

97. Beryl Smith

(1) Tell me about your background.

I was born in Stoke-on-Trent in 1935. We lived with my grandfather, because my father was out at work - he'd left the sea. And my mother was Welsh; she came from Milford Haven. And my father couldn't get a job, when he left the sea; he was an engineer. And tried to do everything, but it took him about three years, and eventually moved to Birmingham, but we still stayed up in Stoke-on-Trent. And then he went to Coventry, where he got a job at the Standard that made cars in Coventry. And at first we lived on one side of Coventry, and then we moved into a council house, which belonged, really, to the Standard workers. Now, he was there until war came, and then he decided he must go into the Navy. So, he went into the Navy, and he was a Chief Petty Officer. My mother and I stayed in Coventry, and then I went back to my grandfather's quite a lot, and he came over to us. My mother wasn't very happy on her own; she never got over living out of Wales. And then, in 1944, my sister was born, and I was nine years, nearly, older than she. She didn't see my father till 1946. He was in the Pacific: he went into Tokyo with the Americans, and then he went to New Zealand and Australia, and then he came home. And then, when my father came home, he decided, after a short time, that he wasn't going to work with Standard, and he started off his own business. He made dumpers - in our back yard, to start with - and gradually he did very well.

(2) My education was at state schools - they were run down schools. It was a secondary modern school. Very few people, where I lived, got scholarships, in those days. I think, in my school, there was fifty in the class, and I think three got to take... got a scholarship. I didn't like school. I had one thought in my head, from when I was a little girl: I wanted to be a nurse. My aunts had been nurse, and my great aunt, who'd trained at Birmingham General Hospital, was a matron. My aunt was at Guildford, a big mental hospital. So, there was a kind of history of nursing. Anyway, I wanted to be a nurse, that's all I could think about. And I left school at fifteen, and I went to Coventry and Warwickshire preliminary nursing school, where we spent half a day in the hospital, and half a day at the technical college, to bring our education up to some kind of decency, I suppose. Then I fell and broke my back, and I was in hospital for a very long time. And then I went to live with my grandfather, until he died, when I was seventeen and a half. I did have a job - I did some secretarial work, which I hated - and then I applied to go to Birmingham Children's Hospital, and I was accepted. I also went, in the meantime, to technical college, at night, to take some O Levels. And anyway, I got in at Birmingham Children's Hospital, and there were fifteen of us to start with, and in several weeks there were only seven of us left.

(3) I started the course in 1953, and within about three months, seven had dropped out. Now, some came and only stayed two or three days, couldn't stand it. Others didn't like the discipline, which was very strict, in those

days. And then one girl didn't pass the little exam we had to take at the end of the first three months. So, there were seven of us left. It was hard work. We worked from... we were on duty from seven in the morning till eight thirty at night. We had three hours off, and we rarely had a weekend off - it was a red letter day when you did. And you had one day off, you had something called the five o'clock - that's when you finished it's five o'clock at night - and you had to be on duty the day after your day off by twelve, twelve o'clock. It was hard work, but we really enjoyed it. The teaching was excellent. We used to be released... to go from the ward to do theoretical study, and to be taught further practical aspects of nursing. We liked it, because it was five days a week, and we only worked from nine till four o'clock. The people who taught us were the professors from Birmingham University, and tutors. And then, at the end of this month of being off the wards, we had a little exam to see if we passed. You had to pass; you know, if you didn't pass, then you were out, and one girl was out on the first lot. Now, we were also... when we first started nursing, we had three months being taught how to apply practical and theoretical aspects of nursing before we went on the ward. Then we were allotted to a ward, which we stayed on for three months. The first ward I was on was ward eight, which was a private ward - well, part of it was a private ward, and part of it was just for the other children. We had children from the age of five to fourteen, on that ward, with every kind of illness you could think of. The sister was excellent, and I was taught an awful lot. And the doctor, Professor Smellie, was also very good. He was the medical professor. And in Birmingham Children's Hospital, wards two, four, six and eight were medical. And then the wards one, three, five and, I think, seven, were the surgical side. It was in two kind of distinct halves, with a big stairwell between the two.

(4) And can you talk about your first encounters with children with diabetes?

