

1. Ann

- (1) I was born in Kashmir in 1936, and I led an idyllic childhood, mostly in Kashmir, where my father was working as a hydroelectricity man, and he was extremely busy. My mother was a King's nurse and had gone out there and met him out there. And we led the most beautiful life up in Kashmir, living at five thousand feet through the winter, going up to nine thousand feet through the summer. It was an idyllic childhood, well away from the war, but the only thing that spoilt the whole thing was that my father died suddenly in 1941, and my mother had to start working again. And then at partition in 1945, of course, we were sent home to England, and arrived in the Cotswolds in Cirencester to live with her family, as we had no home and no means of support. I was horrified, I was horrified. The journey was awful, on a troop ship. I was absolutely thrown into this awful country which was grey, grey, grey, grey. People's clothes were grey, their eyes were grey, the sky was grey, the houses were grey, and they were in a frightful state after the war, rationing, the food was grey, everything was grey. And to my horror I was sent down to a prep school by the sea, which was grey! And our uniform was grey! And the food was appalling. It was so cold, I've never been so cold in my life. Although we lived at nine thousand feet some of the time and we were in deep, deep snow, the cold wasn't the same, there was no dampness. And I felt miserable, and I got thinner and thinner and thinner and I felt extremely ill. And one day I was having a bath and matron walked in and she said, "Ann Walton, what are you doing drinking the bath water?!" I was lying in my bath just drinking the water. I said "well I can't stop being thirsty, I'm thirsty the whole time", and she said "right, you must see the doctor tomorrow". She was marvellous, she was as quick as that. Well, I saw the doctor tomorrow, and two days later my mother turned up and said "I've got to take you to London". She took me back to her old hospital, King's College Hospital, which was
- (2) extremely lucky for me, because in those days it was the leading hospital on diabetic control. The man who really got this going was a Dr Lawrence and he had started a diabetic clinic there, and not only that, a diabetic wing, which wasn't just one ward, it was several wards, and the whole thing was beautifully, beautifully set up. I was horrified though, landing in this great enormous hospital and being told, and all these tests going on, and being told suddenly out of the blue that I'd have to inject myself for the rest of my life. I'd never had an injection in my life! I'd had no childhood diseases and nothing wrong with me at all. Well, I'm afraid I wasn't at all brave, but this had to be done and I immediately started feeling better. They were very, very strict in those days. I was taught from the beginning, in fact I was made to go into a hypo and feel what it was like to be hypo, because my mother always used to call it "are you feeling giddy dear?", and I said "yes I am", and this was when your blood sugar fell down rapidly and you needed to be given glucose. And I thought

this was a wonderful thing to do, to teach me what it was like to feel like that. And that has been a wonderful help to me all my life, to be able to recognise those symptoms when they start very early, and only once during my life have I been completely out with a hypo. And in those days, the worst thing was the, well the syringes were glass, the needles were thick and they were re-sharpened. And you used to have to choose your needle for the day, or for that injection, and you'd rush over to the trolley and try and find the thinnest one, which you had to push into you. Well I screamed like billy-o for about an hour 'til I'd do it. And it was very, very painful and I wasn't at all good about it. And the other thing was, the other frightful thing in those days which seemed to be so degrading, your urine had to be tested, collected and tested by, well I couldn't do it, by my mother in a test tube over a Bunsen burner.

- (3) Now this is extremely difficult and embarrassing to control, I mean if it boiled over it would go shooting right across the room, so if ever you were staying with terribly fussy people they used to get very annoyed with me having diabetes and upsetting their beautiful furniture and rooms and things. And so I felt rather a leper really, and no-one understood diabetes very much in those days. I think the only bonus was, which was a tremendous bonus, we had ration books, and diabetics were given three ration books, so all my friends' mothers used to say "do you think you could have Ann to stay this holidays", because we used to gather up my three ration books and enjoy all the extra cheese, butter, meat, but not sugar of course. We were allowed to have the sugar for preserving, because in case we went hypo we were allowed to eat a spoonful of jam or something sweet. So, in that respect I was quite nice to have around, but in most other respects I felt I was a great nuisance. The school wouldn't let me eat with the other children because I had to have a special diet. I had to take sandwiches down into the playing fields to eat my own lunch, I had to weigh my potatoes on little scales, my bread had to be cut against a metal thing at a special size, and it all had to be done out exactly. Well this didn't work so it was pretty difficult for me, so my mother did a wonderful thing. She came and she found a school that would take her, as Sister, and educate me, and for the first, I suppose this was until I was about thirteen, she stayed with me at that school and got me thoroughly used to being totally independent, doing my injections, coping with meals. They were very sympathetic in this school, and I managed to get strong. I was about two years, I should say, physically behind the other girls but slowly I developed, and she suddenly said to me "now, I'm going to leave you behind here, you're to cope on your own", from about the age of thirteen or fourteen, "because you've got to cope in the future on your own, and I think this is the best way of doing this".
- (4) So I'll just ask you to recap on the ages then.

