87. Isobel

(1) Tell me about your background.

I was born in a small, rural market town. My parents were both in their mid forties when I was born, and so, although I had a brother and sister, they were very much older than me. They were born when my parents were in their twenties, so it was almost like being an only child. I had a very happy childhood. I think, perhaps, I was rather spoilt. I went to the local grammar school, after having passed what was then the Eleven Plus; went to work for a small local government concern; went away for higher education. I couldn't go back, although I would probably have liked to do, because there was no employment, as such - I'd had to resign from my job in order to go into higher education. Then I went to... I eventually came here, where I worked for the local authority, in order to gain wider experience. Then, I was here... oh, I don't know, maybe, I don't know, perhaps for a couple of years. I met my husband, actually, at British Council; it was a social function. I belonged to an organisation called the International Friendship League.

Tell me about him.

My husband was born in the late 1930s. He came here as an overseas student in the early 1960s. We met, as I said before, actually at British Council. He came across to me, then, as being a very pleasant sort of person. He was very outgoing and friendly, and just generally a nice person. Actually, we got married a couple of years after he arrived here. I was very young, but I think there were potential problems, as far as our families were concerned. I think, maybe, a lot of it was founded on fear of the unknown, which I think is a fairly normal sort of reaction. And, of course, in those days, mixed marriages between English and Asian people weren't acceptable. But, over the years, we both... well, certainly, even in the early years, I think once we'd met each other's families, we were both accepted. And I must say that my husband's family are a very nice family; always been very supportive of me - in fact, very protective towards me. And my family, also, when they realised what kind of person he was, their attitudes changed entirely.

(2) Were you able to go out together?

Yes, we did. And, in fact - looking back on it, if my memories are correct - I don't really think we met overt prejudice. Maybe I was just oblivious to it anyway. It was quite interesting, because, although we came from very different backgrounds - particularly since my family were from a very sheltered, rural sort of background, and basically had had no contact at all with anybody from any other culture - we seemed to have the same kind of values, which I think proved to be important. Because, I suppose, my parents, because they were a lot older when I was born, maybe their values were perhaps old-fashioned; I don't know whether that's the right word or not. So, we didn't really find difficulties, I think. I mean, obviously there were difficulties, a lot of things I had to get used to, but neither of us were used to sort of... I mean, I didn't... for instance,

alcohol is one point of issue, if you're looking at the social scene. I'd grown up in a strict Methodist family, so I didn't drink anyway, so that was never a point of contention, really. We just used to go for walks, we used to go to the cinema; this kind of thing.

And he was a Muslim?

Yes, he was a Muslim, by religion; that was his cultural background. So, I think maybe, as I say, although, obviously, we were from very different backgrounds, but in terms of values - maybe because of my background and because of my parents - somehow, I don't know, I seemed to slot in with his sort of values and ideas, really.

You said there were some things you had to get used to.

Well, certainly after we were married, because, for instance, getting used to cooking, and liking the kind of food that he liked. But despite the fact that probably, when I lived at home, I'd never had any kind of food like that - I mean, in the 1960s, it wasn't widely available anyway, and especially if you came from a very small rural town - but I accommodated myself to it without too much difficulty, I think. It's difficult to remember, obviously, exactly, but I remember the early days as being very happy, and, you know. . .

What kind of diet did he have, after you got married?

It was mixed, really; it was a mixed diet. I started learning to cook Asian food, with the help of friends, probably, and also because my husband was interested in food, so I suppose that was the motivation. And as I learnt to do things, I started liking the food anyway, so. But it was mixed; we used to have some English food, and... But I think, obviously, in those days - I mean, not just us or me, perhaps - we weren't aware of things that people are aware of these days, in terms of the level of salt, and, you know, the levels of fat in your diet; this type of thing. And although there was a history of diabetes in my husband's family, because he'd moved away when he was in his twenties, he didn't actually perhaps see the kind of adverse affects that can result from someone having diabetes. So, I think, generally, we just weren't aware, you know, of the dangers.

