

(1) Tell me about your background.

I was born in the war, during the war, where my father worked on aircraft building in Worcester. And then, when the war ended, we came to Birmingham - don't know why - and they had a shop. And they left that shop, and my father started to work at a little factory nearby, and he became the works manager, until he retired. My mother had all sorts of various little jobs; she always worked. And my sister and I both went to grammar school, and we went through there. I went to work at Dunlop as a laboratory assistant, and I was still working there when I got married. My husband has a similar background. He was... he came from West Bromwich. We met at work, actually, because he worked in laboratories. He lived in West Bromwich most of his life. His parents were factory workers, but they, again, were works managers. And he went to Handsworth Grammar School, and he left there and got a degree, so he was a research chemist for many, many years. And we got married in 1962, and our eldest daughter was born 1967. And then - I'd stopped work, then, for a little while - and then Julie was born 1974. My husband was a research chemist at Dunlop, but, as a say, I'd left work. At that time I'd only got GCEs, but, since then, I've taken an Open University degree. Gosh, I don't quite know what else.

(2) Well, it's Julie that we're going to be talking about most, so tell me about when she was diagnosed with diabetes.

Right, she was four years old, nearly five, just started school part-time, and was quite enjoying it. And then it just hit us: she started losing weight, drastically losing weight; she was getting up all night long going to the toilet; having drinks of water. And it just suddenly hit me, with a shock, that something really wasn't quite right, and I just had it in the back of my mind; I don't know why. So, I took her to the doctor's, with a urine sample, thinking along the lines of diabetes. Unfortunately, the doctor I saw was a locum, and he didn't really have much idea of what he was doing, and he insisted on having a blood test. So, I took her up to the hospital for a blood test - he didn't seem to make it any urgent - took her up to hospital for a blood test. I took her back to school afterwards, and by the time I got back home - lunchtime - my GP was on the doorstep: "She's got to go into hospital immediately". And I said "well, I've just taken her back to school. Can't she have the afternoon at school?", and he said "No. Hospital, now". So, I phoned my husband to say "can you come home?", and by the time he'd got home, the doctor had rung me and said "it's all right, she can go in tomorrow morning. I've made arrangements for her to go in tomorrow morning, but if she starts vomiting or she starts to look a bit woozy, then take her straight in". So, fortunately we were able to leave her at school, but it was still very difficult to bring her home from school and say "look, I know you feel well, but tomorrow you're going into hospital". The hospital were absolutely brilliant. The only problem I've got, and I know that it's been addressed now, I couldn't stay in with her, and it was very, very difficult, four years old, just to leave her. Staff were fantastic, but it was still very difficult. She coped very well. She's a child... she always was a child who just got on with things. My husband and I

used to go in every morning to do her injections - we did the usual thing with oranges and that. And we'd go in about seven, do her injection and see to her breakfast, make sure she had her breakfast, come home, make sure my other daughter went to school, because she'd just started secondary school. And I'd go back to the hospital maybe mid morning, and spend most of the day with her. I'd go home for when my daughter was coming home from school, and then we'd all go up in the evening. We'd do her injections again and put her to bed. We found out later that, in fact, although we did put her to bed, as the nurses had asked us to, they all got up and went and watched television afterwards! I think she must have quite liked her stay in hospital, because it was at this point she decided she wanted to be a nurse, and she never wavered from that: wanted to be a nurse.

(3) What did you learn about diabetes, while she was in hospital in 1978?

Well, we had a fantastic dietitian, who helped us very much with the diet, because it was very rigid then. It was based on rations: ten grams of carbohydrate per ration, I think. And the hospital - the Manor Hospital, which is where she was, in Walsall - they were very good; they'd got all sorts of booklets and leaflets. We also joined the British Diabetic Association, and had loads of information from them. The hospital dietitian came out to school with me, to instruct the school on what she should be doing, which was fantastic. And the hospital - the doctors and the nurses - they were really so helpful. There was a problem, at the time: there was a bread strike - I don't know, something silly - and I did find that, particularly like for breakfast, because she'd got to have a certain amount of breakfast, carbohydrate-wise, they couldn't do toast, so she had to have an enormous amount of cereal and milk. And that was the one problem I had with the hospital: they didn't cater for diabetic children. I wanted to take fruit in, but no, the food had to be what they provided. And it wasn't a wide enough range of food. So, at that time, food was a bit of a problem. We learnt to do the injections, and that was a bit frightening, because they were great big glass syringes. And only being four years old, and having lost a lot of weight, there was no flesh on her. And it was terrifying trying to inject; I always thought "I'm going to hit the bone", or something. But the hospital were fantastic. She was in three weeks, all together, but during that time, she came home during the day. The important thing was that we were there morning and night for her injections. She spent the night there, and she just came home during the day. And so, although it was three weeks, she wasn't consistently in hospital. I did pop her into school for a couple of the days, to get back into the school routine, and again, they were very good.