I'm recapping now on when I became diabetic. I was diagnosed when I was still

nine, and my mother supervised me very carefully through my schooling until, through the prep school and also for my first two years at the next school, until I was twelve or thirteen and when she decided that I had to become independent. And now this was an... I was horrified, but it was an extremely useful thing for me, because it made me, from that moment on, realise that I had to look after myself and I couldn't blame anyone else if things went wrong, only me, because no-one else would understand me as well as I did, how I was feeling, what I needed to eat, if I was going hypo or if I was becoming sugary, although in those days it was extremely difficult to control it by having no easy blood tests, as there are these days. It was a matter of hit and miss really. You had a blood sugar done perhaps three times a year when you went to the clinic. My mother always took me to King's College Hospital because they were such a leading light in all this, and they would regulate my insulin, say put it up one unit here or one unit there. From the beginning I was on one injection daily, a mixed dose of soluble and protamine zinc, and then when I was round about thirteen they decided I should have two injections daily, two mixed doses, which I did, and this kept me under excellent balance and I really had no bad hypos. I did everything at school, I was determined. Although I had started out being very, very thin, I got stronger and stronger, and I kept up with all the games and ended up in all the teams in the end. And I think all this exercise I had, which was quite difficult to regulate because, you know, in the middle of a tennis match with all the school cheering you and so on, you'd suddenly go

- (5) hypo, you know. I found I... It was very useful, my mother used to make little bags with glucose tablets in and pin them inside my pockets, so I could always reach inside my pocket and eat a glucose tablet if I felt my blood sugars sinking. And never once did I have to be helped over that, and it was such a very practical thing that I can, you know, just always thank her for doing that. And, of course, with regular meals at school, I could always get my injection at the right time, and I never forgot it and I didn't try to mess around with it at all, so I really had a very healthy childhood in school days.

How did your fellow pupils react?

They were pretty good at this school - they were fairly understanding. They didn't know anything about it, no-one really knew the disease in those days. I did have to take my little scales into meals, which I found quite embarrassing. I found it more embarrassing as I got older, because by the time I was in the sixth form and, you know, having to have all these younger ones watching me. They all wondered what on earth I was doing, why I had to do this, and it was quite difficult explaining it, so in a way the younger you are the easier it is. And I think this goes really for diabetes, because if you get it when you're young you just accept it, you never feel sorry for yourself, it's just one of those things. You hate giving yourself the injections in the beginning, and in those days they really hurt, so that wasn't good, and in that way I suppose I was quite sorry for myself but... In fact, I used to keep myself awake at night so that I wouldn't

have to wake up in the morning and give myself an injection. But then you get used to it.

How did the teachers react?

The teachers were very, very sympathetic, very good, and treated me like the other children, and if ever I felt extremely tired I knew I could go along and say “could I have the afternoon off and have a sleep”, because I did get tireder than other children. So around about once a week or once a fortnight I’d have the afternoon off and go and sleep it off and feel better. But I did get stronger and stronger, and by the end of my school days I really didn’t feel I was any different to anyone else, and this is largely due to the very, very good training. I knew exactly what to eat; I was brought up on a strict regime of carbohydrate counting. I had one hundred and sixty grams of carbohydrate a day, forty for breakfast, ten for mid morning, forty for lunch, twenty for tea, forty for supper and ten last thing at night, and I never wavered from this and everything went swimmingly. This was quite easy at school. The problems started, I think, really, when I left school and I was on my own, and I had a gap year where I had to earn my own living. I looked after children, so I was thrown into different families and had to eat what they ate. I had to do a lot of guessing. I managed it, I didn’t get ill. I even went to France looking after children, and that was quite jolly because I don’t think I’d even had a glass of wine in my life, and I didn’t know how much sugar there was in a glass of wine. Anyway, through trial and error I managed to get through those few months, and then went to Oxford and was a student for three years. And that, I think, was possibly the hardest time of my life.