So, are you saying that you cooked quite salty, quite fatty food?

Probably, it's very difficult to remember. But I must say that his tolerance of salt, it was quite high, and I'm sure that was... that came about because, generally - particularly for that generation, I think, of people who came from the Asian subcontinent - quite high levels of salt were used in cooking. It's a very different scenario now, because the younger generation are very... well, a lot of people, certainly, are very aware of the dangers, particularly where there is a history of diabetes in the family.

(3) Could you perhaps describe a typical meal in the 1960s?

Yes, the basis of the meal would be either rice or chapatti, and then you'd either have a meat dish, which could be chicken or red meat. Red meat, again, was a

thing that I think featured, and particularly in my husband's... I was going to say family, really. Red meat featured a lot in their diet, and I think this generally was the case for the better-off families, if that's the right word to use. Often the diet tended to be less healthy, because it had a high content of red meat. And I think my husband would have freely admitted that, as a child growing up, he didn't like things like dhals, and he wasn't very fond of vegetables, he would have preferred to have meat. So, in a way, people who came from a rural background, where they might not have a lot of meat in the diet, because it was too expensive, but would have had a lot of dhal, vegetables, wholemeal flour would have been used... because, you know, it was produced in the villages, the diet would have been a lot healthier. But because he grew up in a family where money was not really an object, so... and also, things... the sort of sweets that were eaten were high in sugar. And although... I mean, he wasn't that fond of sweets, but he would eat them, you know, if they were there, and probably they had a high fat content as well.

Where did the salt and fat come in, in the meat process?

Well, when cooking meat - or, I suppose, any dish, really - because you're actually frying onion to start with, and then you're putting spices and salt, maybe tomatoes, or whatever, but it was always thought... I don't know, people just generally put too much salt, on the grounds that the food wouldn't taste very nice if you didn't have enough salt in it. But obviously, salt is an acquired taste, and if you grow up having a high level of salt, you know, your taste buds are accustomed to it, and it's very difficult, I think, then, to lower that threshold.

And would you say that you had much exercise after you got married?

Well, we used to walk, and because I'd grown up in a family, although we'd lived in a small town, we were on the outskirts, and we used to walk a lot. And I grew up enjoying... I liked the countryside and I enjoyed walking; it was something my family always did. So, I think, you know, my husband enjoyed it as well. We used to go out, and we used to take the children, so, within the constraints of working, obviously, we did have a fair amount of exercise. And my husband had always... well, before he came here, in fact, had enjoyed sport, and continued, to some extent, here, so I think he had a fair amount of exercise.

(4) And can you give me a brief summary of your lives together, between your marriage in the 1960s, and his diagnosis with the diabetes?

Yes. I gave up work, once I had the children, partly because we didn't have... neither of us had family here, so there wouldn't have been adequate backup, in terms of childcare. And also, my husband didn't want me to work. And I suppose I went along with that, really, because the background I'd grown up in my mother hadn't worked - it just wasn't the thing that, you know, women did, in those days, really, I suppose. And I think, by and large, I was quite happy to be at home with the children. It would have been very difficult for me to go back to work part-time, because, in the profession that I was in, there weren't really a lot of part-time opportunities; certainly no... there weren't the professional

posts, anyway. So, really, I didn't work until... I went back to work in the 1980s - I think it was probably about 1986-7, I can't remember, exactly - once the children were grown up.

And now can you tell me about your husband's diagnosis?

Yes. My husband was diagnosed with diabetes when he was actually working for a company, who happened to have... I think they had a small medical centre. He hadn't been feeling well; I think he'd been very tired. And I think, as far as I remember, what happened - I don't know whether he was carrying some files or books, or something, down a flight of stairs - and I think he fell. Whether he collapsed, I don't know. Anyway, so that sort of entailed him being taken off to the medical centre, and they must have done some kind of routine tests, and it seemed that they found, you know, that his sugar level was high. But it was confusing, because obviously he'd gone, or been told to go, to his own GP. And whether the sugar levels sort of fluctuated, so it wasn't diagnosed immediately, if you like, but then, eventually, there was a diagnosis.

