81. Joan

(1) Tell me about your background.

My mother was born one of nine children, and her father died when she was very young, so it was a struggle for her mother to bring up that number. My mother, as she grew older, didn't want to live on the farm where they lived - didn't want to work on the farm where they lived - so she decided that she'd like to work in a local dress shop and milliners shop, which pleased her a lot. My father was a young man, of course, and working with his father, until he met my mother. And then he decided he wanted to earn more money, so he then trained to be a carpenter, which he did until he married, and after they were married, indeed. I was an only child, unfortunately for me; it was lonely. I think, perhaps, this might have been because I was such a sick child, that my parents decided not to have any more. And when I was, I would think, around three, I started to be really quite ill. I had a terrible thirst. My mother was getting up in the night to change the sheets, because I'd wet the bed so badly, and she was taking me to the doctor's, also, with pains in my knees. The doctor asked "does your daughter treat this as a joke?" My mother wasn't happy about this, because she knew that I couldn't pass this much water in the night. My father was working away, at the time, because it was towards the end of the war. And I gradually became thinner and thinner and thinner. And my grandfather called every morning to see how things were, and things were changing from the night before to the morning. And so, on, I think it was the 21st of May 1945, my grandfather went to the doctor, and the doctor then sent a note to my mother saying "you must take your child to Addenbrooke's, without a moment's delay. I am sending both... a note for you to take with you. Take her ration book, identity card, et cetera, but waste no time". And it was signed by the doctor. It was quite a trauma for everyone. My father had compassionate release to come home, because I was so ill, and my parents were asked to stay in Cambridge for, I think it was three weeks. They were allowed to be with me, at the time, because it was feared that I would die. When it was explained that I'd have to be put on to injections daily, one nurse showed on another nurse how it was done, and it made by father feel so ill, he had to sit down! But my mother had to do these, because I wasn't old enough to do them myself. And in those days, there were no pens, or anything of interest; useful things. To test urine, my mother had a test-tube, into which she put, I would think, about an inch of blue solution - I think it was called Benedictine solution - and a trickle of the urine, which she then had to boil over a meths boiler... meths burner. And if the colour stayed blue, there was no sugar; if it was green, there was a trace of sugar; if it was yellow, there was a bit more sugar; and if it was orange, it was quite a dangerous level of sugar. There were no blood testing meters, in those days. Life was very difficult.

(2) You just read out the original note that the GP gave to your mother to take to Addenbrooke's Hospital. Do you think it's significant that she kept that note?

Yes, indeed; very, very significant. And she gave it to me, when she was quite an old lady. She also gave me another note, which came from the people who employed her before she was married, and who'd kept interested in my condition. And it says "Mr Near and I are very sorry indeed to hear of the illness of little Joan. As you know, we are both very fond of the child. We do hope and pray that she may be spared to you both, and that you and your husband may be given strength for this time of trial and anxiety. With kindest regards to you both. Yours sincerely".

It's quite dramatic that, you know, you were to be spared. So, were you really at death's door?

I was. I was at death's door, yes.

What memories do you have of the hospital?

Well, to begin with, I didn't go into a hospital. It was a school, and part of that school had been taken for hospital use, because the main hospital was being used for injured soldiers, and that kind of person. So, my memories of the school were that the nurses were there, and the beds were rather hard, and that, strangely, I was given kippers to eat every morning for breakfast - full of bones! And then one of the other patients did tell my mother this, and she said that she would have a word with the nurse, which she did. And so, after that, I didn't get the kippers. I remember the kippers as much as anything, really.

Can you remember the injections?

Yes, I do. I know that my mother struggled to learn to do them, but I couldn't do them, because they were glass syringes, with rather long needles - rather thick needles, in fact. People wouldn't want to use those today; I wouldn't.

Can you remember what you or your mother were taught about diet?

My mother was taught mainly about the diet. I had some scales, which... bread had to be so accurate, that the scales measured it in quarter ounces, third of ounces. And so, if we went anywhere - which people didn't go out and eat so much as they do now - but, if we were fortunate enough to go out - and we weren't that well off - then the scales went with us, and my mother would have to cut a piece of bread on a plate, on a table, you know. Got some odd looks, sometimes, but it went well. I'm still here to tell the story, anyway.