- (6) From 1954 to 1957 I attended Dorset House School of Occupational Therapy, and went through three and a quarter years of hospital practice and the rest of the time in Oxford as a student, which was very interesting. One had to be totally responsible for myself again. From school days this was vastly different. Also very short of money, I had a pound a week to live on, and so broken biscuits and Marion margarine were the thing, which doesn’t go down very well for diabetics, but still, never mind. I think I only ended up in the Radcliffe once with a nasty boil, but my fellow students were extremely good. Socially, of course, one had a whale of a time, and this too had its problems, as you can imagine, being a student and having to somehow fit in an injection when you go out in the evening when you never know what’s going to happen. All right if it was a formal dance or something like that, then you’d go to a May ball, dance the night away and expend an awful lot of energy, so then you had to be careful that you were actually taking in enough sugar, not too much, not too little, and not too much alcohol, because of course that sends you into a hypo extremely quickly, which I didn’t know in those days. Now this was something, I don’t know if it’s only recently known, but I certainly didn’t know about that. We didn’t drink a lot, no-one had any money to do it, and mainly cider, which of course was rather sweet. Anyway, I did find that it was an

eye opener when I started working in hospitals, responsible for patients. I couldn't afford to go hypo and specially working with children and mental patients. With other patients, one could always explain if you were feeling a bit strange and you needed a sweet drink, but when I had a job in the children's hospital eventually in Bristol I did find this, I did have to keep on the high sugar side rather than risk going hypo and letting the children down and not being able to look after them, because this would have been

- (7) disastrous, and I would have lost my job. Driving - I learnt to drive during this time, which was no problem because I never had unexpected hypos, and I never had any problems, my eyesight was excellent. I had no complications at all during the whole of this time.

Why did you describe this period at Dorset House then as the most difficult time?

Well it's most difficult because you are more than ever entirely on your own, you're not attached to a family so nothing's regular, nothing at all. Your meals are all over the place, apart from lectures, and then you'd always have to find your own food, buy your own food, plan it, and if you were in a flat, to make it. For the first six months in a hostel, that was easier, so that was a good breaking in time, but I had had this extremely good experience of having a mother who made me independent, I would say from, really from thirteen or fourteen. I think that's quite late enough to be made independent, and to be responsible for your own intake of food and making sure you have your injections at the right time and not forgetting them. She was rather an amazing woman because it must have been extremely worrying for her, leaving me alone in this boarding school, and then eventually letting me go to France for a few months on my own with a lot of insulin, a lot of extra needles and so on, and in fact at one stage she flew out to France to bring me over some more insulin so that I would have the right kind. I wrote to her to say I thought I was running out - she was really excellent to do this for me. And another very scary time she had was when, at the end of my training, I'd just taken finals, got on my Lambretta with another friend, and four of us, four girls, we drove down to Spain on our Lambrettas, over the Pyrenees, and I put one syringe on one Lambretta and one syringe on the other, and off we went. My mother didn't say a word. She said "as long as you send me a postcard dear, every four or five days would be quite useful", well she got one I think twice! She still didn't worry! And so she was a very remarkable woman, and I have her to thank for being so tough and brave over this, and this has helped me through all my life.

- (8) Were there restrictions on your social life while you were at Dorset House, you've mentioned drinking sort of. Did diabetes affect other aspects of your social life?

I did find that sometimes people, boyfriends actually dropped me because I was diabetic. I found this very hurting. One person I was particularly fond of, I kept it from him because this had happened to me before, and then directly he

did know, that was it. I'd think people do find it a difficult thing to cope with, to feel they're taking on. They know it's a life-long disease, that it has to be reckoned with every day, every single day, and there are complications from it, and really, in a way, unless they're particularly fond of you, you're not really worth it! Sorry!

Before we move on to your marriage, could you just reflect on how much contact you had with medical practitioners up until you were twenty one, twenty two?

Well, very little to do with GPs because I was very seldom ill, just, you know, if I'd got sore throats or something like that, but I did keep up very regularly with the diabetic clinic.

Where?

Mainly at King's. My mother would take me up there because she felt that they were such a leading hospital in this, and in fact later on I went back to them when I particularly needed help. When I was a student I used to go to the Radcliffe in Oxford regularly. I was quite strict with myself about this. I hardly ever - I don't even remember seeing a GP in Oxford. You know, you're very fit really as a diabetic. There's no need to feel that you're ill. You actually have a very, very good diet, healthy diet, and you're encouraged to take exercise, which I did. I played a lot of tennis, even after leaving school, and that went on as long as I could. So really one needed just the support on one's dose of insulin, how many injections to take a day, and on the results of blood sugars, which were pretty useless because that was only one every sort of three or four months which didn't help very much, but one went on doing the urine tests. By that time there was something called Clinitest, so you had a little test tube and you popped a tablet in and it used to boil up, so that was a little easier. Even so it was quite an embarrassing thing to take around and cope with it.

