

(1) Tell me about your background.

My mother was from Egypt, and my father met her while he was serving over there, in the army, just at the end of the war. And he brought her back to England, to Cradley Heath, in what was then Halesowen, and I now believe it's West Midlands. I was born in '44. I started primary school in Cradley Heath. My father was posted around a lot, and we travelled abroad. I was in Cyprus, up until I was in my early teens, but I was in grammar school before we left this country. After that, my education was pretty well finished at a convent, in Cyprus, where my father was stationed for six years. And then, when I came back to England, I started work at the age of fifteen.

What did you do?

I went into an office job, as an office junior. And I studied shorthand and typing at college at night, and progressed through a number of jobs, from telephone receptionist, receptionist, secretary, clerk, filing - numerous jobs - till I met my husband. And I got married, and then I carried on at work, full-time, for five years after I got married, until I had my first daughter. And then I became a full-time housewife, doing jobs in the evening - twilight shifts - to earn extra money. And that's about it.

And it's your eldest daughter who has diabetes?

My eldest daughter is Lisa, and her sister, Joanne, was born nineteen months after her, and it is Joanne who has diabetes.

(2) Tell me about Joanne's diagnosis.

Joanne was born a healthy, seven-pound baby. She was a robust, healthy eater, up until the age of four. And then she seemed to develop all kinds of symptoms. And, with hindsight, I look back, she had the normal childhood illnesses. Her sister was that little bit older than her, and we mixed... she used to go to playgroup. And there were a group of friends, all with young children, so every time measles, mumps, German measles, et cetera, came about, we mixed our children, so that they would all get it at the same time before they went to school. And there seemed to be a period from when - and I'm not sure, up until this day, whether it was German measles or the ordinary measles - Joanne never seemed right after that. She had numerous... She used to be a happy child, and she suddenly became... she wanted to sleep all the time. She complained of headache, tummy ache. She became a really whiny, miserable child. And she just didn't seem right, and I couldn't put my finger on it. And I used to go to the doctor's, take them regularly for their check-ups, and I'd say about it, how she seemed... She started wetting the bed. And we used to get her... catch her in the middle of the night, coming down the stairs, and drinking anything that was in the fridge, or she'd be in the bathroom drinking from the tap. And we used to shout at her, because she'd wet the bed. And I remember taking her one time to the doctor's, and explaining about this. And they insisted that... the doctor said "oh, stop her from drinking, stop her from drinking", you know,

which was very hard, especially when she sneaked in the night. My husband seemed to sleep with one ear open, hearing her do that. And then, I don't know why it was, but we... This went on for a few months, and I kept taking her back to the doctor's. She was losing weight, she was continually ill, no energy, and they just told me I was an over-anxious parent. But we started to... Her urine smelt very bad, and we could smell... her breath smelt. Now, we didn't know, at the time, what it was, but we could smell... her breath was smelling. And this one day, I made an appointment, took her to the doctor's. And I can always remember, it was an old woman. And I said, "I think - I think..." and I don't know why I pulled diabetes out of the air, but I said "I think she's got diabetes". And she said "what do you mean, diabetes?" And I said "she's losing weight, she's wetting the bed, and we can't stop her drinking". And I said "and her breath smells, and her urine smells". And this doctor said "you're an over-anxious parent. Go away, stop her from drinking". And they wanted to give her some tablets for anxiety, or give her this medicine for anxiety. This is just a vague idea of what this appointment with the doctor was like. So, I came away thinking "there is nothing wrong with her". The doctor says there's nothing wrong with her - it was just Joanne.

- (3) And that night, or the following night, she started... she'd gone to bed poorly, and she started crying. And we went upstairs, and she had actually emptied her bowels in the bed, and got tummy ache and she had a high fever. And that night, until four o'clock in the morning, it was continual. And we called the doctor out at four o'clock in the morning, and he came, this locum. And we explained what had been happening, and that I'd taken her to the doctor's and she'd told me there was nothing wrong. And all he did was put his nose near her mouth, and he was on the phone to the ambulance, and she was rushed into hospital, practically in a coma. And that was Joanne's diagnosis.

And what happened next?