At the end of my first year, I went onto ward two, which, in those days, had the diabetic children on. And the first diabetic child I met was a little girl called Rachel; she was twelve years old, and she had Type 1 diabetes. In those days, the children came in for two weeks, twice a year, to give the parents a rest, and also to make sure they were stabilised. Also, they only had soluble insulin; they didn't have any of the new kinds of insulin that came much later. The diets were very strict, and Rachel used to try and pinch the other children's biscuits, sometimes. So, she used to go, what we called, "orange", because, in those days, we had to measure up the... whether they were blue or orange. We did this with a urine test; I think it was ten drops of urine and five of water. If it came out blue, it meant there was... that they were stable. If it was orange, it meant they were over 2% higher than they should have been, and we had to watch them very carefully. But you also had to watch them carefully when they were what we called blue, because, of course, they could have a hypo. And children run around, and they can suddenly, you know, start sweating, and you had to watch. They acted as though they were drunk; I suppose that's the only easy

way of saying, with a child. They became uncertain on their legs; they were like little drunks; their speech became a bit blurred, if they were really bad, so you used to have to give them sugar very quickly. We used to give them sugar cubes. They used to have injections, four hourly, of soluble insulin. Now, their diet was strict. We used to have to measure all the potatoes and everything out. In fact, they had special diets from the kitchen, which were different from what the other children had. Sometimes they used to rebel, but mostly they were quite good. Now, to try and educate the parents, we did used to have them in and talk to them. The sister on that ward was Sister Todhunter was excellent. But most people don't understand that insulin and the food intake have to balance, and so, it really wasn't very easy for them. And if you have no chemistry, and you don't know what's really going on in the body, most people don't understand diabetes. Well, that's... I've thought about this a lot, and, thinking about it now, even today, most diabetics don't really get to understand their own diabetes, and how their body reacts to insulin and food.

And did the children get any education?

They did; we tried to teach them. We used to teach them how to inject themselves, because, although some parents could do it, some, obviously, couldn't, you know, push a needle into a child. This took a bit of doing, and we used to do it by teaching them with an orange. And we used to get an orange and make them to stick it in, because it was like the skin, we said, and then, gradually, into their arms. But it's not easy for a child to do this, so they'd be about twelve-ish before we did it. If we had very young children, we didn't push it, unless they wanted to. Some little ones did.

And did most of the children do what you suggested?

Oh, they did, in the end, but a lot of them were very frightened. They didn't know, really, what was going on, except somebody was going to stick a needle into them every four hours. And it was difficult, and they couldn't eat sweets or crisps, or all the things that children loved. We didn't allow them to have ice-cream, because we couldn't measure it. So, things weren't easy for them, really.

(5) That was at the end of your first year, so in 1954. Can you tell me about the rest of your training, up until 1956?

Well, for the rest of my training, I went onto different wards. But in my last year, I went back, as a junior staff nurse, onto ward two, which is where the diabetic children were. Things hadn't changed that much; they were still on strict diets, and the insulin was still soluble. And also, I think, at that time, I had to teach the children how to test their urine. And they quite liked that, because, you know, little... well, when they're eight to twelve, or seven, or so on, they quite like the idea of testing their wee, and little children are funny about things like that. They thought they were rather special.

What did you do after you qualified?

I got married. And my husband moved around a lot: we lived in Leamington, then we moved to Loughborough, for a couple of years. He was a research chemist. And then we moved... he got a job at Cranfield, which I believe is now a University. And we had Catherine, just before we left Loughborough. And then we lived in a caravan for three months, in a scrap yard, which was part of Cranfield, which had been an airfield. Catherine was born in 1959. We lived in this caravan, which was not very nice, really, but we endured it; we never got a cold. And then we moved into one of the college houses. We were there until Catherine was three. I started to teach music, because I'd got a baby, and we were too far out for me to do any nursing, and I didn't want to leave Catherine. We moved from Cranfield, and we went to live in Bedford. I continued to teach. And then, in 1964, on the 13th of October, Catherine was diagnosed with diabetes. Now, the previous ten days, she had shown every sign of diabetes, and I was sure she'd got it. She was drinking water from the bath. At first we thought she'd got schoolitis, but she hadn't. A teacher had smacked her there, she'd never been smacked in her life, and I think she would have got diabetes anyway, but personally I think the shock brought it on. So, we took her to the doctor's, who wouldn't believe she'd got diabetes, and then, when he tested her, he found that she had, and had it quite badly.

This was your GP?

Yes.

Why wouldn't he believe she'd got diabetes?

Because I said she'd got it. He was a very nice doctor, but he couldn't believe it. And then, when we weighed her, she'd lost a stone and a half in ten days. So, the next day we took her to Bedford Hospital.

(6) And tell me what happened at Bedford General Hospital.