(4) You say that you thought in terms of ten gram rations. Is that what they were called: rations?

I tend to call them rations now, because that makes more sense to people, but at the time we called them lines; now, I don't know why. She'd maybe have four lines for her breakfast, and that would be... like a line would be a third of a pint of milk, or a slice of thin bread, so that would be a line. And we had all

different books telling us what various rations were, yes.

What about testing for sugar levels?

That's changed a lot. It was urine testing, at the time. The only blood tests that she had were in hospital, and they tended to be little pricks, you know, just a little drop of blood. It was urine testing, so that, not necessarily every time she went to the toilet, but quite frequently, she had to collect her urine. We'd got a little beaker... And we had a urine testing kit, which was a little tiny test-tube which she had to put a bit of urine in, and then tablets. We had a tablet for testing glucose, and then another one for ketones. The tablet - I think it started out blue, and I think if it was blue it was okay, and the colours ranged right through from blue to green to yellow and orange. And that, actually, went on for quite a long time. And I wished I'd kept all the equipment, because Julie said she'd love to see it now, but I was just so glad to get rid of it!

How did she react to all these new things?

She was fantastic. When I look back, I can't see that she... I don't ever remember her refusing an injection. She quite liked the urine test, because, you see, it had to fizz, and that was like a little experiment. I mean, at four years old, that was exciting. I don't ever remember her having any problems about the injections; she just got on with it. I think the hospital must have gone about it the right way.

Was there any question of her doing injections herself?

She was only four years old, and at that age, no. They said they usually start about five or six, and, in fact, she didn't learn to do it herself till she was about eight. And it wasn't us that taught her, I'm glad to say. Somebody else taught her, because it would have been very, very difficult.

Once she was out of hospital, did you pass into the GP's care, or did you stay under the umbrella of the hospital?

It was a bit of both. She would go to the hospital, I think, probably about once a fortnight, then once a month, and then every three months. And I think it stuck at three months for a long, long time, where she would see a paediatric consultant and a diabetic nurse. And they would do occasional blood tests, and she had to keep, or we had to keep... she and I had to keep a record of all the urine tests, and they just glanced through those and made sure everything was okay. We also went to the GP - fortunately not the locum; he'd gone by then! I didn't have much faith in him, because he didn't think children had diabetes, which wasn't a very good start. So, she went back into the GP's care, and again, they've been fantastic. They have, as time progressed - it didn't start immediately, but as time progressed - they had diabetic meetings, and you could go to the meetings and... or they would do, every year they would do an extra long appointment for her, and give her a check. And the hospital does the same: they check her eyes, and they can also do a blood test, now, which tests what

her blood sugars have been like over the previous few weeks, so there was no cheating on that one!

(5) How did the family adjust to Julie having diabetes?

Pretty good, actually. Our meal-times were fairly rigid. Nowadays, it's far more flexible with the pens, of course, but then, it had to be fairly rigid, because she had to have her food at regular intervals, including the snacks and supper, which she didn't always want. And strangely enough, our meal-times are, as far as my husband and I are concerned, our meal-times are still the same. We tended, of course, to work round school times as well, because, obviously, my eldest daughter had got to get off to school. And it's something we've always done, and we still do: when we sit down for a meal, we sit down together, as a family, so that my eldest daughter, if she'd come home from school, we'd have a meal about half past five at night. My husband would be home from work, and my eldest daughter would sort of fit in with that. And she was brilliant. There were times when she couldn't, if she'd got something after school, but we did sort of stick pretty rigidly, and strangely enough, and I don't know why, we still do. My daughter doesn't - Julie doesn't. She has hers at all sorts of times, because she's now got the pen and she can eat at any time, and she doesn't need the snacks either. And she'll go without a meal, even, which, that would have horrified me at the time, yes.