(3) Did your mother know anything about diabetes?

No. People, in those days, certainly wouldn't have thought of it in a child. And we came - my mother and I - came to visit an aunt, one day. And she was so worried that she went to see a friend, who was a district nurse, and said "look, what can we do? We've found this child with her head under the tap in the garden". And the nurse said, "well" - because I was so thirsty - the nurse said "well, take her home and do something to take her mind off this. Why not give her some sweets?" - the worst possible thing. And so, my auntie found a tiny Christmas tree, and they tied - between them - they tied sweets onto the tree.

And I was tempted to eat the sweets, rather than drink the water, which was the worst possible thing. And also, the GP, in our own village, told my mother that he didn't even think of it in a child so young. He had never known it.

What was it like when you came out of hospital?

For me, I suppose, quite easy - I was feeling better. For my parents, it was hard work; my mother particularly. But one of the benefits was that, with a child who had diabetes, in those days, I had - or all children, I suppose, if there were many, then - had a farm worker's ration of certain foods: cheese, meat, fish, those kind of things. And the fishmonger was particularly kind, because he would save little pieces of plaice for me, and, I'm afraid, have to tell older people that he hadn't got them. The butcher did the same. He would ask people, or ask my mother to wait in the queue - or at the back of the queue - and serve other people. And then, when the other customers had gone, he would go to the fridge and find things for my mother that I was entitled to, because it could have caused a bit of a problem for everybody.

(4) So, a lot of people were concerned about this very sick child?

Well, yes. Diabetes, in a child, was almost unheard of, in my day. I had problems, later, when I started school. I was unable to start school with other children of my age, because I had a bad scald on my foot, and the nurse was coming in to dress that every day, because there was a huge blister. And then, once I'd got to school, I started catching colds, and all sorts of things. And diabetes couldn't be so well regulated, in those days. It was a blood test, at the hospital, which we had to travel by taxi to get, which was very costly, and my father wasn't earning a lot of money. And, at the hospital, it would take two hours' wait to get the blood test result back, so it was a whole day away from our home. And then, the insulin dosage was calculated in a different fashion, to give me either more or less units of insulin, on that one particular blood test, unlike today's people, who can test - well, I can - every half an hour, if I want to, or if I need to. School was not easy, because, being so ill, so often, meant that I didn't have a lot of time at school. I had a long spell with having tonsillitis. I would probably have a week off... a week at home... oh sorry, a week at school and two weeks off school, because of the tonsillitis. And I became allergic to penicillin, so I couldn't take, really, the necessary tablets.

Can you remember at what age you started injecting yourself?

I think I was about seven. It wasn't easy, because the syringes - as I think I might have said - were glass, and I wasn't really too happy about using them. And if I could get out of it, I would. I would encourage my mother to do them for me. But I had to learn, and as time goes by, like with everything, it gets easier. I think, to begin with, I had two injections of soluble insulin a day. That happened, I think, for nine years. Then, I think, for the next nine years, I was on a different insulin called Lente, and then a mixture of Lente and Semilente, and I can't remember after that.

(5) What were the attitudes of other people to diabetes, when you were young? We're still talking about the 1940s.

Quite strange, in some ways. Adults were fairly helpful, to an extent, but nobody really wanted to take me out for a day. If I went to some other child's birthday party, then I had to take a lot of my own food, because it was weighed and packed before I went. And at one of the school's Christmas parties, which I actually managed to get to, somebody told my mother, afterwards, that I'd been seen eating jelly and sweet things. And so, I was questioned about this, and no I hadn't. I felt quite angry, and also upset, because I didn't ever tread sideways either way on what I should and shouldn't do. And so, my mother went back to the person, and said "look, my daughter has said no, she didn't do this", but their child had said yes, I did. So, it was a... well, who do I believe? But I can promise you, to this day, that I didn't, because it wasn't worth my while; I knew that. And, if you don't tow the line with diabetes, then there's big trouble. Other people, it seemed, would not be prepared to take me anywhere, because they were afraid, I think, more than anything. I think people were afraid of a diabetic child, in those days. But there was one family who took me for one day to the seaside, and I've never forgotten that. We went to a hotel, and had a meal, and that was extra special. And - I think I was about eight, at the time, possibly a bit older - and I always remember we had, or we were offered, fresh salmon. And there was enough for all of us, except for one, so I volunteered to have the tinned salmon. But the father said "oh, no, no, no. We've brought you out for the day, you have it; you must have it". So, I did, and it was lovely. I've never forgotten that day.