We took her in, and for her first meal, she had chips and egg, which I thought was, you know, crazy. She was in for a whole fortnight, and after a fortnight, the consultant asked me to take her home and stabilise her, because they couldn't stabilise her in hospital. Well, the food they were giving her, there was no likelihood that she would be stabilised. So, I brought her home, and rang our GP, and I put her on the diet which we'd had at Birmingham Children's Hospital. And I did stabilise her; it took me about... I think seven or eight days. She was very good. The diet I put her on was a bit different from Birmingham Children's Hospital. We used to have about five or six pounds of bananas a week, ten or eleven oranges, lots of apples, lots of fresh vegetables, and meat. No biscuits, no cake, no crisps, no ice-cream. It really was, I suppose, a bit savage, but she seemed to take to it, and we all ate the same diet.

And how did her school cope with a five year old with diabetes?

Well, at first they said she could only go for half a day, and then the teacher came down and suggested she went into a special school. And I was absolutely against it, so, I had a friend who said "well, let's see if we can get her in at

the convent". And this is what happened, so she then went to the convent. They were extraordinarily kind to her, and, you know, looked after her very well. Now, when she was six, she suddenly became ill. She became very feverish, and I thought she'd got some kind of 'flu. But anyway, she had chicken-pox, and she was really poorly. Two days - only one spot came out, and that was on her forehead - and about two days later, I went in and I heard this sound, because she was in bed, and she was unconscious and having a convulsion. I was very, very frightened. And I turned her upside down, because her tongue had slipped to the back of her throat, and it came back down again. And then an American friend of mine came, and we had to rush her into hospital, where they diagnosed her with encephalitis. We took her in, and they gave her a lumbar puncture, and diagnosed the fact that she had got encephalitis. After two or three days, they said that she was catching, and they wanted her to leave, so I took her home. She was twitching and jumping, her diabetes was completely out of control, and she was off school for a year. Now, during that time, at night, she used to jump and twitch round the bed. She didn't obviously know she was doing it; it used to frighten me to death. Gradually it eased off. And our local GPs were marvellous to her, and they did offer us the chance to go to Great Ormond Street. Unfortunately I didn't take that chance. And she did go back to see the consultant at the hospital, who, to be quite honest, wasn't terribly good. Our GP told us mostly everything.

- (7) Just back-tracking to when Cathy was first diagnosed. How did you and your husband react?

Well, my husband was very shocked, and then realised that his grandfather had had diabetes. No other member of the family had got it. And the old boy had evidently fell out of a tree, because he was a very stubborn old chap, and he died that way. But David hadn't thought any more about it. He was very shocked, and he felt he was to blame, which, of course, he wasn't. I suppose I wasn't that shocked, because I had nursed it. My parents were very supportive, and my sister, especially, was very helpful. At the time, she was at Oswestry; she did a physiotherapy course there. Anyway, the family stuck around, but David's parents were very cross about it. And Mr Smith - David's father - suggested to Catherine that if she prayed three times a day, God would take it away. Now, I thought I'd got a little girl who was naturally terribly religious. And then, when she was eight, she suddenly came to me, and she said "I'm not praying any more", so I said "oh, why?" She said "well, Granddad said if I pray three times a day, my diabetes would go away, and it hasn't". And there was no answer to that!

And can you talk about who did the injections and the urine testing, and so on?

At first, I did the injections and the tests. And then Catherine was interested, like all small children: she wanted to do a wee test herself. Now, now and again, she used to put all water in and say she was blue, when she was orange, so I had to test on the quiet! But, she really was very good. And then, when she was about seven to eight, I said, you know, "would you like to do your own

injections?” And she thought she would, so she started to do her own injections. I don’t think it was the right thing to do, now, but this is what we did do. We used to put a bit of ice on her arm, to deaden the pain of the prick, because, in those days, they didn’t have throw-away syringes and needles. They had to be boiled, and you had to be very careful, because sometimes the needles got little kind of hooks on them, and it could be a very painful injection, and, you know, so you really had to watch that. They had to be boiled for about twenty minutes - the syringe and the needle - and they had to be kept in sterile conditions. She was very good, and she did do it. Now and again she’d get fed up, and say “I’m doing it no more”, and then I would do it. David never did it. He couldn’t bear the thought of it; he just couldn’t hurt her in that way. And it was hurting her; it did hurt. And then we had neighbours who said “oh, well, it must be just like cleaning your teeth”. And I used to say, “well, you try sticking a needle in your arm, and seeing if it’s like cleaning your teeth”, which, looking back, was a pretty awful thing to say. In those days, syringes and needles were not on prescription. Insulin was, but you had to buy the needles and the syringes, which, in a way, could be quite costly. Some people used to sharpen them, but I never did. I used to throw them away after about three or four times of use. At first, she had two injections a day, until she was about twelve or thirteen. When she was ten, we moved into the Cotswolds, into Moreton-in-the-Marsh, because David got another job with the Civil Service and the Fire Service College. And so, we then started to go to Oxford, where we saw Dr Baum, who was really fantastic. He was most understanding, very, very kind, and very helpful.