Well, we rushed her into hospital, and, of course, all the doctors were rushing around, and put her on a drip. And the difference was amazing; within an hour she was back to her normal self. But, of course, they asked us what had happened, and I explained about how I'd taken her to the doctor's and had been told to go away as an over-anxious parent. And between themselves - there were a group of doctors - they were looking at each other, and you could see the horror on their faces. And that was... from that day on, I never went back to that practice. I many times think about it now, in this day of litigation, how I could have probably... I could have lost my child. I was that close to losing my child, because of the incompetence and the ignorance of the doctor, at that time.

- (4) And what happened at the hospital?

Well, I can't exactly remember, now, how long she was in, but it was a good couple of weeks, maybe a little more, until they could stabilise her and get her right, and obviously educate us, as parents, on how to look after her. We

were seen by nutritionists, who gave us booklets on what carbohydrate contents each... every food had, how much we could feed her for each injection she had, which at the time was four a day. We were both taught to inject an orange, which is a hell of a lot different than injecting your child! There weren't... the nurses who looked after her, and the doctors, weren't... it was a paediatric ward, so there weren't, as such, people who knew... they didn't specialise in diabetes. Some of the nurses hadn't even... They treated the child as a sick child, they didn't know about diabetes, in particular, and that was hard. And at the time Joanne was in, when she was first diagnosed, there wasn't another child in the ward with her who had diabetes. That came much later.

(5) What was it like when you got home?

Very frightening, I think, for both her and ourselves. I think the... she was a good eater before she was diagnosed, and once she started to get better with the injections, she was always ravenous. And the hard thing is to say "you can't eat, because it's not time yet", you know, "you've got to wait". And trying to give... find something as a stopgap, you know, I mean a carrot or a piece of celery, or something that's got no carbohydrate, just to fill the gap until the next meal. Learning the contents of each food, having to say "you can't have that", or "you can have that, but if you do, you can't have that", you know. And for a five year old to have to make choices about food, when they're hungry, is very difficult for all of us. And the fact that I had a so-called normal child, who could eat anything whenever, was hard to explain to somebody who's got diabetes, and has to learn to moderate and work to a regime. But you manage, you have to manage. We tried - and I think we did it, even though Joanne will look back and say she always felt different - we never pulled any punches. She had diabetes; you've got to live with it. Yes, it's sad - "it's not right", as she used to say, "it's not fair" - but you've got it. And that's how we tried to say "if your sister has..." - somebody gives her sweets - "I'm not saying you can't have a sweet, Joanne, but if you have a sweet, or you have a Mars bar or you have six biscuits, then you can't have your dinner. So, which would you rather have? A dinner that's going to be filling for the rest of the day, or you want to eat a Mars bar for so many carbohydrates, which has took up two meals in a day", you know. So, she had to learn early, and she found it very difficult. She was just starting school; she found it very difficult. She had to eat snacks, and the children in school weren't allowed to eat snacks, and so it made her feel different, so I used to get that fight, and "I don't want to eat it". And having to monitor outside the home was even harder than monitoring in, because teachers and other mothers, at the school, were ignorant about what it's like to have a diabetic child.

(6) So, tell me about school, then.

Having been diagnosed just as she was starting primary school, I was advised to go and see the school about accommodating her diabetes. And I remember going to see the headmaster, and he was very apprehensive about taking "this child", because they didn't want the responsibility. So, I had to explain that she would

