly about it. It was the usual diabetic clinic of being weighed, blood test, urine test, that kind of thing, and kind doctors, yeah. But I don't know whether they changed insulins or anything; I have no memory of that. So I must have been doing fairly well for them not to need to see me, you know, very often or anything, so I think it boiled down to a six monthly visit. It must have – I don't have any memory of doing anything different. They must have been fairly happy with what I was, you know, what was going on in my life.

Well the nurse was able to check your notes, just as far back as '73, and it says Isonphane 80 in 1973 and Lente in 1974, but you don't have any memories?

I don't have any memory of it, no. I absolutely don't, because when I saw that, I thought "well, I don't remember that", and doubting whether it had actually happened. I don't have a memory of it at all.

You've mentioned some very kind doctors as well as some not so good doctors. What are your memories of the nursing profession over these years, right from the time when you were diagnosed?

Oh kindness, yes, except for the maternity nurse on the night that my first baby was born, and I think she was a sadist, quite honestly, I do. She was absolutely horrible for no real need. But always kindness over the years of nurses, from the West Suffolk on really, young people.

How have you felt that the knowledge of doctors and nurses about diabetes compared with your own knowledge of your condition?

Well, sometimes you do end up thinking "you don't know as much as I do"; you don't say it, of course.

(19) And good doctors and not so good really, but you see, if you're well and in control of what you're doing, you can shrug them off and think "oh well, I'll maybe see you again, maybe not", you see. I have one - and this was while I was in the States going to see a surgeon with a lump in my breast, and him, oh, very officious, and saying "come back in a month and we'll see you again", and not a word of "don't worry", just leaving me there, "come back in a month". And I've never forgotten him because of, just him not being very nice, you know, sending me out in tears and not able to drive home for crying. I'd got three young children and I thought I'd got a death sentence, you know. And this was back in the, it must have been in the '60s, '67 maybe - it may have been while John was away - and arriving home and bursting into tears at the sight of the children, calling my friend

and not being able to say what hardly was the matter. And she said “wait there, don’t move”, and she came over with a bottle of champagne! And we sat and drank champagne, and of course everything was all right. Well, I mean, it probably was right, you know, to come back in a month, but you don’t send someone out in tears, do you? He could have said “I don’t think it’s anything, don’t worry”, but he didn’t say that. There we go, that was just one thing that happened. But mostly doctors are nice, and really I’ve only got a few that I thought weren’t, and a lot of that was ignorance. And always, in England, kind nurses, always.

How was your eyesight progressing after you came back to England?

I can’t remember. . . it says the year that I had the haemorrhage, doesn’t it? So it must have been. . . “a retinal haemorrhage in right

(20) eye”, okay, and I remember that happening.

What year?

That says ’83, so if that says it, it must have been ’83, but I can’t remember the year for my own experience. But, you see, I also had a time that I couldn’t see very well out of my left eye, and I can’t remember why that would have been. I must have had haemorrhages in both eyes at the same time, because I had a period of not really being able to see very well and of resorting to books on tape. Well, I wouldn’t have done that if I’d have still got one good eye. So, I have had haemorrhages in the left eye, and they’ve been cleared up by laser treatment, so there must have been a point where both eyes were not good at the same time.

Can you remember how old your children were then perhaps?

Fairly grown up, yeah, they would have been teenagers then, so they weren’t dependent on me for looking after them. But I do remember just having books on tape, so I can’t. . . maybe John would have had more memory of that, but I don’t. I must have coped until I had the laser treatment and it cleared it up.

Have you been registered blind again since you were in your teens?

No, not at all. I’ve usually had one very good eye and got through with one good eye, and that must have been just a period of time when they were both on the fritz at the same time.

(21) How much have you been in hospital?