(8) How did the medical treatment at Oxford compare with the medical treatment at Bedford?

Well, there was no comparison; the treatment was excellent. The doctors were very good, and the nurses were very helpful. And we tended to go there, I think, about every two months, unless something happened. And we could phone up at any time and take her in. Now, sometimes she used to go what I call orange, which meant that she had possibly up to about nineteen, twenty blood sugars. If it continued, I would then ring up and take her in. And they always accepted her; there was no, you know, worry about beds and things like that. One funny... well, a couple of times, Catherine suddenly would go orange - and I’m saying orange, because I’m old fashioned - anyway, her blood sugars would go out of control. And I was terrified she’d go ketose. And this one particular time, I couldn’t understand it. And in the end, I said, “well, look, I’ll have to ring up the hospital and go in”. And then she said “well...” - I always said to her “if you eat what you shouldn’t, you tell me. I won’t be cross” - so she said “are you going to be cross if I eat what I shouldn’t?” So, I said “no”. Anyway, her friend had been buying her crisps. She had given her friend the money, so she hadn’t technically bought the crisps, and then she shared them. And then, of course, her blood sugars went completely out of control. And then, we... you know, I could do something about it.

Any more about the treatment at Oxford in 1974?

I should think it was about 1975, they changed her insulin; different insulins were coming out. And it would seem - because she then had long-acting insulin - and after a short, well, say a year, she seemed to become sensitive to it, or something. Anyway, the diabetes used to go out of control. Then they would have her back in, and, you know, give her a new kind of insulin. I think it was cow's insulin, and I think there was pig insulin - I'm not sure, but I've got an idea this is what it was. And then she'd be all right for a bit. She did go in on several occasions. And Catherine, until she was thirteen, was more or less on an even keel, but when she reached puberty, things changed drastically.

- (9) She started her periods, and each time she had them, her diabetes would go out of control. She also had her eyes tested, and they found that she needed some treatment around her eyes, because there was bleeding, which I believe is common to diabetes. She... well, she became a bit moody, as all young teenagers did. She realised she couldn't do what other teenagers did. I realised, suddenly, that she was depressed. She didn't... you know, she'd had lots of friends, she's always had lots of friends, but she kind of became a bit reclusive, and also very depressed. She didn't think much of herself; she reckoned her face wasn't right and her hair wasn't right. It was kind of teenage things, but the depression was bad. And I can remember taking her to the Radcliffe, and she tried to run in front of the car. I did stop her, thank God. Anyway, we saw Dr Hockaday, who was very understanding, and she went into hospital for two or three weeks. And she also saw his wife, another Dr Hockaday, who was in psychiatry. Anyway, she gradually improved, but she was prone, really, to a bit of depression. And her self-image was very poor, and I could do nothing about it, and this was sad. If she got a cold, of course, she became very poorly. If she cut herself, it took a long time to heal.

- (10) And how did her school cope?

Well, she went to a country school, Chipping Norton, where children of all classes, from top to bottom, and all types went. It was a very good school; they were very helpful. She did very well, because she was... well, she is intelligent - very. And although she was off school quite a lot, she always caught up. She had to have her tonsils out, and that didn't help, because she was ill for a long time. She had quite a lot of time off school. But, however, she did get... I think it was seven O Levels, and then she went and took three A Levels. And then she went to Birmingham University.

And how was her diabetes up until the time she went to University?

Well, her diabetes, she was considered to be "brittle". The problem with Catherine was, she didn't know when she was going to have a hypo, so she could just drop down. I knew, and used to administer, you know, the... well, we used to give her lemon and sugar to drink, quickly, but she didn't know it was coming on, so it was difficult. But she had friends at school who'd always got a Mars bar, and used to shove it in her mouth. Because she... even when you're grown up,

when you are going hypo, you do seem as though you're drunk. And that's why some diabetics, when they're adult, are taken to be drunk, and they're really having a hypo. Some can go unconscious.

And what attempts were made to make her more stable?

She did have... she went onto four injections a day, to try and make her more stable. It didn't really seem to work too well, though I think it might have been better than the two injections a day.

- (11) And before we talk about her leaving home, can you talk about what effect her diabetes had on you and your husband, throughout her childhood and teens?