How did you manage to measure these ten gram lines or rations?

The books that we had would tell you all the... like, something like a Mars bar or baked beans, they were proprietary brands. It was a book that I think it was the BDA published, and that told you how many grapes you could have, how many apples. I remember, it was four ounces an apple, which is a normal size apple, and a small banana. And we also had a set of little dietary scales, which my father got me - he found them - which would weigh very small amounts. So, everything was weighed very rigidly, and I don't know whether we needed to be quite that rigid, but we were.

How long did that go on for?

Pretty well until Julie left home. I know she doesn't do it now. She's... over the years, you do get to know, but, of course, if you go out for a meal, you've got absolutely no idea how much carbohydrate's in there. But because things are so much more flexible now, it is easier now, yes.

And how did Julie adjust to these restrictions?

Very well - I keep saying that, don't I? Fortunately, we had never sugared her cereal or her tea, or anything like that, so that was a good start, because we didn't have to cut out sugar. Sweets: she was very good. We'd been told by the dietitian not to cut them out entirely, because she would then rebel. So, she just had sweets at weekends, and, of course, nowadays, that's what a lot of children have to do anyway, isn't it. My eldest daughter, Cathy, was very good. She

wouldn't eat them in front of her. She'd maybe have some in her bedroom, and she shared - at the weekends - the sweets, the same.

How did Cathy react to her sister having diabetes?

She was fantastic - I'm using that word again. She was eleven, at the time. She'd just started secondary school, so she had her own adjustments to make. And we made sure she was included in everything, because it was import... then, she's a child that was included anyway. I remember her saying that it should have been her, because she was older, and she thought she could cope better. But I think I've since learnt that actually, probably, at four years old, you can cope better than if you were eleven years old, because eleven year olds have an identity problem, don't they. But at four years old, Julie just took it in her stride.

(6) How did Julie cope at school?

Again, she just took it in her stride. School were very good. I was invited into a staff meeting to discuss any problems Julie might have, and just the whole situation, 'cause nobody... they hadn't had a pupil, before, with diabetes. I think they've had them since. And the hospital dietitian came in with me, as well. Unfortunately, we couldn't work out school dinners, because it was just impossible to work out what carbohydrate was in there. And everybody had to have school dinners, and Julie wanted to stay, so the Head very kindly said she could take a packed lunch. But it wasn't long before half of the other children wanted to take a packed lunch, so we set a trend there. Her friends were fantastic. If she went somewhere to play, the parents would ring me up and say "what can she have?" And all of her friends that she regularly went to, I would give them some squash - some sugar-free squash - so that she'd got something to drink. And the school the same, she'd got plenty to drink. She did have one or two hypos in school, and the school nurse I don't think coped very well. Julie came home one day, and that evening she actually ended up in hospital. Her blood sugars had dropped and dropped, and then the school nurse had said "no, don't give her any glucose", which was the wrong thing to do. But we got through that one. Secondary school: again, I went to the school and explained matters, but they just seemed to think "oh, so what?" And fortunately, she got through school without any problems. Her friends - she'd grown up with these friends, and her diabetes - they knew what was what. They knew that if she was starting to look a bit funny, or argumentative, "Julie, have some glucose or something". So, secondary school, although they really weren't that concerned, it really didn't matter that much, yes.

When you say that at primary school she had a few hypos, do you mean, sort of, she was out cold, or... what do you mean by that?

I'll give you a for instance. They did... I don't know what they called it then, whether it was the Eleven Plus. It's now Key Stage 2 exams, but I think it was called the Eleven Plus, at the time, which is sort of the exam at the end of your junior school. And the Head was walking up and down, and just sort of glancing

at people's papers. And she noticed that Julie's writing was deteriorating, to the point where it wasn't legible any more. So, it was more that sort of thing. And, in fact, the Head was very good: she wrote on the paper - she put a note on the paper - to say that Julie had gone hypo during the paper. And then, for the next paper - because there was two of them - she phoned me beforehand, and said "could you make sure Julie's well stocked up? There's another paper coming up". So, it tended to be things like that, apart from this once when it was, as I say, she ended up in a coma when she got home. And that was actually quite frightening, because she was sitting on the settee, and the next thing I knew, she was... she'd wet herself, and she fell on the floor. So, my husband just whisked her up, we put her in the car, drove her into hospital, and they put her on glucose straight away. And she was in overnight. But that was the only time that we had a real problem with school.