At the time, I don't remember, thinking about it, that we were horrified by it, or probably because we didn't know what the implications were. I didn't really know a lot about diabetes, I suppose, and, as I say, because although it was in my husband's family, I think he hadn't really seen what could happen, you know, as the illness progressed. But, having said that, as soon as we found out, I did get advice - in fact, we both went to see the dietitian together. And he immediately - we didn't eat a lot of butter, as such - but we immediately stopped that, and also, I think he went onto sort of semi-skimmed milk; eventually he went onto skimmed milk. And we did try to, you know, regulate our diet, as far as we could; tried to cut down on any oil that was used. In fact, I can't remember, prior to that, what we'd actually been using as a cooking medium, but I remember we started using sunflower oil, because that was recommended, I think, at the time. I think the fact that... he stopped having sugar, didn't even use an artificial sweetener. The only thing was, I think, sometimes, you know, he would eat Asian sweets, if we went somewhere, or... But, in a way, it was quite good that he wasn't that worried about having sweet things, so it wasn't so traumatic for him to, by and large, cut out those things.

(5) And when you went to see the dietitian - this is in the mid 1980s - did he seem to be knowledgeable about Asian diet?

If I'm honest, I can't actually remember. I just really can't remember whether the person who saw us made any reference, particularly, you know, to Asian diets, or not. It's such a long time ago. Obviously, as time went on - and my husband, over the years, had seen, you know, at different times, a dietitian - and obviously people, I would think, had become more aware, you know, of the sort of pitfalls of Asian diets, if that's the right word. Yeah, it's very difficult for me to remember back to the mid 1980s. I just distinctly remember going with him to see a dietitian, and I think we were probably kind of given measurements, in terms of how much oil, you know, should be used, or... I'm not really sure. As

I say, it is a very long time ago.

But you don't remember lots of weighing and measuring going on at home, after his diagnosis?

No. Whether I did weigh things, and then just kind of, once I could see by eye what quantities - whether I just relied on that, I think, probably, as far as I can remember, anyway.

How did your husband react to being diagnosed with diabetes?

There again, it's all a bit hazy. As I said, it is a long time ago, but I don't remember him being particularly horrified or depressed by it. But there again, I think -and I think, in general terms, this is... well, certainly then was the case with diabetes - because it doesn't immediately adversely affect your life in fact, he led, what I would say, was a fairly normal life, until complications really started to set in - so, in a way, it's almost... I can't actually think of the right word. In other words: you know that you have this illness, but because it doesn't really manifest itself in... not in the early stages, and things that limit your life, maybe that's the danger, because you don't realise, you know, that if you're not as careful as you might be, what might actually happen.

What kind of treatment did your husband have at first?

At first it was just diet; then it progressed to tablets, to medication. And, as far as I was aware, it seemed to be under reasonably good control for a long time. He was actually involved - I can't remember the name of the project - but he... it was some kind of research or survey into diabetes, I think, with respect to the Asian community. So, he was quite lucky in that he had good input from the hospital, and he was checked and monitored on a very regular basis. So, maybe... well, I think it was really helpful. But, no, as I say, as far as I remember, he led what seemed to be, you know, a reasonably normal life for... well, it was quite a long time, really, till complications started to set in.

(6) How long do you reckon he managed his diabetes on diet alone?

I think it might have possibly been only a couple of years, and then he was put onto medication. And because he managed the medication himself, I can't actually remember the names of the medication. Eventually, he was actually put onto insulin. That happened... he'd had an angioplasty. He'd been diagnosed with angina - that was very late nineties - and went into hospital. When he came out, he developed an infection, had to go back in again, and then he was put onto insulin. I think it had been talked about prior to that, when he was attending the clinic at the hospital, but, for some reason, he hadn't actually been put onto insulin at that point. But certainly, after he had the angioplasty, and, as I say, developed an infection after he'd had it done, went back in, and then, at that point, he was put onto insulin.

Apart from cooking the meals, what involvement would you say that you had in your husband's diabetes?