Can you remember when that came in?

No, I can't exactly, but I think it must have been fairly early, and in fact I've still got a set upstairs somewhere, I think. It was a very useful thing until being able to buy one's own blood sugar instrument came in, which was only really about twenty years ago. Even then, they were about seventy or eighty pounds. Now they're much cheaper and everyone has one, but this is where diabetes has changed so radically, where now it's so much easier to look after one's self.

(9) Moving on then from Spain, what happened after that?

After Spain, I married.

What year?

In 1958, and I went on working as an occupational therapist very happily. And then in 1961 my daughter was born. Now this was a bit complicated. I was working near London and so I used to go back to King's College Hospital, where Sir John Peel looked after me. He was particularly interested in diabetic babies, it was his special thing, and so I used to travel right from one side of London to

the other to be checked up, because I felt it was so important. My mother was then living in Nottinghamshire, and her local nurse told her that she'd never known a diabetic mother's baby to live. This horrified me and her, and King's though told me that if I had three babies, I would probably have two alive. The still-birth rate was still as high as that, but they kept very good control of my diabetes, helped me to do that through my pregnancy. I was quite well, but suddenly I blew up with a lot of fluid, so they took me in at about six months and kept me on complete bed-rest until my daughter was born three weeks early by caesarean. And she was healthy from the beginning and her weight was six and a half pounds, so this was excellent. I did have trouble with the wound, it took about three months to heal, but I did manage to feed her. I was told I was one of the first diabetics they'd ever known to feed her baby, so I believed in it very strongly and I managed to do it. I fed her for about three months.

How did that affect you physically?

Well I needed a lot of extra carbohydrate, a great deal of, well I really doubled my dose of carbohydrates, but I managed to do it, and I think it gave her a very good start. And then everything settled down again and two years later I had a son, and then unfortunately after that our marriage broke up.

(10) Before we move onto the next stage of your life, can you talk about how you monitored your own health over the first thirty years of your life?

Well monitoring your health for a diabetic is just one simple thing, keeping your blood sugar as normal as an ordinary person's, and to do that, the only way to measure it was through urine tests. Now these are very impractical. I mean when you're working full-time as an occupational therapist or in hospital or wherever, even in a domiciliary way, it's difficult to get all the gear, to collect the sample, to do these things, so you tend not to do it. I didn't do it unless I was ill, and then I would regularly do it and get myself on the straight and narrow again. But it was really impossible to do it all the time. I mean I didn't know another diabetic to ask whether they did it or not, but I remember meeting a very little boy when I was once in King's and I told him how awful it was having injections and "do you think so?" he said, and he said "oh I just keep my gear in my pocket". And he got out a dirty hanky and there was his syringe! So I started being a bit more relaxed about this, and actually from the time I left school I don't think I ever sterilised another needle or syringe. I used to keep it in a case, I didn't keep it in a hanky in my pocket! But I used to keep it in a case in, well actually nothing, just in the case, and I don't think I... I might have boiled up a new one, but after that it only touched me, it only went into me, and I never had an abscess in my life from it. So from that point of view it was very easy to control the diabetes, but from knowing what your blood sugar was, this was impossible until the time of being able to monitor our own blood sugars, which was really only about twenty years ago, and that has transformed, it must have transformed the whole business of being a diabetic. There was no way of doing this before unless you went to the surgery every day and had it done, or you were in hospital where of course it could be done. But it was hit

and miss, it really was, and if you were a fairly brittle diabetic, as I am, your blood sugars obviously went up and down and you had to more or less control it by how you felt. I could feel, I can feel, I always know when my blood sugar's falling and when you're burning up more sugar than others, and so you had to rely on this enormously.

(11) Will you talk about any complications that you had?

Yes, the first complication I had was when the whole family was camping, and I woke up one morning with a black dot in my eye and this spread over the eye. It was right inside, and I went to the local optician, and he said "I'm afraid you've had a haemorrhage", took me straight to the hospital; he was excellent. And this was a vitreous haemorrhage, which was a great shock, and in those days there was no laser treatment to stop the bleeding or to prevent the deterioration of the eye and stop new vessels from bursting. So from then onwards, this was after I'd had diabetes for twenty-eight years, and I was then confronted with the fact that I had to be very careful of my eyesight and couldn't bend and lift anything heavy, do any strenuous work in that way, and I had to be careful even picking up the children, to use my knees in other words.