(6) As a child, I didn't get that many days out. It was quite costly, and my parents weren't particularly well off, and I was an expensive child to keep. We went to hospital by taxi, simply because I had to be there at a certain time. And there was a train service, but we tried the train on one occasion, and when we got to the hospital, we were told "this child is too late for a blood test, and you must come back next week". So, this we had to do, of course. And it cost the train fare that week, and taxi fare the next. But then, as time went on, and blood testing became a quicker thing, rather than wait for two hours, then we could go on the train. And that was a bit more convenient, and a little bit cheaper.

How far was the hospital from your home?

Roughly twenty miles, I should think. Probably a little less.

Were there any other expenses associated with diabetes, apart from the taxi fares?

I think my mother had doctor bills. I think my insulin was free. I would think that the syringes would be - they were glass, and the needles were enormous. And at one point, when I was a little bit older, I was told by the doctor that I mustn't ask for so many needles, because "I shall have the health people back at me, because I'm prescribing too many needles for you". Size nineteen, I

remember, was the thinnest and the smallest one. Sometimes I had to have a sixteen or a seventeen, and they were, I think, about an inch long, and quite thick. And I had to keep using them over and over again. They were boiled; all my syringes and needles were boiled every day.

Was most of your medical care at the hospital, or did you go to the GP much?

I tried to avoid the GP, but when we had... after he'd almost let me die, because I did almost die. Then we had another GP, who was a very, very good one. But, because he was so good, his word was law, and that caused me problems later. But I'll talk about that in a few minutes.

(7) Before we move on to your teens, do you have any more memories of earlier childhood?

Yes, I'm an only child, and often people say that only children are spoilt. I strongly disagree with that. I think, because I was diabetic, I was over-protected. For instance, I really did want to learn to dance, and I joined a dancing class. But I was stopped from going there, because this was not considered to be right for me. And I used to cry, when I saw other people going, because they had to pass our house. But it was considered that it was better not for me to go, because it would look like I was spoiled. That was my feeling, anyway.

So, it wasn't because they thought the dancing would be bad for you?

No, I don't... No, not from the exercise point of view, because exercise wasn't really included in my regime, in those days - as it is today. I wish it had been; I might not be the size I am now!

Were you restricted, at all, in the amount of exercise you could take at school?

Exercise was never mentioned as part of my regime; I think I've said that. But, no... I did ride a bicycle, and that was something my parents allowed me to do. I could ride around the villages with my cousin. I never, ever felt that my mother was checking up to see what time I would be back, and getting worried, but I always was given a time at which I should be returning home, and I always did that. I know I'm sounding like a very good girl, and I'm sure I wasn't all the time. She'd probably disagree with that, if she heard me now. But I did try, because I've always believed that if you look after yourself, as a diabetic, then that's the best for you. And it's up to everyone. And if anybody's listening to this, I hope they think "well, if I get it, I shall do as I'm told"! It was difficult for me, as I came into puberty, really. I had a really, really bad winter - a whole... a really whole winter of very high blood sugars. It was between the age of fifteen and sixteen that I had really high blood sugars. And I wasn't allowed even to get out of bed. The GP would call, see me most days, and say "well, this girl must stay in bed". And on times when I was due to be at the hospital, he would tell my mother to get me up the day before, sit me in the chair, and not let me move out of the chair all day. And then, the next day, go to the hospital in the taxi and back again. And that, I think, was the most boring time of my life, really, because I wasn't allowed to have visitors, because it would all upset the

blood sugars. And all I did, really, was read. The GP was a very good one - a very, very good one. I have quite fond memories of him, because he looked after me well. But, when the point came for me to leave school, I was in his surgery one day, and he asked "Joan, what would you like to do when you leave school?" I told him - and it was something I'd wanted to do since the age of five - "I want to nurse sick children". He said "no, you can't do that, because you're not fit enough". I was really hurt and upset. And then, to add insult to injury, he said "find a nice job in an office", which is something I never, ever wanted to do. But my parents managed to pay for me to have some shorthand and typing lessons with a teacher that I'd got on well with at school. And he taught that, and piano lessons as well, so he would have one person playing the piano, and I would sit doing my shorthand and typing. And I did eventually get a job in a solicitor's office, when I left school, which I did enjoy, but I still really wanted to nurse sick children. I think, today, people would be encouraged to try, and then find out for themselves whether they were fit enough or not.