Well, really, he managed his diabetes himself, in terms of the medication, and his hospital visits; that kind of thing. So, really, other than trying to make sure that he had a reasonably healthy diet, trying to make sure, you know, that we did have exercise - both of us, really, not just for him - he actually managed the condition himself, and he seemed quite happy to do that. It was only later, really, when complications started to appear, that I became more involved, really, in terms of perhaps going with him to the hospital, perhaps trying to... I mean, because I was the one doing the cooking - most of the time, anyway - so I had sort of monitored, you know, his diet, in that respect. Perhaps I became, in a lot of ways, perhaps too over-anxious, in terms of his diet, you know, once I realised complications were setting in. But certainly, up till that point, he'd really managed his diabetes himself.

(7) Tell me about the complications.

Well, it's... they really started to become apparent in the late 1990s, when he was diagnosed as having angina. That had happened... we were actually doing some heavy gardening, and he kept complaining that he'd got indigestion. And he wouldn't go to the doctor - I mean, that's what he thought it was, I think. And then, I think, in fact, my daughter might have said "look, you have to go to the doctor" - because she happened to come one day when he wasn't feeling well - which he did, and he was diagnosed as having angina. And, from there, he had an angiogram, and the first angioplasty. And, in subsequent years, it just seemed that one complication sort of developed after another.

I can give a list of things that happened - I can't give exact dates, maybe, or the chronological order - but he'd actually had... he'd got diabetic retinopathy. He'd had diabetic neuropathy, which was very frightening, because the diabetic neuropathy caused him a great deal of pain. And also, he had a period of until it was sort of brought under control, to some extent - whereby he used to fall down. And we had several incidents, which could have been very serious. Luckily, he didn't fall down in the middle of the road, but it did happen several times outside. He fell down the stairs, and it seemed to happen, really, without any warning. And he'd had... he certainly had another angioplasty, at some point, because the artery in his leg became blocked. They had great difficulty in doing that, and were very unwilling to do it, because there were inherent, or potential, dangers. Then... I'm just trying to think, there were so many things. Eventually his diabetes had an impact on our, sort of, personal relationship if you like, which was very sad because obviously... I mean the physical side is part of a marriage and, you know, is a great comfort often in a close relationship, so that definitely, you know, had quite a bad effect really and also I think probably contributed to depression as well.

He'd had quite a lot of invasive procedures. It became obvious that his kidneys were becoming weak. Then, I think it was in... I can't remember which year it was - maybe it was 2002 or 3, I can't remember - he had, I think it was one or two heart attacks. He was admitted to hospital, and from there, things just sort of accelerated, really. And all this was compounded, really - it was very

sad, because he really tried to keep up his exercise, and that was our plan, that when we were retired, we'd do more walking, and so on - but he'd developed a back problem, a spinal problem, to which there wasn't any solution. I think it was just degeneration in the, I think it was facet joints; I can't remember the details. But he was extremely anxious to try and get that sorted, because he wanted to walk. And, in fact, he tried to walk, but it was just so painful, so it obviously developed into a vicious circle. Because he couldn't get the exercise, he was putting on weight. Whether this had anything to do with the insulin, I don't really know, because I don't understand the chemical, you know, effects and reactions of drugs. But it was definitely a vicious circle, and I think that's probably when he started to get really depressed.

(8) Luckily he was still able to drive, but the fact that he couldn't walk easily was a big factor in, I would say, in depression developing. And he got to the point where I think - not all the time - but for a lot of the time, you know, he felt that his life, really, was becoming quite intolerable. And his heart problems sort of accelerated. Certainly over the last year - well, it was in 2006 - it... he sort of seemed to have very low blood pressure, which was being investigated, and there didn't seem, at the time, to be a clear explanation for this. But, as it transpired, it was obviously his heart. But, having said this, although I think he did become very depressed by it, at times, he still tried to... I mean, in some ways he was quite philosophical about what had happened. But the limitations, obviously - particularly this lack of mobility, really - had a very bad effect, not only on him, but on both of us, really, because it was very painful to watch him sort of... it was just a very, very slow deterioration.