The effect that Catherine's diabetes had on to us: it made my husband very anxious. He was always worried that something was going to happen to Catherine, although he told me, when she was sixteen, that, you know, we had to let her go. And we did let her go. I mean, you wouldn't have kept Catherine back, because she fought diabetes all her life. But I think it did make us a bit anxious. Well, during this period, David wrote quite a lot of research papers - he was in plastics, and so on, for the Home Office - and I went on teaching music. And then, when I was thirty six, I thought I would like to take a Open University degree; they'd just come out. And I was in the second year of the Open University, and I took a degree in Social Science. And then, I wanted to be a social worker, but... they accepted me at Oxford, which I thought was hilarious, however, I had to stay there nine weeks, and I couldn't have left Catherine to do that. So, I went to St Mary's at Cheltenham, and took a Postgraduate Teaching Diploma, or something. Anyway, the year that I went to Cheltenham - I used to go every morning at seven, and come back, I don't know, between four and six - Catherine didn't speak to me! She took it amiss, I think. She said, since, she was really cross, because I went out of the house before she did - and we've often laughed about it - and sometimes I wasn't there when she got back. And she was used to me being there all the time, you see. And the other thing that perhaps we kind of suffered with, in a sense, I couldn't... I had quite a few miscarriages, and couldn't have any children. And we wanted to adopt a child, but they wouldn't let us, because they said we couldn't give a child the love that we gave Catherine, which, you know, is absolutely wrong.

Do you mean the kind of extra attention you had to give her, because of diabetes?

Yes, they said that we couldn't give a child the attention it would need, because our daughter had diabetes. Now, this was crazy, because I had fostered three children, when Catherine was about six or seven, when we lived in Bedford. So, I suppose, in a way, the diabetes affected us in a strange way. You know, I would have loved to have had a lot of children, but couldn't. That wasn't Catherine's fault, but we couldn't adopt, either, though we could foster.

You used an interesting phrase, that Catherine "fought diabetes all her life". Can you spell that out?



Catherine decided that diabetes was not going to get the best of her. She was going to overcome this diabetes, and she did. Although she was so brittle, and she had endless periods when she was ill, she always came up smiling, and she got there. I mean, in those days, for a young... for her, she'd had it since she was five, there weren't very many diabetics who'd gone to University, for example. And she was a real fighter, and she still is.

(12) How did you feel about Catherine going away from home to university?

Well, in a way, I was relieved and pleased for her, because I felt that, you know, she became like everybody else, in her own eyes - you know, her friends, and so on - to go to university, like her father; she went to the same one. And she wanted to be a social worker, however that didn't come about, in the end. But she did take her Bachelor of Social Science there. She wanted to go on to do social work, but they wouldn't have her, because she was diabetic. This is how life is, really. And when she was eighteen, before she went to university, she thought she'd like to be a speech therapist. And at first, they said no, and then Dr Baum sent a letter asking why, and they then had her for an interview, and then refused her. And it was the same in the social services. She was going to do this four year course: she did the three years and got her degree, but they wouldn't let her do her social science one, Social Services Diploma or whatever. So, then she did her... and then she did a Dip Ed at Birmingham, but she still wanted to be a social worker. And when she had finished, and she'd got her degree and a Dip Ed, she then went to a place called... to a home near Tenbury Wells, called Kyre, where there a lot of people with awful physical disabilities. And she became an ordinary scrubber, really. And she stayed there for a year, doing everything. However, her diabetes wasn't too good. And by this time, I was a lecturer at Evesham College of Further Education. And next door to it was a day centre, which was attached to the college. And she then got a job as an instructor, teaching and helping all these clients. And she was there for about three or four years, I think. She liked it there very much, and she got a little house, not far away. And she was very good. And, at the time, I was teaching something called BTEC Social Care, and these girls could then go on to do a degree in nursing, some went to do teaching, and so on and so forth, and there was boys as well. And I got together with the head of the day centre, and we had it so that there was one of my students with one of their clients, and we had a pantomime. And Catherine was a great help. She wrote the script; she got the songs together; she had all these clients singing and carrying on. And my students thoroughly enjoyed it, and it gave them some insight into the disabilities and the difficulties that the clients had. Now, during this time, her vision became worse. She got tunnel vision, and she did have quite a lot of laser beam surgery on her eyes since she'd got tunnel vision. She was still ill - you know, if she got a cold, she became very poorly - but she carried on. And then, while she was at Kyre, she met Stephen, who was to become her husband. And so she... they got married, and she went to live in Hereford. And she got a job at a day centre in Hereford, which she liked, because it was dealing with people who were less able.