(8) What was the attitude of the people in the office to your diabetes?

Wonderful. They were all very kind; I mixed well with all of them. My boss was an excellent boss, in that he would always still pay me my full week's wages when I had a day off to go to the hospital. And I always reminded him that I'd had a day off, and he would tell me that "well, you never mind staying when the post is a big one, and you stay and help to get that off. You are always good at your job, and so no, I won't stop your wages", which I really thought was very, very nice of him. He was a lovely person.

And now talk about meeting your husband.

Well, at the office, one of the women was married to my... now my husband's friend. And that couple had a baby, who had a Christening. Now, I was invited to the Christening, and so was my husband, and he volunteered to come to my home and fetch me to the Christening, to save a lot of running around for the baby's father. This was quite nice. We got on very well, and, not long after that, he turned up to my home one day - one Sunday evening, actually - to see if he could take me out. I was in the bath, and my mother came to the bathroom door, and told me that he was there. And I had sort of kept him a bit of a secret, and I thought "oh, my goodness. If I stay here long enough, he'll go away". But he didn't! I wonder, sometimes, if perhaps he thinks he should have done! But, anyway, she came and called me again - my mother - and so I got myself dried and put some clothes on, and went to meet him. And my mother suggested, with a rather straight look on her face, as she could do, that I made a cup of tea, which I did. But I didn't really know how many spoons of tea I put in the pot, but it was sort of strong enough to stand the spoon up and it wouldn't fall over. He always tells people that I threatened to poison him!

How old were you both, then?

I was... I think I was nineteen, and he was twenty nine.

(9) We were engaged, I think, a year later. And then, in those days, you couldn't go out and look for a home, but we were - because there weren't homes to look for - so we were offered one by a man who wanted to sell one, and he knew we were engaged. And my mother was not really pleased, because she didn't want me to get married until I was twenty one, which was the marrying age, then. And anyway, we took the home and we were married another year later than that; married in 1962. And then, I did tell my husband about the diabetes - well, he knew before then, but he didn't know what it was like to live with - and I think it must be equally difficult to live with for the person who lives with the diabetic as it is for the diabetic. He found out, then, what low blood sugars were, and a year later, when our son was born - just over a year later - he really did find out, because I used to have really bad hypos in the morning. And he would try to wake me, and I wouldn't wake, couldn't wake, so he would fetch a cup of water, a basin of sugar and a teaspoon, and then hauled me up in the bed, filled the spoon with water, put a bit of sugar on it and turn to me. And by this time I'd slid back down into the bed again. And one morning, I took the teaspoon from him and threw it across the bedroom. I didn't know I was doing it, and it missed the dressing table mirror by about half an inch, I think! That was a long winter, because I had to go into hospital, because, in those days, when diabetic mothers were having babies, it wasn't a 'stay at home, look after yourself' regime. It was go into hospital, and I think I had ten weeks. And it was the winter of '63, 1963, when there was a lot of ice and snow on the roads. And I don't think my husband missed one night coming to visit me, in all that time, except Saturday nights, which were the hardest day at work for him. It was really boring, because I felt very, very well. And eventually I was delivered of my son; he was an eleven pound two ounce baby, which was quite big, I suppose. It was not unusual for diabetics to have large babies - I think their weight is more controlled today. He was really very heavy for me to handle, to start with, because it was a Caesarean birth, and the row of clips in my tummy, he would press on them. And I didn't see him for a couple of days, so there wasn't an instant bonding, which was a great pity; I'm a great believer in bonding. This was... my son was born in Mill Road Hospital at Cambridge, which is twenty five miles away.

(10) So, tell me how things went on, after your son was born in 1963.