have an injection before she went to school. I would inject her at lunchtime, when I came to fetch her - she would have her meal at home - and when she came from school, that was the next injection. There was no responsibility for the school. The only responsibility they had, or the only difference - allowance - they had to make for us, that during her break she had to have a snack. And, of course, the other children couldn't, and the headmaster didn't want to have to make allowances, because it wasn't fair to the other children. And I'm afraid I really... I was a very angry mother, at the time, because of how all this had come about, doctors, et cetera. And I told him what for. And he said that the school... I tried to explain - well, I did explain - how the only responsibility they have is to really just keep an eye on her. I would explain all the symptoms, I could supply all the paperwork, and I know - I'm positive - at the hospital, they told me they would send a health visitor up to the school to explain to the teachers, as well, who would have dealings with Joanne, of what to look for. Nothing was foolproof, but what to look for if she was a bit low on her sugars, how she could behave. And he was very, very apprehensive about it, but he finally agreed, and I know the health visitor did go and see them. And, with that, she was taken into the school. But they were very apprehensive, and I could understand it. But, you'd got children, I remember, had learning difficulties, and there was a child who could have epilepsy, or anything like that, you can't sort of say they need to go to a special school. Diabetes is the lesser of the two evils. And Joanne was an intelligent child, and did know - and, bless her, did she use it! She used it to the inch. If she didn't feel like doing a certain lesson, she would use her illness, which... And I had many a phone call from the school saying could I come and fetch her, 'cause she wasn't very well, which most times she was. But I did make mistakes now and again, and she was actually ill. But, this is the difficulty of looking after a child. When they suddenly tell you "Mummy, I'm having a funny", which Joanne used to call when her blood sugars were low, do you jump quickly and give them something, and push their sugars further up? And in the middle of the street, you can't stop and test their blood sugars. And it's a big responsibility, and I understood it was a responsibility for them. That's looking after a diabetic child.

(7) You think her diagnosis was the end of 1977 or the beginning of 1978. How were you testing blood sugars then?

We had a scalpel, a small scalpel thing - vicious looking thing - and urine tests. And that went on for a long time.

What did you do with the scalpel?

We had to dispose of it... What did we have to do to inject, you mean... to take a test? We had to jab her with it, jab her thumb with this scalpel thing. It was terrible.

And then what did you do with the blood?

They had to put it onto a strip, and watch it change colour. There were no machines, in those days, it was just by eye. We had a chart, and you sort of had

a look to see where the... what colour it had turned. And the urine test was the same; you dipped a stick in the urine test.

And what are your memories of giving her her early injections?

Sterilising kits; big, glass syringes and big fat needles; and we used to have to sterilise everything in between. And dragging her out from under her bed, behind chairs, screaming her head off, because she's got to have an injection. It was horrendous. She is still, till today, needle-phobic. But you have to harden yourself and just stick it in. But they were horrible cumbersome things, for... gosh, from five till about ten, and then they brought in the disposables. Or maybe it was... no, it was a little earlier than that, they started bringing in the plastic disposables. And I used to have packs of those, and needles were already attached; very fine needles. So, yes, things changed. Within the first two, three years, it was the big, old-fashioned syringes, and then we had disposables, which they gave us on National Health.

And can you talk about preparing meals?

Meal-times: I had a pair of scales, but you could also measure by scoopfuls, or spoon... tablespoonfuls. So, things like potatoes, it was two medium-sized potatoes equalled so many carbohydrates. A scoop of mash equalled so many carbohydrates. Peas - a tablespoon of peas - so many too, et cetera. Meats, vegetables, except for the peas, were carbohydrate free. And Joanne loved her vegetables, so she could always fill up on those. Snack times were mainly plain Marie biscuits, she liked, or Petit Beurre, they were called. But her eyes used to light up if she saw a Bourbon cream or a custard cream. So, she could have two plain biscuits for ten carbohydrates, or a Bourbon for twenty. So, she had to make choices. So, even when it came to the food, or the snacks, or the puddings, she had to make a choice, which, again, is hard. But she was more of a savoury person, so puddings didn't cause too much trouble.

(8) Had you had any experience of diabetes before your daughter was diagnosed?

No, none whatsoever. I mean, I found out later my aunt had diabetes, which I'd known about for years. I mean, she always had to watch what she ate, and then as she got... she used to control hers with diet, then tablets. And then I remember, in later years, she was on injections, going to visit her and seeing those syringes there. But that was age onset, and my mother also was diagnosed with age onset diabetes, when she was in her early sixties, and that was managed with diet. But Joanne's was infantile diabetes, which is a completely different thing, so I had not experienced that at all. That was a one-off to me.

You said that Joanne talked about having "funnies". Was that a frequent occurrence?