- (13) After a short time, they offered her a few hours up at the technical college, again with the less able, who went there for stimulation and for learning, because some of them were very bright, even if they were physically very handicapped. After a time, about nearly two years, she became pregnant. She started to be ill. She couldn't continue with her work - and the only time in her life. Her diabetes went sky-wise. She came to stay with us for some time. Then her husband had a terrible motor accident, and then he came to stay with us. Now, Catherine stayed with us, on and off, throughout her pregnancy. The reason was that she came back to Hereford for about, I don't know, a month or two, and then Stephen rang us up to tell us that she was very poorly, he didn't know what to do. We rang the Oxford hospital: they said bring her in, so we came, we fetched her, and we took her there. She had meningitis; she was very ill. So, then she came back and stayed with us for a while, and Stephen came down at the weekends - this was when he got better. And then she had Alex. She had to have a lower-section Caesarean birth. Again, she was ill, and she then went to Chipping Norton, to the little hospital there, for a fortnight, to recover some. And then she went back to Hereford. Now, her diabetes was not good, at this time. She was very brittle, and it really was worrying because of the baby. And I had the baby quite a bit. And then she got carpal tunnel syndrome in both hands, really badly, and Alec was about... I think about nine months old. So, she had to go to Oxford, and she had them both done. She couldn't carry anything at all for a month, or do anything, really, and they took some time to heal. Meantime, her diabetes was terribly brittle again. She gradually got over that, then she went back to Hereford, with Alec, and they... back to Hereford. And she - by which time, I suppose, Alec's nine or ten months old, he wasn't a year, I don't think - and she decided she'd have to go back to work. She went to work part-time. Alec went to a very good childminder, I believe. However, she still became... she still had some very rocky moments with her diabetes, and she had to keep on going back to hospital, and Alec stayed with us.
- (14) All these things gradually passed over. And then, she went to work, but she never went full-time, though she went between twenty eight and thirty five hours a week, which I think is more or less full-time. And this, then, was at the college. She was working at the college, and is still working at the college. Now, things went on; she was brittle, she had endless hypos - she used to have them all over the place. People who she knew always carried something in their pockets for her. They were extremely kind to her, at the college, and all the staff were, and also the pupils. Then, two or three years ago, she had an offer from Professor Matthews to take part in an experiment to have an islet transplant. They'd already done, I believe, about thirty-odd in Canada, and they'd done some in America, but there was very few being done here. Anyway, she was absolutely keen to go in for this. And she had her first transplant in 2006. It seemed to be quite successful; she was no longer brittle, she no longer had constant

headaches, which she'd always had, and she couldn't believe her luck. And then, Professor Gray thought that it would be a good idea to have a second transplant, to make the diabetes even more stable. And he was hoping, of course – because, in America and Canada, they had had one or two that had come off insulin altogether - and that was his great hope; this was Professor Gray. Now, Professor Matthews thought, you know, that this perhaps wouldn't be so. So, she had a second transplant in 2007. It did improve her diabetes even more. She was only taking, and is only taking, half the amount of insulin. She no longer has hypos, no longer has headaches, and thought she'd gone to heaven.

And before we leave the subject of your daughter's diabetes, can you reflect on your involvement with her diabetes while she's been an adult?

Well, overall, it's been a continual caring situation. We've had to be there when she needed us, but to be very careful not to intrude into her private life. This is one of the faults of people who have children who have long-standing illnesses, that you do think you can run their lives: you can't. They have to go on, on their own. And I only help when she asks me to, and that's how it still goes on. On the other hand, if I'm ill, she's extremely kind to me. I have continued to go to her hospital appointments, because Catherine can't drive, so I take her. And that's how I know the doctors, and so on. Well, saying I know them, I don't really have much to do with them; they just give me a nod, and that's it, really!

And what have been your impressions of the National Health Service, during your visits with her?

Well, throughout, I can say that the National Health Service has been marvellous, as far as Catherine is concerned. The hospital treatment at Oxford has been outstanding, the nurses have been marvellous. And really, I'm so grateful, because if we'd lived in America, or something, we'd be in skid row; and here, the attention has been wonderful. I can't say anything else, really.

(15) And now can we move on to your husband's diagnosis with diabetes?