You say it was a shock, had you had no warning that your eyesight might be affected?

No, I mean I had knowledge that people's eyesights, but I had shown no trouble, they saw no aneurisms in the back of my eye. Every time I went to the clinic my eyes were looked at, it was all very thorough, excellent treatment, and then this suddenly happened. And it wasn't until quite a few years later that I had my first treatment on the eye which they did with a light coagulator, which was a very, very unsympathetic machine. I mean it wasn't exact like a laser, I mean so you got bursts of sort of light into the eye and it was all a bit hit and miss, but it was the only thing they could do at the time, and I've had very many laser treatments since that day. Unfortunately I have now lost the sight of one eye, but the other eye has had laser treatment and it is still keeping going, and I'm still working now as an artist.

(12) In the late 1960s my first marriage broke up, and I was left alone with two young children, age three and five, to bring up on my own. I couldn't manage this and do occupational therapy. By that time anyway, I was working in children's hospital and the work was too heavy for me, because the children I was treating there were usually unable to move on their own, had to be lifted, and I had to do a lot of work on the ground with them, giving them exercises in balance and so on. So that work was very unsuitable for me and I would regularly get vitreous haemorrhages and the doctors advised me to give it up and go and live quietly in the country. This was a great disappointment, but luckily I had another career going at the same time which was being an artist, so I was able to totally rely on that, and I managed to buy a cottage in the country and live quietly in a very, very good village, where there was a lot of support, fairly near



Oxford. So there again, I had enormous support from the diabetic clinic there, which has helped me since 1969. The children, this was a great responsibility because I was the only one looking after them day and night, and so I think I possibly made sure I didn't go hypo too often and didn't keep my blood sugar as low as I could have done, because there was no-one to look after me and they were far too young to worry about anything like that. We had a very happy time in Bampton, and the complications that I had medically were really due to my eyesight, nearly entirely. Now these were still the days before good laser treatment came in, so if I had a haemorrhage I used to lie down for a week and completely rest and it would clear. And time after time after time this happened, and the children got used to it, and they were very good, and I'd get extra people in to help me, you know and so on, and the village all supported me, and the doctors. And occasionally I'd have to go into the eye

- (13) hospital and have various things done. I suppose then the laser treatment came in, and then eventually I had a cataract removed off my good eye, so now I can see well enough to still paint and still earn my living by painting. By the time the children were almost off my hands, I married for the second time. With this marriage I've had absolutely wonderful support and understanding, and I wouldn't be alive to this day without this, I know, because the older you get, the more complicated diabetes becomes, the more you need moral support. When you're young, you take it in your stride; it's easy. You can make yourself almost invisible as far as it's concerned to other people, but when you get older you get complications which can't be hidden. They're depressing, you find yourself older than you are physically but not mentally, so mentally you rather crumble I think. It's very depressing. You need a lot of support on this side, a lot of support to keep you busy, to keep you occupied, to keep you focussed, and away from seeing the awful things that can happen to you in the later stages of diabetes. And in this I've been extremely lucky and I've had someone to do exactly this, and also from the diabetic clinic point of view, absolutely wonderful help and support from everyone in Oxford. I have not one, anything to grumble about there. I've had nothing, nothing, nothing but support. And now, even nowadays, you get your own nurse you can 'phone up if you need to. Now this never happened in the old days, but if you're worried about anything you can always 'phone your particular nurse, which must be a wonderful thing for new diabetics. Well the diabetic department there covers you on all the other things that start going wrong when you get old. I'm coming on really to ordinary things that happen in life, other illnesses, because they're not always related to diabetes. For instance, I broke my ankle in Greece in 1987. It was
- (14) beautifully put into a plaster there and it healed. I came back after a fortnight and it healed beautifully after about eight weeks, ten weeks. Well, then disaster. Three years later I broke my ankle in England and I was put into plaster very beautifully at the John Radcliffe, and then I was