Mainly I remember winters, because it seemed to me there was at least three winters when I ended up in the hospital. Started out with bronchitis, it developed into pneumonia, and either the antibiotics that the GP gave me didn’t work or they made me very sick, mainly that, and then I’d have to go into hospital with dehydration. And that may be where the ketones came in, because I would be so dehydrated from being sick with the antibiotics. I think that probably was it. I was in a couple of times, Geoffrey Harris, and I’ve been into the JR a couple of times, and it wasn’t until about. . . I had a ’flu shot every winter, but that

didn't prevent bronchitis. And then, about four years ago, the doctor suggested I have an injection that was to stop pneumonia - had some effect against it, and I got that, and then I never again went into hospital in the winter. It became just a thing that happened in January: I ended up in the hospital, very ill, either from the pneumonia and pleurisy or from the effects of antibiotics. And that was the keto-whatever.

Well, you've had quite a lot of experience of hospitals over more than fifty years.

Yeah, I have, haven't I?

What changes have you noticed in the way doctors treat you or nurses treat you, or changes in the National Health Service?

Well, the main difference you notice is the informality, from going in where you didn't dare have a sheet creased, the nurses wouldn't allow - you couldn't sit on a bed, to today when very informally treated. And they ask you what you would like to be called, and they'll call you whatever you wish to be called. And yes, informality of young doctors dropping by, which is much, much better, and you feel you can say what you'd like to them; to not being afraid of them. Yeah, absolutely. And always kindness. And I can remember, when I had this - the end of my toe taken off. I was in hospital in the Radcliffe Infirmary for, well, about

(22) a month on intravenous antibiotics to try and avoid that, but in the end it wasn't avoidable. And it's nothing even to think about, because it's just the tip of my toe. But I can remember the doctor, and I still see him now around and we always stop and chat; a young Chinese doctor, I think he's Chinese. But him and another young doctor came and sat with me, because I couldn't make up my mind whether I wanted it done or not. I didn't want it done if it wasn't absolutely necessary, but they almost wouldn't know it was absolutely necessary till they did it. And he sat for about an hour talking to me about this, not advising me - they're not allowed to say "yes, you must have it done", and I was very ashamed afterwards, because I thought, there's people having breasts removed and legs removed, and here I'm worried about the tip of a toe. And it took so much time. And I, in the end, said - the word he used was probability against possibility, and there's a slight difference between the two of those isn't there - and I asked him "do you mean probable or do you mean possible?". And he did come right down to saying "I mean probable", so I said "well, if you're saying probable, then I think I'd better have it done", and it was decided. But he spent so much time, so sweet and kind. As I say, I felt terrible afterwards, because I'm sure down the ward he had other patients much, much sicker than me. But he was right, and I did have it done, and there was an infection in the bone, so it was good that I did go ahead, but I was very tempted not to. But, as I say, I still see him around today and he's just as nice.

(23) What changes have you noticed in the nursing profession over the years?

Almost the same as with the doctors. Much more informal, no less kind, but a different atmosphere on the ward, that you don't feel restrained in any way. You can do really what you want to do when you're on the ward, and even to, you know, the drinks and that. I mean, when I was first diagnosed, you wouldn't have dared bring a piece of fruit onto the ward; not allowed at all. And I find that a little bit difficult to get used to, that I'm allowed to have fruit juice of my own and fruit that people can bring in. I'm still geared to the 1950s I think, and it isn't like that at all. But I don't... I have never run into - oh no, I'm going to backtrack - I have ran into one case of the ward not being as good as it should, but only that one case, and that was at the Churchill, and that was the bathroom. Now, I don't know whether I even want to go into that. But it was on one occasion when I was in with a chest infection, and I walked into - it was a mixed ward, and I'm still a bit old fashioned about mixed wards I have to say, especially on this occasion they were elderly gentlemen and didn't half know what they were doing. And I'm not criticizing that - they can't help it. But on this occasion, the bathroom, which you shared, which I didn't like because the locks are not always good, and the bathroom was in a state from incontinence, and when I walked in, soft slip; god, it was awful. And when I came out, I said to the nurse "are the cleaners coming in today, or because it's Sunday maybe they're not?". She said "yes, they are due in". I said "well, when they do, send them to that bathroom, because it is disgusting". And that is the only time I've ever complained or had cause to complain. Because I know what you read now in the papers,

- (24) about the bugs and the cleanliness and that, but I have to say we have never - and I'm including my husband in this, because he's had to spend some time after surgery - we have never seen anything that would make us think "oh god, never, never". So although we read about grumbles about the NHS, personally, and I'm going to touch wood, we have never had cause to complain about anything. We've always had marvellous treatment and everything that we could wish for. And John had a surgery for cancer in the past year, and marvellous treatment: his own nurse to call on any occasion that he was worried; it's been tremendous.