Depending on what was happening at school, or whether she wanted a little bit more attention. And, as I explained, it was a hard one to judge, sometimes. You have to judge it right, fetching them out of school, or some mornings when she

wasn't... Mornings weren't so bad, if she didn't want to go to school, because it was easier to test then, and keep an eye open for any symptoms of anything else. But I can remember one occasion where she'd pulled the same trick. I ended up going up the school for her, fetching her home, and I was so angry. She'd pulled it quite a few times in a short period of time, and there'd been nothing wrong. And I sent her to bed. I said "if you're ill", you know, "you can go up to bed. You're not watching telly or doing any playing". And I carried on with I'd been doing, and I suddenly heard these horrible noises, and rushed upstairs to her bedroom to find her fitting. And she actually was ill, that time, and I'd left it too late. I had to quickly get... I had a Glucagon injection, which you could give if the patient had gone into a coma. Because she was fitting, it was too dangerous to try and force anything into her mouth, plus she wasn't compos mentis, so I couldn't get her to eat any thing. So, I had to give her this Glucagon injection, and contact the ambulance at the same time to rush her in. And that was the one and only time where it was really serious, but very frightening. And the guilt afterwards was awful, because... This is the problem when you've got a child that cries "wolf!" - you're not always right. But, touch wood, she didn't pull that one too often, after then.

- (9) So, how much was she in hospital during her primary school years, this is 1978 to about 1984?

Except for the occasion where she rushed in a coma, because of my ignoring her, childhood illnesses, things like colds, tonsillitis, infections would usually send her sugars way out, and she would spend a few days in hospital, or a week in hospital, now and again, to try and stabilise her. And that, again, was a hit and miss thing. There were many occasions where her sugars were low and she needed glucose, and the doctors, in their ignorance, are giving her insulin, and fetching her sugars down even lower and sending her into a coma. And we, as parents, saying "no, her sugars are low! She doesn't need insulin, she needs glucose", and being treated as "go away, parents, we know what we're doing", when they really didn't know. And there was one occasion where my husband said... had his hand on the drip, and he said "if you do not take that drip out of her arm", he said, "I'm taking it out". He said "she needs glucose, not insulin. You're sending her into a coma, and she's already heading that way". And these were the sort of things that happened in hospital, where the parents were treated as if we didn't know anything. We knew our own child. We were with her twenty four hours a day, seven days a week, fifty two weeks of the year. We knew every nuance. But when you got into hospital wards, you were pushed to one side, and you had to watch them make mistakes.

- (10) What other parents did you meet with children with diabetes, when you were at the hospital?

One time Joanne was taken in, for some illness she'd got - and I think she was about eight, seven or eight - and in the next bed to her was a young girl, a couple of years older, I think. And her mother came to visit in the afternoon. And I found out she had diabetes too. Joanne was telling me "that girl's got

diabetes". And her mother and I got talking - so, this was a couple of years after Joanne was diagnosed - and we got talking, and her daughter had been diabetic for a good number of years. And she was telling... I was asking her how she managed, and she was explaining to me what she'd found, and how things were with her daughter. And she was so laid back about it. She understood how I was feeling, but she was so laid back about it. And she told me a lot... I thought I'd learnt a lot, talking to doctors and nurses and different things, but by talking to another mother who was so laid back about it, in that week that we were... that both our children were in hospital, it... I came away with a completely different attitude. It was more of a help speaking to a mother, who had already gone through what I was going through, and still had to go through, than any so-called professional help. And we stayed... not friends - funnily enough, she worked at the local supermarket, so I would see her occasionally - but her daughter and my daughter, for a year or so, would... she'd come to our house, and I think Joanne went to her once. So, Joanne met her first diabetic friend, kind of thing.

And what was it that this other mother taught you?

I think, things like I was saying: Joanne having to make choices. Her daughter was... She'd had the same attitude as me: "you've got diabetes. This is how it is, sort of, live with it", you know. It's a very hard thing to do. You want to look after your child, protect them. But in the same time, when a child has an ailment - a life-threatening ailment, which is for life - you've got to teach them, you've got to be hard, and you've got to say "this is how it is, and you've got to get on with it". You can't let the softer side get to you. You can do that in private, but they have to learn to grow up very quickly, and they do. They take responsibility for themselves much earlier than any other child would have to do.

So, how was your attitude different, then, after you'd met this mother?

I think I felt... I stopped feeling so guilty. I stopped agonising over whether I was doing right or wrong. I could see that, whatever I had to do, it had to be done for Joanne. Whatever you didn't want to do, you had to ignore. It might have seemed cruel - it seemed cruel to other parents, it seemed very cruel to Joanne's grandparents - but I had a child with diabetes. She had diabetes, and this is how it's going to be for the rest of your life.