These complications began when he was in his late fifties, early sixties. What effects did they have on his personality?

He'd always been a very sort of extrovert kind of personality, and, as I said, in the earlier days, when he was able to have what I would call, you know, a relatively normal life, he'd always been very active. And, we'd always sort of done things together, you know, around the house, and although he was no gardener, but he'd always help, you know. And we used to like to go out and about, and certainly, you know, being able to go for a walk, just get out into the countryside, this kind of thing. And I think it really... I don't know, he just, as I say, in some ways he was sort of... he tried to be philosophical about it. He used to say that he'd had a good life, and that there were a lot of people worse off than him, which was very true, obviously. But then, other times, you know, he did used to get very low. And I think, also, he used to get very angry with himself, sometimes, because I think he could see that because of his inability to do the things that he'd done - for instance, helping with heavy work in the garden - meant that it was putting a lot of pressure on me, and there was really not a lot that he could do about it. And he was obviously also aware that it was putting limitations on my enjoyment of life, you know, because we couldn't do... we'd had a lot of plans. Because he'd worked hard all his life, and we'd

had a lot of plans for retirement, you know, for holidays, and this kind of thing. And really, we didn't really enjoy what retirement there was, because of the limitations.

(9) Did he feel that he'd caused his own illness?

I think he may have done, to some extent. But I think, obviously, as I said before, in the early days, because... To me, diabetes is an insidious sort of illness, in that, basically, you don't really start to... you're not in a lot of pain, for instance, which you are with some things, you know, in the early stages. So, maybe... I don't know. He did say, sometimes, that if he'd been more aware of, you know, the potential outcome, if you like, of not perhaps being as careful as he should have been... Although, I think, as far as I was concerned, I think he did try. There were lapses, obviously, with diet, sometimes, but he did try. But then, I think he probably just used to get fed up with the constraints, because it's not sometimes very enjoyable when you have to watch your diet all the time. But I think yes, definitely, with hindsight, he perhaps thought he could have been more careful. And by the time, you know... perhaps when he really started to be really strict with himself, it was too late; the complications had set in already. But luckily, one thing, he never smoked. He didn't smoke or drink, and I suppose food was perhaps his one vice, if that's the right word.

(10) How did his depression affect you?

I became quite... well, at some points, very depressed myself, because I felt absolutely out of control. There was nothing, really, I could do, or I felt that I could do. And if I'm honest about it, because of - I mean, I'm sure it was a result, you know, of the fact that he was depressed, sometimes - he became irritable. And sometimes, when I tried to sort of... if I thought he was doing something - for instance in terms of diet, or whatever - that I thought wasn't a good idea, he would often say "don't keep reminding me, you're making me feel more ill", you know, "don't remind me that I'm ill all the time", which I wasn't doing; I wasn't doing it for that reason, really. But yes, it did, it became difficult.

And the other factor, as well, I think I became very anxious and depressed myself, not... part of the reason was that I have a chronic condition myself, a chronic long-term health problem. Part of my worries were, as his health deteriorated, that I had to stay well in order to look after him, because otherwise, you know, we really would have been in trouble. And I think, actually, it frightened me, because he'd... I mean, I was diagnosed with the health condition that I have, it wasn't all that long... I can't remember the exact date - probably, maybe, three years after he'd been diagnosed with diabetes - and, in fact, I'd had some very bad patches with my health, and I'd relied on him. He was very supportive, and maybe part of my fear was, I was anticipating what was going to happen, I suppose, as I saw his health slowly deteriorating. In fact, I think I'd even said possibly to my daughter or to a friend, I can't remember, really - that as his sort of condition... I could see it deteriorating slowly, and I'd said, you know,

that I felt almost as though he was slowly dying in front of me, and I felt there was absolutely nothing I could do to arrest that process. And I think, you know, I was probably afraid, you know, what was going to happen to me, really.