meant to be in plaster for fourteen weeks. It had to be removed and my skin looked at very often because you very easily get ulcers, especially if you have no feeling in your feet. I lost the feeling in my feet in about 1985, and from about ankle sock height, ankle sock downwards rather, I can't feel. Now, when my ankle was plastered right up to the knee, two of the times the plaster was put on too loosely and I got very, very bad ulcers which took about four months to clear up, but when one specialist did it, and he took it on in the end to change it every fortnight for me, he was the only person who could put it on tightly enough so that it wouldn't rub, and I never got an ulcer with him. Unfortunately I went for a check-up one week when he was away, and the consultant told me, this was after six weeks, he told me "the x-ray looked good, my ankle could come out of plaster". My husband and I and the person in the plaster room begged him not to do that. I told him I was diabetic, I'm not sure if he had my notes there in front of him or not because they got lost five times, and he refused to put another plaster on. He put a removal plaster on and told the physio' to give me exercises. I knew this was wrong, didn't do the exercises, but I didn't have enough support for my foot, got myself back to see the other consultant a week later and found that the three bones in my ankle had moved and they have never mended since then. I'm now confined to wearing a special boot to be able to take my weight at all. I can't put my foot down at all to take my weight without this special boot. Now this is the only thing that has gone so disastrously wrong

- (15) with me in all these years, so perhaps I'm lucky, but to find a consultant who wouldn't listen to me on something I knew about. I knew it had to be in plaster for fourteen weeks, because the other consultant had told me this. It absolutely horrifies me. I wouldn't dream of doing anything about it. I suppose I could sue him but I wouldn't dream of doing this, I've had far too much good treatment over my diabetes to ever do it, and I just feel this is my cross in life perhaps. But it is making many complications in my life, in our life, and I'm very, very sad about it, and I hope these sorts of things won't happen in future. And the patient themselves very often knows far more than the doctor and knows what's bad for them, and I just wish people would listen to them sometimes because this has absolutely has been disastrous. I've had to put a stair lift in at home, I can't walk very far at all, I've bought myself one of these electric scooters to be able to get around. I can walk without a stick and. . .

How often do you need to see any medical practitioners?

Very often, I'm under constant surveillance at the Nuffield. I'm allowed to 'phone up and say "please will you see me", because my ankle could completely collapse any time and I don't know quite what would happen. And at the moment I'm suffering from a septic toe because I didn't feel it rubbing in my boot, and I've now got an ulcer on the end of my toe and it's proving very, very difficult to heal. The diabetic clinic is being wonderful, seeing me three times a week. You see

these accidents make so much more work. I mean, I must have cost the whole service a fortune over this, just because someone wouldn't listen to me and be told that my foot shouldn't have come out of plaster.

Have you had chiropody?

Chiropody, a lot. These days you can't get it as easily as you could. You have to travel further to get it. We used to be able to get it in our local doctor's surgery but now that can't happen, so I get a chiropodist to come to the house to do it here. For one thing, there's less likelihood of infection, and I get it done once a month, and I pay for it because I think it's very important. Diabetics have to look after their feet.

- (16) The damage to my ankle has resulted in the fact I haven't been able to take enough exercise, and I've had trouble with my heart because of it I think, although it was probably coming anyway. And I've had to have an angioplasty done in 2000 and this year I've had a laminectomy, because obviously I'm walking in a strange way and this affected my back. This one mistake, just because a consultant wouldn't listen to me, has really caused all these problems. I think it's so important that people listen to diabetics. They live with their disease day in day out and they know very well how to look after it. In the past, when I've been in hospital, right up to about ten years ago, whichever ward you're in has looked after your insulin and you've had no say in it really, and the medic on duty has to authorise your insulin every time. This, in the past, has led to problems with me. For instance, when I was in the eye hospital having an eye operation, I couldn't check my own insulin and I was given the wrong dose. By lunchtime I knew this. The French doctor that was on said "quick, give her sugar, give her glucose", and I had to say "no, I refuse to take glucose, I'm going the other way", and I insisted on having a blood sugar test done first, and they did it and found that I wasn't in fact hypo, I was very high, my blood sugar had gone up to over twenty. And I said "well how much insulin was I given this morning?". Well I was given a quarter of my dose, so this is what happened. Now if I hadn't understood how I felt, I'd have been given more sugar and got into quite a state. Well nowadays, they are very good. When I had my laminectomy, although I was under drugs for the pain afterwards, I managed to look after my own diabetes. Once or twice they had to help me with the injections, but this I think, I suppose you can't do it with every patient, you've got to understand what you're doing and I do regulate my own dose
- (17) almost daily depending on what... I started doing this rather off my own bat, but I believe now that more people do it. I found that it was easier to change my insulin if I was going to have a lot of exercise, and I was low anyway in blood sugar, rather than eating too much, having to eat too much sugar and get fat, or fatter, and so I have used a sort of mini sliding scale in my own right. Now, I think it's quite approved of now and so this makes life a lot easier, but of course this is quite difficult in hospital and I

don't think the nursing staff like it very much, but as long as I know it's going to work for me I'm afraid I'd rather insist on doing it.