(7) You sound pretty calm about everything. Were you calm at the time?

I'm sure we weren't, but we are the sort of people who just get on and do things. What... I mean, the doctor panicked me by saying "well, she's got to go in hospital, straight away". That panicked me, because, yes, she'd lost weight and she was going to the toilet, but she didn't seem ill. But, of course, once we started to learn about it, we realised it was a little bit more serious than we thought. But I think what brought me to my senses was, each day that we walked into the children's ward, on the right, there were little, like, amenity rooms with children in. And there was a child who was obviously very ill, and, as things progressed, the curtains were shut, and then the next day the room was empty. And I thought "yes, that child's died". I walked into the ward with Julie, and she was using the bed as a trampoline. So, I thought "what am I worried about? Here's my daughter absolutely full of life. I'm just thankful that we've still got her".

You mentioned that you joined the British Diabetic Association right away. Can you talk about the role that they played?

Yes, she became a life member straight away. We paid a subscription, over a period of years, and she's now a life member, so she gets all the regular updates. We also used to go to local meetings, fund-raising, and just meetings that would inform us. And we met the main diabetologist at the Manor Hospital, which was Dr Harvey. We met him there, because he gave talks. And when Julie was about... I can't remember quite how old she was - she was still, sort of, junior school age - her paediatrician retired. And rather than go to another paediatrician, Dr Harvey said he would take her on, although he really only dealt with adults. So, she moved over to Dr Harvey, and was with him until she moved away from Walsall. And he's been fantastic.

How did that work: an adult diabetologist looking after a child?

He actually took on more and more children, so I think he was developing that side of it. And I think it's... I may be wrong here, but I think he'd got someone in the family. And he was quite eager to take it on. I mean, the childhood

problems - well, I don't see that there were any childhood problems that created a problem for him. Diabetes is diabetes, whatever; yes. It did create a problem, at one point, when she was admitted to the hospital in a coma. She went onto the children's ward - Truro ward - at the Manor. They knew her well, of course. And unfortunately - they asked who her doctor was, and we said it was Dr Harvey - and he wasn't allowed to go and see her, because it was a children's ward. He didn't have a bed allotted to him on the children's ward, and they said "oh no, we can't call him, because he's not got a bed". In fact, he'd given us his home phone number, which was very good of him, and we phoned him at home, and he did go and see her, on his own bat. And I think, after that, things changed; yes.

- (8) About this time - we got to know Dr Harvey quite well, because we'd gone to the meetings - and he suggested the British Diabetic Association camps for children, and he said "why don't we put Julie's name down?" And it's a bit traumatic, as it meant her going away for a whole two weeks, no contact with us - they weren't allowed to... we couldn't ring them, and they couldn't ring us - which is very difficult. But we did agree to it, because we realised that it would take her a big step forward. So, she went to one in York. I remember dropping her off there, but everybody was so... well, it was sort of overwhelming, really; they just took her.

How old was she?

She was about eight or nine. But they just sort of took over, and she went away quite happily. We went and saw her little dormitory, and she was introduced to all the other children, and, of course, they got talking. And they were little girls, so they'd all got clothes. I found out, afterwards, that they shared clothes. And at this camp, she learnt to inject herself, which was a great weight off my mind, because I didn't know how we were going to do it. I'm sure the hospital would have helped. And she came away with a little certificate that said... and that's still got pride of place at home; very proud of that, she is. She learnt all the... that other children had the same problems. I don't know how many were on the camp, but they'd all got the same problems. You'd got dietitians there, you'd got paediatricians, you'd got nurses, and lay people as well. And, in fact, my eldest daughter, Cathy, came with us to pick her up. And having seen how it was, and how Julie talked about it - she was doing her Duke of Edinburgh award at the time - and she decided to apply to be a helper on one of these camps. So, I think it was probably the following year - she'd have been just sixteen - she went as a helper. And she enjoyed it so much that she went for the following two years. So, these camps are fantastic. Julie has recently been asked to help, but she can't, because of her little boy, but she says she wishes she could.