Yes, David got diabetes - Type 2 - on Christmas Day, 1983. And his blood sugars were suddenly nineteen. Right, now, he was what is termed, I suppose, obese; he was a very tall man, but he weighed eighteen and a half stone. So, we took him to the hospital, at the Radcliffe, and the doctor who he saw said to him: how tall was he. And he said "six foot something", and the doctor thought... told him that if he was seven foot six, his weight might have been more in order, and that he'd got to lose weight. He was on tablets to start with, and he came back home. And he was a bit shocked, but he knew from Catherine that these... you know, what was going on. Also, he was a chemist, so he really did know what was going on; he did understand it. So, he went on a strict diet, and, within a year, he had lost four and a half stone, was off his tablets, and was on diet only, which I think was very good. He just had one little problem, and that was he treated his body as though it was some research in the laboratory, and that was a bit difficult. Now, the change in him was he became anxious. He'd always

been a bit of a worrier, but he became very anxious. Also, his work was onerous. And then he had high blood pressure, which wouldn't come down. And in the end, he was retired early from the Civil Service.

- (16) You said he was diagnosed on Christmas Day. That sounds quite a sudden diagnosis, with Type 2 diabetes.

Well, the thing was, I suppose I was used to diabetes, by this time. And he had stayed at his father, who was a very difficult old man, and had said David had to stay there for Christmas. And he came home on Christmas Day for his lunch, and he was a bit twitchy. And then he did a very unusual thing: he drank a whole bottle of wine for lunch, just glugged it down. And I was a bit surprised, and then I saw he was kind of sweating, and I thought "God, he's got diabetes". Now, I had the testing equipment, so I tested him, and his blood sugars were nineteen, and that's how he got it on Christmas Day. On Boxing Day, I rang up my local doctor, and told him that, you know, I was almost certain David had got diabetes, so he then suggested that I rang up the hospital and took him. And that is what I did, about two days later.

So, it wasn't exactly an emergency, then?

No, it wasn't an emergency. I realised that it wasn't like Catherine. I don't know why I thought that, but it wasn't, so, you know, he wasn't drinking bath water. He was drinking quite a bit, and he was urinating quite a bit, but nothing like Catherine. It was the start of it.

And now, this huge achievement, really, of losing four and a half stone by diet only. To encourage anyone who wants to do that, can you say how he set about it, and what the diet consisted of?

Oh right, the diet that I put David on... First of all, I said, you know, "you'll have to eat less", because David ate a lot. So, he was on fruit - he loved oranges, he liked bananas - so he had pounds of those a week; that was... they were his pudding. It was, perhaps, a little bit expensive, because he had steak and salad, he had fish and salad, he had a lot of different greens. I rationed his potatoes, so he only had about two or three, and I mean fairly small ones. Cut out - he had a very sweet tooth - and we cut out all biscuits, all cakes, he didn't like crisps, thank God, and he cut out booze. I don't mean he drank a lot, but we used to have, you know, wine at the weekend, and sometimes we'd have a glass at night, and all that went, we didn't... And he cut out beer completely, because the calorific value of beer is huge. A pint is about eleven hundred calories. So, I think, calorifically, he was on - although he didn't know it - but he was on about twelve hundred and fifty calories a day. Now, he thought he was on fifteen hundred, and I didn't tell him, because I was the one who was doing it out. And another thing we had, which you can't get now, I had a pack of cards, like playing cards, which had all the vegetables and the meat and the fruit and everything, which told you exactly how many calories you could have. Now, that's something that I've never seen since.

(17) And what would you say was your role in his having lost four and a half stone?

Well, I think, really, it was the food. And we both did it together, so I had the same kind of things as he did, though I don't like bananas or oranges, so I ate apples. But I think it was, you know, we had to work together on it, because David couldn't cook. The only thing he ever cooked - he once did, when I was pregnant with Catherine - I asked him to do me some bacon, and he put it in a saucepan, and kind of brought the saucepan in when it was cooked. It was horrible, it was all fat, and David never could cook!

And I remember you also said that you and your husband tried to keep to the same diet as Catherine when she was diagnosed.

Yes, we did. I think the thing about diet and diabetes, I think it's very important. The thing is - I really believe this - that the whole family has to, more or less, adhere to a diabetic diet, or else they have to hide when they're going to eat sweets and things like that. And even when we went down to my parents', who'd retired to Cornwall, we all stayed on the same diet. They were very good like that, so I think that's important.

You've mentioned that he treated his body as a chemical lab. What did you mean by that?

Well, everything that he did had to be almost measured, and... well, measured, thought about, and sought over. I mean, even when he was on the diet, he wanted to know exactly how much, how many calories. I admit, sometimes, I used to lie; he didn't know. But he was very careful of himself, then. He became ultra-clean - I was very pleased about that. And I think that's important with diabetes, as well, both kinds: you have to be extremely clean. You really do have to bath every day, you really do have to have clean underwear every day, because diabetics, if they get any little scratch or they cut themselves, it takes a long time to heal, and therefore... Their immune system isn't terribly good.