Have you noticed any changes in attitudes on the parts of doctors and nurses to diabetes over the time you've had it?

Yes, they're very much more flexible to the patient now. They will listen to how you are, because I would think that every diabetic's different. I should think it's an extremely difficult thing to control exactly. There must be ways of doing it on dosage of insulin at times like, especially when you're being anaesthetised and so on, but day to day there are so many things that affect your diabetes. When I was last talking to the medical students in Oxford, Dr Matthews asked them for twenty reasons for going hypo, and they just managed it, which I thought was extremely clever. And I'm sure that wouldn't have happened a few years ago. There's a lot more awareness. Everyone is becoming more aware, but it is still rather an unhappy disease in a way. No-one really wants to face the fact that it could even happen to them. It's happening to more and more people with the lifestyles we lead and people, I think, are afraid of it. It's not a very fashionable, if you can call illnesses that, but I do think it's a very dangerous one.

Have you noticed any changes in attitudes on the part of lay people?

Yes, everyone's much more aware of it now and they're starting to realise that there are two types and

- (18) ask more questions, and of course things are a lot easier than they used to be because you can get diet drinks. Everyone's very much more aware of their diets now, and also on packaging you can usually tell the carbohydrate value of things and so on which you couldn't in the past. So in so many ways it's easier because there was nothing like that, you couldn't get any low calorie drinks, you drank water or nothing, which is very difficult socially really. You couldn't even get a diet tonic water and pretend you were having a gin and tonic! It used to be quite difficult, things are a lot easier and so they should be. It's not a very pleasant disease to have because you know it's like... It's really, I was asking a friend the other day how he felt about it, he developed it about fifteen years ago, and he said "it's like walking a tight rope". He has Type A diabetes as me, or Type 1 or whatever you say, and he's on insulin and he has managed to keep working all right, but he said "it's like walking a tight rope with a drop either side of you of eight hundred feet". And I suppose it is, that's a very good description really. You've just got to keep yourself on that straight and narrow and understand how to keep yourself there, and if you topple over too far you're going to go down.

Has diabetes really determined the course of your life?

No, not at all. No, I've done everything I wanted to do. I've had a wonderful life. I really have done all I want to do, and still working now at sixty six and still putting on exhibitions of, well, my husband is also an artist, and this year

we're putting on a show with a hundred pictures. They've all had to be painted. In fact we've been to France, we've been to Greece, we've been. . . Well in the past we've been a lot to Venice, I've walked all over Venice, now I can't do that with this ankle, but all over the country painting. We work almost full time so it keeps you. . . I think since we've been together he's been healthier because he keeps to my diet, which is of course no puddings! And a very, very healthy diet

- (19) with lots of vegetables, and, you know, it's a good diet. From that point of view, that's very much a plus side. He's extremely intelligent and takes it in his stride and it doesn't faze him at all, and in that way I'm so lucky. But I can see how it could really faze people and upset people's marriages, as it really did mine, my first one. This is a tricky point of it.

When you're telling people about yourself, do you say "I'm a diabetic"?

No, no I don't, I still don't. I don't think it's the important part in life. Nowadays you can say "oh I'm sorry I can't eat this". I mean a lot of people don't eat things because they don't like them now and because they're slimming or something like that. People happen to know because of, you know, for the sort of health things that have happened, so oh no, I never tell people unless it's obvious that I need some help. I mean, if I'm travelling I do get help at the airports, and I don't tell them on the plane because you don't get a very good meal if you get a diabetic one. It doesn't suit me at all, it's much too heavy, but also. . . Oh, a very funny thing happened to me once. I did tell someone I was diabetic, because she, it was someone I didn't know at all really very well, asked me to dinner, and she said "can you eat anything?", I said "well I happen to be diabetic", "oh dear" she said "oh that's alright, I know exactly what to do". So when we went to dinner, I found there was no carbohydrate at all, and I was slowly going hypo through dinner because I'd had my insulin before dinner, and I had to sort of creep out and take my bag with me and eat all my glucose in my bag to stop going hypo! These things can happen, so I just shut up about it on the whole and just manage.