- (9) How did Julie react to having diabetes when she was at secondary school?

It didn't create a big problem. All her friends knew about it, and she went up to secondary school with her friends. In fact, she was... they were going to send her to another secondary school, away from her friends. And we had to fight to

get her to go to the same school, because we felt it was important she was with people who knew her. She did get a little bit rebellious, and it was a little bit: “oh, I don’t want that to eat”, and “I don’t like that”. And we found about the age of fifteen, sixteen, it was getting a bit of a battle - not with the injections, but with the food. And, of course, at the same time, we were having a battle with homework and GCSEs and revision. So, I felt as though I was on at her all the time, so I’d think “something’s got to give here”. So, I just said “right, you know enough about your diabetes now. It’s up to you. Whatever you do, you know what you’re doing”. So, I stopped nagging her; rightly or wrongly, I really don’t know. I do wonder whether any problems that she’s had - she has eye problems - and I do worry that maybe it started around then, because I went a little bit lax, and maybe she did rebel a bit. But I felt that we’d got to cope with it that way, because I couldn’t keep going on at her. She was old enough to know, and it was up to her to make the decisions. I do know she cheated at times. I know that... the local sweet shop have told me, they used to... They rang me up the once, and said... she hadn’t gone in to buy sweets, but her friends had, and they’d seen her having sweets off them. But I had to sort of let things like that go, because you can’t keep going on at them. But, in retrospect, I don’t know whether I was right, I’m sure.

Did her diabetes affect her social life at all?

I don’t think it did. We did try very hard not to let it. She did all the usual childhood things: she had ballet lessons, she played the flute, she played badminton, tennis - she had tennis lessons. And she’s a brilliant swimmer, and I’ve always said that’s because a Mars bar went along with swimming. She’d have half a Mars bar before she went in, and half a Mars bar when she came out. So, she went one day a week, for swimming lessons, and it progressed and progressed. And she was exceptionally good, and she still is; she loves her swimming. But I think a Mars bar has something to do with that! It was... She went on a school trip to France, when she was about thirteen, and that was the hardest, because I wasn’t with her. But, again, we felt we had to do it, because - or let her do it - because we had to be normal. I didn’t take into account the fact that French food is different to ours. For example, breakfast: she actually didn’t have enough carbohydrate for breakfast. I’d sent her with lots of snacks - biscuits and sweets, and that - for hypos. But it never occurred to me that the food wouldn’t be adequate. Stupid of me. And she was spending a lot of her money just buying food. And, in fact, the teacher had to sub her, in the end, because she ran out of money, so I felt a bit awful about that. But a very traumatic time, that was, because that was the first time - apart from the BDA camp, when I knew she was being looked after by doctors and nurses - this was the first time she’d actually gone away from home.

(10) As she grew older, how did you react to her being away from you?

Very difficult. I mean, any mum will say the same: with any child, it’s difficult when they get their independence. When they go to secondary school, for example, they’re out of your... well, not out of your mind, but they’re out of



your control for most of the day. But, again, it's something that you've got to come to terms with. She was very good at communicating, so if she was going to be late, she would let me know, so I was lucky in that. But, you know, if you go off at nights - she'd go off with her friends, when she got older, and they'd go to the pubs, and things like that - that was a problem, because... I didn't mind her drinking, but I didn't want her lowering her blood sugar too much, because that was something that you have to learn, how much it lowers your blood sugar; you've got to judge for yourself. And I do know, the one time she ended up in hospital was, she'd gone to a disco with some college friends, and - whereas, we'd always stressed: when you, say, ask for a diet Coke, don't say "diet Coke", say "a no sugar Coke or a sugar-free Coke" - but I think what her friends were doing were bringing her normal Cokes. So, by the time she got home, she was in a hell of a state. And she was vomiting, and eventually she said "Mum, I hurt so much", she said "my whole body hurts". So, I got the doctor in, and he called an ambulance - she was ketoacidotic, or whatever the word is. And that was, you know, something that I had no control over. And she'd thought she'd got control over it, but obviously her friends hadn't realised that, even if you... a little bit of sugar in a Coke might not matter, but if you keep drinking it, it's going to cause a problem. So, that was a lesson learnt.

You mentioned that your daughter had eye problems. Can you talk about those?