We've talked about doctors, nurses. What treatment have you had from chiropodists?

Oh, there again, I can't talk highly enough. I've been going to the podiatry clinic since, I think, 1993 is it, or '94? I have to say, I am walking around now because of the treatment I've had.

Tell me what happened.

Well, I developed - it had, you know, no ominous starts - a spot on my toe, and I went to the GP; probably I was going to him for something else or I would not have mentioned it even. And I would go down every week for a dressing on this spot, and it wasn't getting better and it was getting kind of painful. And I remember the nurse saying to me "Mrs Jenkins, if you were my patient, I

would send you home and say stay in bed for three months". And I thought "oh gosh", but of course I couldn't do that, I mean, you can't live and go to bed for three months can you? And I think she was trying to tell me something that the doctor wouldn't. It wasn't that the doctor wasn't seeing it, and he was a good doctor, he was my doctor for many years. But as luck would have it, I had a diabetic clinic, and they used to do it at the local surgery. And the doctor from the Radcliffe Infirmary came out, saw me, saw my foot, and immediately called the podiatry clinic, said "I have a patient here and I think she needs you to see her". And they saw me that afternoon, which is very typical, and

- (25) it was diagnosed as an ulcer. And I'd been going to my GP for like three months with this - maybe he didn't recognise it for what it was, I don't know. But that was when my treatment there started, and I've been going, as you can see, for the last ten years. One ulcer would clear up, then I'd get another one. And it didn't matter - this is a puzzle to me - because from the slightest sign and it being treated immediately, they seemed to have a mind of their own, and the early treatment doesn't make a scrap of difference. It develops and does what it's going to do. But, having said that, the treatment that you get is marvellous. It's a Mr King that I see, and I have to say he has been my guardian angel, and I'm walking around today because of them. And they always say "if you're the slightest bit worried, call", and on the occasions when I have been the slightest bit worried, they've said "come in immediately", and they've taken care of whatever I've needed. I cannot speak more highly of anyone than I speak of them, and the same applies today. I went a week ago, just for a check-up, and all merry and bright, and they found this little spot on the end of my toe, so I'm going this afternoon, and I don't have the slightest worry that it will not be taken care of. They are just marvellous.

Have you had any other complications in your health as a result of diabetes?

No, I haven't actually. Again, you see, I say, I've been very lucky, I haven't. I mean I had my eye problems, which are now all taken care of, but I haven't, I haven't had any kidney problems or anything really. My foot, but there again, I feel I'm very lucky there.

Blood pressure?

Well, I suffer from blood pressure, but it's controlled, but I don't put that down to diabetes, you see. I don't think there's anybody that's seventy three that doesn't have tablets for something or other, and I'm on less than a lot of people! You know, they say "I'm on eight tablets a day", and I think "oh well", you know, be glad you've got them to take is my... I have

- (26) high cholesterol, which is controlled by tablets, so I just feel we're lucky to have tablets, really, that does that.

Now you've brought up three children. What else have you done with your time?

With my time? I haven't done very much actually; I don't feel I have. I did the



volunteer work for many years, and now we lead rather a quiet life. John teaches, and we work with different retiree organisations and do different things. And he is a mason, so he's involved in lots of charitable things in that region, money raising and that, so I'm involved to a certain extent in that. And we have quite a busy social life, and like I say, it's been quite good. I don't do anything to earn any money any more, which I never did earn a lot of money. But it's probably a life that a lot of people would quite envy, of not... if we didn't want to do anything, we wouldn't have to. And we enjoy our dogs, and I am lucky that I can read, because that is my passion, reading. And nothing much is required of me that I don't want to do, so, you know, what more can you ask, really.