Very well; he was a pleasure to have. As children are, always: they're pleasure one minute and not the next, but that's life. And then, the following year, I had a miscarriage, which was really, really nasty. And, at that time, I was... well, the time I was carrying the baby, something told me I would not have this baby. If it was born alive, it would die. It's just an uncanny feeling I had, and that's how it turned out. And then, the following year, when our son was only two, my husband had breast cancer, and our son celebrated his second birthday whilst his father was having a piece of the lump taken. And then he had to go back in and have the whole thing taken away. So, that was yet another worry,

but we weathered the storm, and so things have gone on quite well since then. I think for about the first seven years we were married, if one wasn't in hospital, the other one was. And by the end of the last year of - I think probably the eighth year - I was beginning to think "well, whose turn is it this time?", but it was a free year, that year. In 1966, I started to have awful pains in my tummy, and I saw doctors, I was into hospital, out of hospital. And, in the end, after many months, because it was not too good a thing, I think, to give a diabetic operations, then - well, it's risky for anybody anyway - but it was decided that I should have some surgery. And it was found that I had an abscess in the left Fallopian tube, which had burst. It had leaked into the other Fallopian tube, on the right hand side; it had stuck to all sorts of major organs; and I was told that I'd never, ever be able to have more children. Heartbreaking, yes, but I thought "well, I shall". I just knew I would. And so, I got better from that. And then, as time went on, I thought "maybe I won't be able to have more children". And then, in 1977, I found I was having another baby, which was a wonderful surprise, but quite a shock, really, having been told, and I'd accepted by now. And that baby I carried for seventeen weeks, and then miscarried again. So, then I thought "well. . . " - I think we both thought, I should say - that "well, there can't possibly be any more, not now. This is just our bad luck". And then, five years after that, in 1982, I found I was having another baby. Thrilled to pieces were we all. Our son was too - he was something like eighteen, nineteen, then. And that one I carried for eighteen weeks, and then miscarried that one too. So, that's been quite a big disappointment.

And do you associate those three miscarriages with diabetes?

Oh yes, yes I do, although, with the last. . . certainly the last one, I was better looked after. I think, perhaps, with the last two I was better looked after. But I think it's possibly just my type of diabetes. It's never been an easy one to control. But of recent times, I've gone onto the DAFNE system, which has helped, but, of course, it's too late to help me with the having of children, because I'm too old, now.

(11) Can you tell me about the history of your control, over the years?

Well, as I've grown up, as a diabetic, I've always been classed as what's termed a brittle diabetic, which I think means difficult to control. And then, it was in the 1970s that I became epileptic, also. Now, it was considered, perhaps, that - from something my mother said as to when I was a child, that she thought that my daytime hypos were different to the night-time ones - the doctors wondered if I, perhaps, had had epilepsy as a child, just at night times. And then they left me, and then came back in that time - I was thirty three, at the time - which caused a bit of worry, because they thought that epilepsy should show up before then. So, I had to have brain readings, ECGs, and various things to sort that out. And so, anyway, that's just another problem, not the diabetic one.

As a brittle diabetic, did you pass out a lot, as a child?

I don't really remember passing out. I remember being trembly; I don't think I

ever went right out. Possibly the worst hypo I've ever had was when I was in hospital with one of my pregnancies; the one in 1977. One of the patients in the ward told me, the next morning, "oh, my goodness, you kept us all awake all night". And I apologised, and said "well, yes, I'm not surprised", because I woke up, and I thought "well, if I've died, and if I'm lucky enough to be in a place called Heaven, it must be a wonderful place to be, because there are these lovely smiley faces all around". And the whole bed was circled with smiling people. And I had apparently had a really bad hypo, gone very low. All my systems had shut down, it was difficult to get blood from me, to do a blood test, and I didn't really know where I was for quite a few minutes. And I was asked constantly "do you know where you are? Do you know what the date is?" And then, when finally I did come to, I was left with a nurse, and she was told "don't let this woman go to sleep again"! That's the most... I think the most scary hypo I've ever had. And, for that reason, I don't like to have a low blood sugar when I go to bed, in case it should happen again; I don't want it to. I think it took about three hours to get me round from this hypo.

(12) You mentioned that you went on a DAFNE course. Tell me about that.