About the age of... well, in her late teens - we really can't quite remember when - she... The hospital always used to check her eyes, probably about once a year. She'd have her pupils dilated, and they look into the back of her eye. And they diagnosed her with diabetic retinopathy. It's actually quite a common thing, I believe, but she was quite young, but then, she had been diabetic since she was four. This meant that we spent a lot of time going over to Wolverhampton Eye Infirmary for laser treatment. And she had a great many laser treatments, because to start with, once you start to destroy the blood vessels that cause it, they create more. And so, for a long time, she was just having to keep going and going, just to keep on top of it. It's destroyed her peripheral vision, but her front vision is okay. And now she has an eye specialist who looks after her very well. Because she works in the hospital, she knows him. And she has to take - I think diabetics have to take a regular driving test anyway... or a driving... they have to have a medical test - and she has to have her eyes tested every three years before she can get her licence back. And so far it's been all right. The only problem she had was during pregnancy, it worsened. But that righted itself a few months later.

(11) What did Julie do after she left school?

She had always wanted to be a nurse, from when she was in hospital, and nothing ever put her off it. So, she stayed on to do her A Levels, simply because she couldn't start nursing till she was seventeen. But she applied to the Manor Hospital - it was the Sister Dora School of Nursing, at the time - and got a place there. So, she was... I think she must have been just eighteen, when she started her nurses' training at the Manor Hospital. She wanted to live

at the nurses' quarters there, and I did encourage it, because I did feel that, maybe, if that's what she wanted, that's what she should do. But they said that, because she lived within a short distance - it's probably about a couple of miles - there wasn't any accommodation. So, she stayed at home, which was a bit of a relief, but nevertheless, I could see her point. Particularly with her shifts, when she did long shifts, it meant that she'd got to get to the hospital for seven o'clock in the morning, and she'd come home nine o'clock at night, or ten o'clock at night. The hospital supplied her with a little alarm, but I still felt that a young girl shouldn't be out at that time. She got through her training, and immediately she'd finished that training, she went on a diabetes course to upgrade her training to specialise in diabetes, which she still does. She met her husband. They worked on the same ward, the elderly care ward. It was her final stint, and he was just, I think, perhaps, six months behind her, so they met there. And eventually they got married. Well, they moved away - they lived in Solihull to start with, because they both got a job in Solihull, so they moved over there - and then they got married. And then, now they've got a little boy.

Was there ever any doubt about whether she would cope with these long hours of nursing?

Our GP wasn't very encouraging. He said that the hours and the shift work wasn't a good idea with a diabetic. Dr Harvey was very good. And, in fact, at the meetings that we used to go to, one of the other mothers, their daughter was a nurse, and she was coping. So, nothing was going to stop Julie, anyway; she'd got to find it out for herself. It did have problems, and it worried me, probably, more than it worried her, because I know, when you're on a ward, you can't stop for a meal. There isn't... you know, you just don't have time; there isn't the staff to cover you. And somehow she got through it. Now, of course, with the injections, with the pen, it would be so much easier. She isn't on the wards now; she's a research nurse, so she doesn't work on the wards. And she does say that she thinks if she went back on the wards, she would find it difficult. But, no, I think she did manage to get through it by the skin of her teeth; I don't know.

(12) You mentioned that your daughter has a little boy, now. Can you tell me about her pregnancy?

Yes, he's just celebrated his fifth birthday. It came as quite a shock when she said she was pregnant, because I think, in the back of my mind - and in the back of her mind - she thought she wouldn't be able to have children, because of her diabetes. People had intimated that that would be the case. But, in fact, obviously, we were all thrilled to bits. Very worried about her. The blood tests she was doing - constantly doing blood tests, to make sure her blood sugars were right, because it's very important, during pregnancy. She was going quite well until, probably... she was probably about twenty five, twenty six weeks, and something happened, and I'm still not absolutely sure what it was. But she was retaining fluid, and she swelled up. And she had to go into hospital and have diuretics, which they don't normally give a pregnant woman. But they had to give it her, and get rid of the fluid. And from then on in, she was meant