Are you able to have much exercise?

I don't exercise a great deal, now I don't, because of my feet. I have to be very careful that I don't rub. I have to take care of them, because the slightest little injury or rubbing or anything - I end up at the hospital. So I really pet my feet and I'm very careful what kind of shoe I put on, so I don't tend to do a great deal of walking. I would quite like to be able to.

And can you describe your current regime now, of blood testing and diet and insulin?

Oh, for my own? Yes, I test my blood about four times a day. I'm quite careful to do that, because I've had diabetes so long that I no longer get the warning signs that most people get, and the only way I know is to test my blood. But I don't have any

(27) other warnings signs, you see, so I have to do that.

What do you use?

I use a meter called a "one step". It's an old meter - I've had it since the late 1970s, but there are newer ones out and everything, but I stick to my old, what I'm used to. And I pretty much stay on a diet, and it's quite a liberal diet any more, something, you know, that we wouldn't have thought of years ago. I never say "I'm on a diet" to anybody, because you're not really. You can choose what... we go out to eat quite often, and you can choose from the menu anything that you like, and it really isn't any different to anybody else, what anybody else is eating; no need to say "oh I'm a diabetic". I can't stand that: people who say "I'm a diabetic, I must have...". No you don't, you know, that's ridiculous.

But you haven't always thought like that.

Well, I've never gone somewhere and said "I can't eat that", never, never. I always, whatever there is, I'll pick out what I can eat, and if it's something perhaps I shouldn't have, very little of it. I've never gone anywhere and said "oh, I can't have that, I'm a diabetic", wouldn't dream of doing it.

Did you ever weigh food in the early days?

Yes, you did have to, and I did, but I can't think that I did it for very long,

because you get used to the way a piece of cheese looks, don't you? Yeah, you were required to weigh, but I don't do that now. And as I've got older, I don't eat as much as I used to. I find dieting very easy, because I don't really require the amount of food perhaps twenty years ago I would have enjoyed.

And what insulin are you using?

I use Actrapid and Monotard. I have a dose of Monotard last thing at night, to see me through the night, and three doses of Actrapid during the day.

Looking back on your life, how different would it have been if you hadn't had diabetes?

I don't think it would have been any different, except for maybe the last few years with my

(28) feet. I'd probably have still got the pneumonia; I don't know, I don't think that's particularly caused... that's caused by chest infections. I don't think it would have been any different. I don't think I would have wanted it to be any different actually. I can't think of anything that I haven't done that I would have done if I hadn't been a diabetic. I suppose the vision was a nuisance at the time, but it wasn't the end of the world either; could have been - it is for some people. I mean, that would be a fear now that I have, I think: what if something happened and I couldn't read. Now that would... I wouldn't be sitting here smiling and talking like this if that had happened to me.

Can you remember what it was like to regain sight after having had such poor sight?

Yes, it was wonderful. I can remember the first headline that I could see, and I could see it with the aid of a magnifying glass. And I don't know whether this was as I'd lost my sight or regaining it, but it was Prince Charles being born, and I could see a big headline. Yes, that's always wonderful. In fact, I've just recently had the same experience, because I've not had vision in my right eye for a number of years, and the last time I went to the hospital I saw a doctor who said "I don't think your loss of vision is because it's haemorrhaging" - I thought I was haemorrhaging. He said "I think the surface of your eye has thickened and we can probably do something about that". And I went in for some laser treatment and the vision has come back. So something new is going on all of the time, and, I mean, that young doctor, he said "you don't have to have it done", but he said it's worth a try. And I thought, he reassured me and everything, you know, nothing would really go wrong, and so I had it done. And next week I pick up new glasses, which I shall be seeing out of two eyes, so, you know, I think that's marvellous, I'm really thrilled.

Do you have any message to anybody who is diagnosed with diabetes now?

Well, I think it would be the same as I told Jenny. Don't let it stop you doing what you want to do. It isn't that big a deal, really, I think.