(11) And can you talk about any other support you got?

I can't exactly remember when - the actual date - but Joanne was still at primary school, when a specialist diabetic nurse came on the scene. And her name was Magda Livingstone; a wonderful woman. Joanne hated her, because Magda told it as it was. But she was wonderful. She made herself available; she rang me, and when she said to me "I'm available morning, noon, night. Any time you've got a worry, or you need to talk about something, ring me". And you hear that many times, but Magda actually meant it. And there was many a time I'd ring her up - you know, Joanne and I would have a fight over something, and "am I doing right?" - and Magda was always there to reassure. And she did try to

help Joanne a lot, but Joanne was so anti this injection, so she tried to talk her... There came a time where new injecting devices became available, and I can remember Magda coming to say to her, finding that she could have two injections a day, one in the morning, one in night, instead of having to inject with every meal - which was pretty well guesswork, you know. You could give so much insulin for so much food, so everything had to be weighed to the inch. And in primary school, as she got older, there were field trips and activities, where, when you're having four injections a day, she couldn't go on a trip, because she had to come home for her lunch, or... And because she wouldn't inject herself, it restricted her from the activities in school. And so, Magda tried to explain to her that she could have this new injection system, where she could have two injections a day. And that wouldn't make it so important that she had to eat at eleven o'clock and one o'clock and three o'clock, you know. It would give her that little bit more freedom. But it took Joanne a long while before she would go onto that regime. In fact, it wasn't until she went to secondary modern school, and could go away on a week's trip with the school, that she finally agreed. So, that was my Joanne: very stubborn.

(12) You say Joanne wouldn't inject herself. When did she start injecting herself?

We were advised, or told about a... I joined the BDA - British Diabetic Association - and there was a lot of different articles; I used to get magazines every month. And we saw something advertised for a diabetic holiday in Llandidrod Wells. And we talked about it to Joanne, and she was about seven or eight. And we explained how it would be exciting, and being with other children with diabetes, and all this, and having a holiday, et cetera. And we actually sent her on that. And it was very hard to do it, and they were very strict with those children. I can always remember her ringing up, crying, she wanted to come home, they were cruel, they made her do her injections in her tummy, and in her arm and different sites. But she was also having a good time, you know. It was only a week. And that taught her an awful lot. When we went to pick her up, she looked so forlorn, and she sobbed her heart out all the way back in the car, "I never want to go on another holiday". But it helped enormously. From then on, she took more responsibility for herself, and she would inject. Not saying every time. Now and again she'd sit there with the syringe and she couldn't stick it in, then I would help, my husband or I would help her. But it took a good... she was diagnosed when she was five, she was a good three, four years before she took responsibility and would inject herself, if push came to shove. But if she could get away with it, she would ask one of us to do it for her.

(13) And then, moving on to secondary school, when Joanne started in 1984, you've already mentioned that she had two injections a day, after a field trip. What other memories do you have of the secondary school period?

Well, when she started secondary school, and until she went on... until this field trip came up, and Magda... That was the tipping point, for Joanne, to realise that she had to go onto these two injections a day, which would be more



convenient for her while she was on a field trip. She was growing up. She hated people to know she was diabetic. It was all right in primary school, even though she'll say now, all the children took the Mick, or were horrible to her and made fun of her, and all this kind of thing. But at senior school, they're growing up a bit more. They were made aware, obviously, that she was a diabetic, but I used to instil in Joanne that she had to tell people. But if she could get away with it, she wouldn't. Mothers... as a mother, I had less input. I couldn't 'show her up', as she put it. So, you had to... I had to stand back a bit and leave the responsibility with her. But it... to be honest, the secondary years... by the secondary years, she took most of the responsibility. I was always there as a stopgap, but she'd gone through the bad periods, and she was responsible for herself; she had to be.

And what about the teenage years?