to rest. And they kept a very, very careful eye on her. Because she works at that hospital, she knew a lot of the people who were caring for her, so I don't know whether she got extra-special care, but they were fantastic. And then, at thirty two weeks, it was decided that her health and the baby's health were deteriorating, and that this was the time to deliver him. So, she had a Caesarean, and all the medics were there; they were fantastic. And she's been told, since, that they weren't expecting a live birth, but, in fact... And he was whisked away from her pretty quickly; she didn't see him the first day. And he was put on a little... can't think what it's called now, but it just helped him breathe. But, within twenty four hours, he was on a ventilator, and all the rest of it. And it was like that... he was in the special care baby unit at Heartlands Hospital - I have to mention them, because they were really, really good - he was there for about three weeks. But his lungs didn't seem to want to work on their own, and they were a bit worried about it, so they said they wanted to transfer him to Birmingham Children's Hospital. And they decided to remove part of his lung - it wasn't working, it was porous. So, they removed part of his lungs, and he's never looked back. It's been absolutely fantastic, and he's an absolute dear. No problems, he's coped with half a lung. It's starting to grow, and apparently it'll grow to more or less its normal size. But, being a mother, of course, Julie does the normal thing and blames herself, but she did do everything as she should do. It did affect her eyesight, temporarily. But she has been told, since, that next time, she could lose her sight completely, so she's been advised no more babies, which is very heartbreaking for her. But she's got a beautiful baby, thanks to the care of everybody who looked after him.

You sound as though you're still very involved with your daughter's diabetes, even though she's left home.

Yes, she'd never... children never grow old, do they; never. Yes, particularly during the pregnancy, because her husband's a nurse, and he was working night shifts. And, as I said, she was very, very careful with her blood sugars, and she was worried about going hypo in the night. So, when Edward was on night shifts, she would come and stay here. And I put a little bell next to her bed, and I said "just ring if you think you're going to go hypo, just give me a ring". And I'd get up in the morning, and I'd find biscuits in the kitchen. And she said "I went hypo in the night", and I slept through it. And I felt awful, but we were there if she needed us, but, like I said, she copes with it all herself, anyway.

(13) Looking back over the years, since Julie was diagnosed in 1978, how big a role do you think you've played in the management of her diabetes?

Well, to begin with, because she was only four, the whole family - my husband and daughter, all of us, grandparents and everybody - obviously she couldn't have done it without us. I think I started to let go a little bit in her teens. I tried to. My husband sort of has the opinion she should be doing it herself, and, of course, she does, but he can't understand why I worry still. He does, in the background, but he's not quite so open as I am. And my eldest daughter's always been very much a part of it. We've always included her, and she's made sure

that she's a part of it as well. It's difficult, actually. I mean, certain things, for instance, with food: I adapted all the recipes that we always did - her favourites - adapted them. Either made them sugar-free - I don't know how she can eat sugar-free custard, but she does - and sort of fruit cakes, Christmas cakes. I remember making Christmas cakes without icing, specially decorated for her. And she started - well, obviously, she helped me - and she developed quite an interest in cooking. She did home economics A Level, simply because it meant she could do cookery at school. And she still does, she still very much likes cooking, which her husband appreciates - but then, he likes cooking as well, so they do it together. Oh gosh, I still can't get away from it: when I sort of look at the foods she eats, and I thought "you wouldn't have been able to eat that, at one time". And she said "oh, it's all right Mum, I can do this now".

- (14) And what effect do you think having a daughter with diabetes has had on your own life, and your husband's life?

That's quite a difficult question, actually, because it's become part of our lives. I think, certainly as far as I'm concerned, it's given me more understanding of people with problems. I worked for fourteen years at a special school with children with learning difficulties. And because I'd got a child with problems of my own, I could relate to those parents - not just the children, but the parents as well - 'cause I knew what it was like to have a child that was just a little bit different. And my husband's the same, you know, he appreciates these sort of things. She's lucky that she's married to a nurse, because he at least had a basic idea of anything. And he's certainly learnt, as he's gone along, anything else. They do have concerns for their little boy, but that's something that they've just got to sort of wait and see, and assume that it won't happen. Yes, because I worked at a school with children with special needs, again, the staff and the headmaster were very understanding with my child with special needs, so they were very understanding with time off for hospital visits. There was a time when Julie had an abscess on her back, and the district nurse would come in every day, and I'd have to be here. So, I'd leave school at ten o'clock - the district nurse agreed to make it a certain time - I'd leave school at ten o'clock, and go back for eleven, because it's only around the corner. They were very understanding, 'cause that went on for a few weeks. So, we spent a lot of time backwards and forwards to hospitals, and we get to know them quite well.