You've talked a lot about just knowing how you were going to be feeling and you amazed me earlier by talking about the hospital giving you a deliberate hypo. Can you just elaborate on that a bit?

Well yes, you see, if you're a little girl of nine and you've never had anything like a hypo, it would be quite scary I think to suddenly feel weak, hot and sweaty, shaky, terribly hungry, and you might not be near an adult you could explain this to. Well, I was told how I would feel, and they said "we're going to give you some medicine which will make you feel like this. Now when you feel like this, you tell us and we'll put it right. But we're giving you this so that you know that when you feel like this, you must have some glucose or a sweet drink or a biscuit or two, or even a drink of milk". Well this has stood me in good stead all my life. I always have good warnings, well until lately, if I'm going hypo, and I really bless the day that the doctor did that for me.

- (20) After I'd had diabetes for fifty years I was sent a wonderful medal from the

Diabetic Association. I thought this was wonderful. It was a great morale boost, and when I've had it for sixty years, which is in four years time, I'll get another medal! I think this is marvellous. The Diabetic Association does this, and if you belong to it you get a magazine every three months, and nowadays it's extremely helpful. They tell you a lot of medical details that you were always hidden from before - it wasn't good for one to know things. I used to get to know them because I asked questions, but I think now people are allowed to know what's wrong with them and how to cope with it and so on, and this magazine, it's called Balance, and it's extremely good, from the Diabetic Association.

Do you feel that in the past, medical staff hid things from you?

Oh yes, oh yes. I mean, you were sort of protected you see and you weren't supposed to be told too much, I suppose. I think it was a protection in a way, because there was a time when I didn't want to know all the nasty things that could happen to me. There was a time when I was young when I used to go to the diabetic clinic and feel quite depressed for a few days afterwards because there were all these old people, usually in wheelchairs who'd lost legs and so on, who were blind, white sticks, no legs or something like this, and I thought "my goodness, this is what I'm in for". Nowadays this, of course, is an ongoing thing and this can't be helped, so it is a problem, but I do think people need a bit of warning, in a way. I don't know how you do it; I'm not an expert in that line. But having been an OT and done quite a lot of psychology and worked in the mental hospitals, and also with children and with adults, as a whole I can see that through the different stages in your life you've got to be protected in different ways. And I think diabetic consultants have a great responsibility in this, because if you're frightened by it you could blot it out. And I think these days when everyone, one particular thing must be extremely difficult, everyone's got to be so terribly thin. So, I mean, when I was a teenager, well I was fairly slim because I was still slim from first being diabetic, then I started putting on weight,

- (21) and I think I would now have been trying to slim so hard that it could have affected my diabetes. I have heard of people who have actually stopped giving themselves their insulin so they don't have to eat, and this is such a dangerous thing that, I mean, I wouldn't have considered doing it, but I think in a way this sort of thing has got to be stopped in a way through psychological means because it's a very, very deep... I mean it must be frightfully difficult getting people to eat certain diets anyway nowadays with this obsession to be as thin as a bean stick. I don't know what else to say really.

Well, when do you feel that medical staff began to be more open with you and tell you whatever you needed to know?

Well, I think it's probably over the last ten years or so that this change has happened, when we're given more knowledge. Of course the great problem is

time, because there isn't a lot of time to talk to your consultant when you go to the clinic. They, you know, I think they're probably given ten minutes for you and that's it, and so, you know, you don't get a lot of time to discuss it, and there's a great deal to discuss when you go. I don't know, I think staff, I mean consultants, I don't know how they manage getting so much over in a short time because it affects your life so much, so completely. If you go off the rails, then what do you do? If you don't, or if you're stuck in a place... Supposing you're stuck in a traffic jam with no food in the car, whatever do you do then? These things must be told to people - they must never go anywhere without a packet of biscuits or something near them. So there's so much to tell them, I don't know how they cope, I really don't actually. I'm getting a bit chatty now.

Have you reflected on why you have diabetes?

I've often wondered why it should be me out of a vast family. I have, well, about forty or so cousins, no-one else has it. I believe a great aunt had it in India, but I should imagine it was type B because she was, it was in her old age, and she couldn't have lived because this was the pre-insulin date. So all I can think of is that it was the shock of coming back to England really. It could have started from the death of my father when I was five because we were very close. When I thought of having children, I thought very strongly about this, but as it wasn't strongly in my family I felt it was a risk worth taking, and so far so good. I have seven grandchildren and everyone so far, touchwood, is very healthy.