Teenage years: she did what most teenagers do, adolescents do. She would miss injections, she would play fast and loose. She didn't actually miss injections, but she didn't measure, she wasn't... how can I put it? It was a bit hit and miss. It wasn't so regular as when a parent is keeping an eye all the time. I can remember saying "you've eaten, have you done your injection?" And she would inject after eating, instead of twenty minutes before, as you're supposed to do. She drank, she smoked, she probably ate many of the things she shouldn't eat. But she was a teenager. The only thing, thank God, she didn't do - and my doctor's saying I'm very lucky - she didn't stop injecting altogether, and ignore the fact that she had diabetes. But she played fast and loose, and she still does. She didn't keep records - she'd go off to the diabetic clinic, and they'd been filled in the same day, you know, that kind of thing, or... It's just the normal teenage rebellion. I think, even if she was a normal child, you'd have the same problems. But, of course, the responsibility of having to inject, having to eat, being different in front of her peers - she hid it. That's as much as I know: she hid it. She didn't tell people, unless she had to; only those very close to her.

(14) And what happened when she left school?

Well, her first job - she did paper rounds, as a young girl, she delivered local newspapers - and then her first job was a YTS. She's very artistic, and she went to work just outside Hereford. And she saved up and bought a motorbike, which my husband and I were so worried about. But she was a tomboy, and she'd always wanted a motorbike, and she saved up and she bought it. And she had the lessons; that was one thing we insisted on. And she rode that motorbike backwards and forwards to Hereford for two years, in fog, snow, hail, rain. And that was my Joanne, she was a biker. And her diabetes didn't affect that. Of course, as a diabetic, you have to notify the driving... DVLA, and she has a limited licence, but that can happen for lots of illnesses. But that was Joanne, until she met boys - well, she'd met boys before - but met the lad and left home.

How much have you been involved in Joanne's diabetes since she left home?

Very little. As they get older, they take responsibility for themselves. So, I mean,

she goes to a diabetic clinic once every six months, or however long it is. You lose touch. Things have changed, obviously, in the last thirty years. Things have very much changed: the injections, the insulin, even the diet. Years ago, it used to be cabbage soup, weighing, measuring. The longer you have it, the more you can tell by eye, you know, you don't have to weigh every single thing that goes into your mouth. And she deals with it, so... I can still, as a mother, when we go out, and I... She has a habit of injecting through clothing, which I'm horror-struck by, when I remember the surgical spirit, and wiping the site before injection, and all this kind of thing. And you'll see a teenager injecting through clothes, or an adult injecting through clothes, and you have to bite your tongue. But things change.

- (15) Talking about white spirit, and the bottles and bottles of white spirit I used, and cotton wool, and that went on for a good many years, and then suddenly you're told "don't use surgical spirit, it makes the skin go hard, it's bad". And this is sort of explaining how things have changed, over the years. We had little swabs in paper, which came afterwards. And now, as I'm saying, I'll see somebody injecting through clothes, and I think "germs, germs". And yet, you know, things change. Over the years, many things have changed.

You sound as though you're still quite emotionally involved in your daughter's diabetes.

Well, as a mother, I think you always - it doesn't matter how old they are - you're emotionally involved. You pull away, you step back, but you're never totally cut off from it. And till today, Joanne hates going to the diabetic clinic. She always has done, from a child. And I'll go... she'll say "will you come with me?" - sometimes, if Nick, her husband, he'll go with her - but I've gone with her, over the years. I don't go in with her to see the consultant, but I'll sit in the waiting room with her. It's one of her bugbears, she hates going to the clinic. She says she still comes out of there feeling like a little kid, and that they treat her like she doesn't know anything. And it's very hard, even for her to explain. She lives with it twenty four hours a day, every day of the week, et cetera, and they're telling her what she should do, and what she shouldn't do, and what it should be like. So, yes, you never totally... you'll never cut yourself off from a child with an illness.

- (16) Looking back from 1977 or 8, when she was diagnosed, until now, would you like to reflect on other people's attitudes to diabetes?