- (15) Your daughter's had diabetes, now, for nearly thirty years. Would you like to reflect on the changes you've seen?

Many changes. I suppose there were two main ones. One was the testing, and the other one was syringes - and now, of course, it's the pen, which is much easier. We started off with a glass syringe, which was a big thing, with a, as I remember, rather a long needle. We'd have to keep this in surgical spirit - which we had on prescription, if I remember rightly - then boil it up every so often; make sure it was clean. This was difficult, because we used to go camping a lot, in a tent, and you don't really want to be bothered with things like that. So, I remember going into... it was a Co-op chemist, and asking for a disposable

syringe, because I thought “why not?” And she just turned and walked away from me. And it wasn’t until afterwards that I thought, I should have explained myself a bit better, why I wanted one. But that upset me a bit, because I thought “do I look like a drug addict?” Fortunately, she was seeing a health visitor, at the time, and she supplied me with some. Then we went onto the disposable syringes. And it was quite difficult, because all these things weren’t on prescription, so sometimes the hospital would let us have them, or the GP, and eventually the British Diabetic Association - Diabetes UK, now - got a lot of these things on prescription. And now, of course, it’s a pen, which I don’t know very much about, because that’s been since Julie’s left home, but I do know that it works a lot better. The testing changed quite a lot, as well, because the tablets that we used to put in, and they’d fizz, and that... We used to have a chart on the bathroom wall with all the different colours, to know what was what. Then we went onto little dipsticks, and, again, those weren’t on prescription. So, it was very difficult: they wanted you to do your testing, but it wasn’t easy to get hold of the sticks. But I think now they are. Of course, now you’ve got the little blood testing kits, and Julie’s very up to date with those. She did go away from the blood testing for a while, and I know that a lot of kids did the same. She would put readings in her book that really didn’t happen. She got caught out on that when they started doing the tests that would say what your blood sugar had been for the last few weeks, so that stopped that.

(16) And how has her diet changed?

The diet, actually, is one of the biggest changes. It was very rigid to start with. As I say, we had the rations, or the lines, and we counted each meal. And that would depend on how much insulin she had, because, of course, it all depends on the insulin. That’s why... it’s the insulin that’s changed, which has caused the diet to change. Then, she was on Actrapid, and I think it was Insulatard, so she had a long-acting and a short-acting. And it had to be... the food had to sort of match the insulin. Also, nowadays, it’s much easier to see just how much carbohydrate is in something. At the time, it didn’t have it on the jar or the packet. So, we had a little booklet that told us what was in them. Now, it’s much easier to see - now that she doesn’t need it quite as much - but she can just sort of... we do check packets - it’s automatic; we check packets to see what’s in them. And so, in that sense, the diet thing is very, very much easier than it was. Sugar-free things, in those days, were very difficult. The only squash I could get was Rose’s - do you remember Rose’s? I don’t know whether they do it any more. And you could get diabetic chocolate. Boots were pretty good, and Thorntons were quite good. And I think Boots have stopped it, because it just wasn’t being used. And there’s a lot of sugar-free sweets that you can get, as well, and toffees. I remember her being absolutely delighted, because a chemist came up with this sugar-free lollypop, so I bought a supply of these lollypops - she’d not had a lollypop, really. And then the chemist called me in, a day or two later - I was passing by - and she said “I’ve come down to the next layer,” she said, “it says sugar-free, but they’ve got...” - I think it was sucrose in them. So, in actual fact, they weren’t sugar-free at all, but that’s just one of the things.

Yes, I think diet has changed quite a lot, over the years, yes. Yes, nowadays, it's much easier for her, because to start with, because she'd had a fixed amount of insulin in the morning and at night, the food had to correspond to the insulin. But now, it's the other way around, because she has her insulin after she's had her meal, and she'll have what she wants for her meal - she knows what's in the meal, more or less - and then she will adjust her insulin accordingly. Sometimes she gets it wrong, and she says "Mum, can I have a snack?", or she has to go and have something else. She's always got something on standby. But it's very, very much better than it was, yes.