DAFNE is D-A-F-N-E: Dose-Adjustment For Normal Eating. It was a week's course, which I took at Addenbrooke's Hospital, and it began, for me, on the 11th of November, 2002. It was rather scary, because it was something so new. And there were seven other people, I think, in my group, and I felt that everybody else was much better at absorbing this than I was. But, as the week wore on, it was very, very nice. The people, helpful; the educators, wonderful. And it has enabled me to have a much more varied diet, because it means that I do a blood sugar, and then I work out the amount of carbohydrate that I take on board, and then, from both of those results, then I adjust the dosage of insulin. So, if I want to have an extra meal, I can. If I want to miss a meal, I can - or I should be able to, but for me, it doesn't work entirely well that way. But it means that, if I go out to dinner, or if we're invited to somebody else's house, and they cook at a slightly different time, I'm not so time-tied as I used to be.

Did you find that you could adjust to a more flexible diet, after so many years of not having a flexible diet?

No. I always say that if there was a cure for diabetes, I don't think it would suit me very well, because I'd want to still look at the clock every five minutes, every ten minutes, every hour, or whatever. It's something that, over this length of time - it's now sixty two years since I became diabetic - and it's something that you just live with. It's there, every day, like a house is something you live in everyday. It's that close to you that you just can't shrug it off. It would be very, very hard for me to adapt to being cured, if there is ever a cure. I remember my mother saying, when I was quite a child - about ten - there was talk of a cure in ten years. And my mother turned to me, and she said "oh, you'll only still be very young then", and I thought "Mum, I shall be twenty!"

(13) In what ways do you think having diabetes has most affected your life?

Children. Children I wanted to care for, from an early age. And then, when I found I couldn't do that job, I then decided "well, it would be nice to grow up, be married, have a family, go to work, work again in later years". But I couldn't have the children, or if I was pregnant, I miscarried. And it's just been a big disappointment; that's the disappointing part of my life. In general, I'm a happy sort of soul. I drift a bit. My husband tells me I should have an aim in life, but I don't like to have aims; I like to drift. And if I want to do something, I do it, and if I don't want to, I don't have to. I did work. We had our own business, so I worked for my husband, after... this was after we were married. People used to say "how do you live together and work together, and still agree?" He always told people that at work, he was the boss, and at home, I was! But it's not been a bad thing. I think that with everything that's bad that happens to you - if you could class diabetes as bad - it gives you more understanding of other people's problems. Miscarriages have made me understand other women who miscarry, and if anyone wants to talk to me, then they're more than welcome, because I'll listen. I think I've become a fairly good listener, because of being diabetic.

And can you talk about your husband's role in your diabetes?

He has been my mainstay. I had good parents, and my husband always treats me as somebody who's absolutely normal. He recognises if things are... if blood sugars are dropping low. He has always backed me when I've had problems with the miscarriages. If he does something which irritates a little, it's that - as the other day, we met somebody different, whose father has diabetes - and my husband said "oh, is he bad tempered?" And I said afterwards "that wasn't really very kind, because people are going to think I'm always bad tempered". He said "well, it does make you irritable, sometimes". And I said "well, I think if you said"moody", it would be a bit better"!

But, obviously, some people with diabetes are single. Can you imagine how you would manage without a husband?

No, I can't imagine that. I think to be on my own with it, it would really haunt me; it would get to me. But then, who knows, one day I may have to be alone with it, and then I shall learn to cope, I suppose, because that's what you have to do with any situation, isn't it?

And then, you've just remembered something that you didn't tell me.

Yes, that is when I left school, at around the age of fifteen, the doctor told me that I wasn't fit enough to work full-time. And so, I took advice, in a sense, from the headmaster, who had been at the school when I was at that school - the little senior school, in our village. And he was in need of a clerical assistant, but it wouldn't be full-time work. So, he offered the job to me, which I took, not particularly because I wanted to do clerical work, but because I wanted to be where the children were. And it was lovely; it was really lovely fun, that. I particularly remember one morning, going into work, and I had a - well, as some child thought - a pretty jumper. Little boy looked up at me, and said "oh, you do have a lot of pretty jumpers, don't you?" And I think ... that child made my

day. And the others would come up and meet me and talk to me, and it was a real pleasure. But I didn't work every day, so... I wished I could have done, but. No, that was another thing that I suddenly remembered, and I thought you should know.

Joan would like to add that she "can't fault" any of her doctors and she's particularly grateful to Dr. Owen Edwards who supported her through her ups and downs for many years.