(18) What was your husband's immune system like after he got diabetes?

Well, it wasn't so good. Before he had diabetes, David was very healthy. He might have been eighteen and a half stone, but he never got anything, he hardly ever had a cold, and he was just a healthy person. But afterwards, if he got a cold, like Catherine, he used to become feverish and ill, and he used to get a high temperature. Now, in 1985, he had to take early retirement, which was sad, really, because he was fifty five, I think, at the time. He got a good pension and everything, but it was hard on him. And I was still at work, full-time, and used to leave at eight in the morning, and didn't get home till about five or six at night, and there he was. Mind, he did a bit of gardening, he tried to help me with the ironing. He did try, and he was interested in trains, and he was very interested in music. And we had a spinet, so he used to play it, and he'd got his records and so on and so forth. However, in 1989, he became ill. He started to lose weight. I took his temperature, and it was high in the morning and at

night. Nobody seemed to know what was wrong with him. He wasn't in any kind of pain, but he had a constant temperature, and he was losing weight. So, Dr Lutter, our GP, said "oh, he'll have to go into hospital", and by which time, he had got down to about eleven stone two. Now, he's a big-boned man, so he was very, very thin. And they thought that he had different diseases, which he didn't have, and he was in isolation for nearly a month. And then, a doctor took him and X-rayed him, and found that he'd got acute diverticulosis, and that the bowels had got abscesses on them. So, he had to have part of his, you know, his gut removed, at the JR. And he was in for another fortnight, and then he spent two weeks in the little village hospital, in Moreton-in-the-Marsh. And that knocked the stuffing out of him.

- (19) Now, his diabetes didn't change - you know, he kept to his diet, so everything was all right - and he did gradually recover, although he wasn't really quite the same again. We were still in Moreton-in-the-Marsh. And then our daughter, in 1993 or 4... we'd been over a few times, and we used to go to stay at Ducklow, which is a lovely little place between Bromyard and Leominster, in a cottage. Anyway, he suddenly decided that he would like to move to Hereford, to be close to Catherine. I have to be honest, I didn't want to come. Anyway, we came to Belmont Abbey on a retreat, with some friends, and he saw these buildings and decided he liked them, and so we moved in when the building was complete, which was in 1994. And we'd been here about six weeks, when the chap who lived next door, who was a doctor, came to me and said "how long has David been diagnosed with Parkinson's disease?" Now, I didn't know he'd got it. I know that he had a tremor in his hand, but he always told me it was part of old age. However, he said "you've got to ask him, Beryl". So, I rang up a friend, who said "get on with it". And I asked David, who then told me that he knew he had Parkinson's disease from Moreton-in-the Marsh, but he thought it would go away if he ignored it. It didn't do anything to his diabetes, but it was fairly acute. And he then started to go down and down. His diabetes was not affected, but his body was. Now, it became a long, slow disintegration of his body - not of his mind, he was clear to the end, until he couldn't speak - and then he died in 2001.

- (20) Just returning to when your husband was diagnosed, aged 53, in 1983. He was advised to diet. Was he given any advice on exercise?

No, he wasn't given any advice on exercise; nobody mentioned exercise. And also, with Catherine, no one ever mentioned exercise for her. But I imagine - I mean, this is looking back - they would think a five year old would be active. In those days, children played out a lot more than they do now.

What about your husband, did he actually take any exercise?

He did exercise. He took the dog for a walk, but he didn't do anything violent, or, you know... He swam when we went away, and that was about the peak of his exercises.

Looking back on your role as a wife and mother of people with diabetes, what support do you think you've had?

Well, not a lot, really. With Catherine, we were young, and I think we were expected just to get on with it. We did have a great deal of help and advice from the Radcliffe, when she eventually went there when she was ten or eleven, but that was for Catherine. As far as I was concerned, there wasn't any real support. You just got on with it. I think my sister helped me more than anyone. She was marvellous, and every time something catastrophic happened, she came down. And my own family have been marvellous to me, and my nephews and my niece have all been extremely kind. But, in the end, you have to stand alone and help people; that's all there is to it, really. I think, because I was a nurse, they said "oh, she's okay".

And can you reflect on changes in diabetes care?

In a way, yes. I mean, going back to Catherine, the care was very different, in those days, because they didn't know so much. Now, I mean, she's had two transplants, and it's... diabetes is... the cure and the research into it has really gone ahead in a big way. However, in David's grandfather's time, there was no... there was nothing, and he died of it. And then, David did some research, and found that in the early nineteenth century, one of his ancestors, who was a woman, who kind of died of a wasting or fading disease, and one wonders if it wasn't diabetes.