It's a bit like anything in life, I think. When we're expecting a child, we learn everything we can from books, and supposed experts, on what to expect, what to do, what not to do. When reality comes, it's flying by the seat of your pants; textbooks mean nothing. The same happened with the diabetes. I was given booklets, I spoke to this doctor, that doctor, learnt everything from books as well. The reality of living with it is completely different. And, in some instances, when you attended clinics, you'd followed what the doctor said, you'd done

everything as the book says, but your child doesn't follow what the book says. And so, when you arrive at the clinic, and the results aren't as the doctor wishes them to be, the blame stops with you. And, as a parent, obviously, with all the guilt you suffer because you've got a sick child, and maybe it's something you've done, and then you've got somebody telling you "what are you doing to your child?", 'cause her sugars are wrong, or "it shouldn't be like this". It's very hard to live with, and I think it's only one time I, again, lost my temper. I haven't got a temper, as such, but I was sick of being told that, as a parent, I was useless, or I didn't know anything. And I actually - he was a wonderful paediatrician, by the name of Dr Cole, absolutely wonderful - and I did what I've said somewhere in the interview: "when you're living with it twenty four hours a day, how dare you tell me I'm deliberately making my child ill". And he suddenly looked at me, and he said "we follow what the textbook tells us, what we've learnt in medical school, you know, and what we think should be done". Not every child follows the rules, and Joanne was one of those. So, you have to live with that, and reconcile yourself to it. And that's ignorance, even in the medical profession. They don't know everything about everything. They learn it, the same as we do, but until you live with it, there's a lot of difference. So, you hit a lot of prejudice.

(17) What kinds of attitudes have you met among family and friends and neighbours?

Family: there have been odd comments about which side of the family it's come from - "there's nothing like that in my family", you know, that kind of thing. In the older generation, they remember the cabbage soup, and I can remember one old dear saying to me "oh well, she'll grow out of it". And a good many years later, I met this little old dear again, and she said to me "how is Joanne, these days? Is she still diabetic?" "Yes!" you know, they don't grow out of it. Mothers at school, ringing me up or stopping me at the school gates: "we'd like to... little Johnny would like to invite Joanne to his birthday party", or "Sarah wants to invite so and so - Joanne - to her birthday party, is she allowed to eat this, that and the other", you know. Even some mothers saying "is it catching?" you know. There is a lot of... I think it's a little more widely known about now, but back in the days Joanne was diagnosed, it didn't seem to be. People didn't seem to be aware of it. And the business about... it used to really hurt that they thought my child was unclean, you know, you couldn't play with her, because she might catch it, God forbid.

(18) And what experience have you got of changes in attitudes?

In hospital, about ten years after Joanne was diagnosed - late eighties, early nineties - a niece of my husband's was diagnosed. She was about nine or ten, I think. And I remember going to visit the mother in hospital, with the child, at the infirmary. And there seemed to be a lot more support, and a lot more help. And the nurses seemed to be more trained for diabetes. It wasn't just general nursing. They were specialising in certain areas of illness, paediatric illnesses, and diabetes came into it, along with lots of other illnesses. But, at

the time Joanne was diagnosed, until that ten year period, it was almost just general nursing, and then suddenly they started specialising. And there seemed to be doctors specialising in specific... I call them illnesses, but that's what they are, in a way. So, there was more specialising, and so you could meet a diabetic nurse, somebody who knew about the diabetes, and actually studied it; it wasn't just general. And I remember, they seemed to settle into their routine much easier, because there was so much more information available. But again, even Sandra, her mother's name was, would occasionally ask me "how did you manage with this?" Because, it doesn't matter how much people tell you, how much information they give you; when you're alone with it, it's very frightening. And you just need that little... have someone you can just ask "is it okay?" you know, "am I doing it right?"

So, what message would you like to give to the medical profession?

I think if you could just - I know it's impossible for them to do, because otherwise they couldn't do their jobs. I've been there, in my professional capacity - but if they could just stop, now and again, and put themselves in the parents' position, and think how it would be for them if they had to deal with their child, and be scared, and things aren't working as they should work, you know. And instead of trying to... instead of making them feel guilty, instead of them feeling as though they've got no support from you, think, before you say "well, this is how it should be", or "this is how you're doing something wrong", or "what are you doing wrong?", you know. Or even saying that to the patient, which, in many instances, has happened to Joanne. And that's why she hates to go to a clinic, because she feels as though the doctor is up there, playing God, and telling her, you know, it's her fault. And it isn't, life isn't like that. Two and two doesn't always add up to four, believe it or not, even though the textbooks say it does.