Then I started to wonder if the fact that I was over-anxious was contributing towards his depression, but when you're in that situation, it's very difficult to say. But it was very difficult, and I make no bones about that. And I think, in general, it's a case that it's often not recognised what a pressurised situation it is, not only for the patient, in these situations, but for the person who cares for them. And I'm sure, with the best will in the world, possibly I was the only person, you know, who realised how ill he was, because when he was with other people, he sort of brightened up, even if he'd been feeling low. And I think he always felt that he didn't want to bore other people by talking about his illness, or, you know... which, there again, I can understand. I mean, if anybody asked him how he was, he would always say "fine", even though, you know, we knew that he wasn't.

Did any health professionals show any awareness of what was happening?

In terms of the depression? I can't ever remember that anybody spoke about it, no. But there again, you see, I think when he was in contact, you know, with the health professionals - nurses, doctors, whoever it was - I think he put on a front, to some extent. This is why I say, really, I think, possibly, I was perhaps the only person who really saw that side of it, because I think part of him just didn't want to depress other people, I suppose. And also, there was a factor, I think, that when he was - because he was a very gregarious sort of person - when he was with other people, he was much better, you know, he brightened up. And obviously that's a factor for anybody, you know, who suffers from depression. But certainly it was difficult.

(11) Do you feel that you and your husband had any support in this difficult situation?

I would say possibly not, but then, having said that, I can't blame anybody - you know, the professionals - because, as I say, I don't think he probably presented to other people. He was quite good at... for instance, the... I mean, he would say to me, sometimes, when he was very low, you know, that he felt his life wasn't worth living, and so on. Well, I can't imagine that he ever said that to anybody else. Maybe it was a matter of pride. It was one of these things that I think he also felt it was perhaps a sign of weakness, you know; maybe because he'd been brought up - perhaps as I was, to some extent - with this attitude that, you know, you have to try and pull yourself together. So, I don't know, really, whether anything could have been done. I think if I'd said to him openly that I felt that he was very depressed, and that he should talk to somebody about it sometimes, I don't think he would have done.

You say you were brought up to pull yourself together. Do you think there were any Asian cultural factors in his attitude to depression?

I think maybe it could be, because - maybe not these days - but in his generation, if you like, I think any kind of mental health issues - obviously, of which, depression is one - tend to have been a taboo subject, if you like. And I can understand that, to some extent, because I think even in, if you like, English society, you know, it's only comparatively recently, and even now I often think people are reluctant to talk about depression, because it's something that you can't actually see, in a way that you can a physical illness. And, I don't know, there's that sort of fear attached to it. And it's very frightening for the person, I think, you know, who actually has to cope with it, so I think it's a difficult issue anyway, but...

All I was going to say was: and also, because he was - for instance, in terms of medication - he was taking so much medication, because of all these complications, I think, you know, even had he asked for help, and if more medication had been suggested, he would probably have refused it anyway.

(12) What kind of support would you like to have had?

To be honest, I can't really think, you know, what kind of support would have been available to... what could be available to him, or... I don't know, is the answer. I don't know whether anything could have been done, because, at the end of the day, you know, things that were causing the depression - for instance, this lack of mobility, towards the end - that, I think, personally speaking, that was one of the major causes of him becoming depressed. Because, while he could still walk, while he was still mobile... A case in point is that we tried to persuade him, you see, to have a mobility scooter, so that we could, you know, go out and find places, where... because, actually, the limitations started to spread to family outings, in that he wouldn't... he used to make excuses not to go, because he knew that he couldn't walk, you know, walk perhaps with the grandchildren, and this sort of thing. So, you know, I think, his attitude was that, you know, you can't... nothing could be done to change the sort of physical limitations, which were probably the root, you know, at the root of his depression.

What was his reaction when you suggested a mobility scooter?

"No"; he wouldn't entertain the idea. We tried to explain to him that "look, you won't have to use it all the time", because he was still able to drive, "but at least if we go out for the day, then, you know, we'll be able to plan days out, we can choose places where..." instead of... I mean, we had sometimes, when we'd gone out, he would try to walk, but he couldn't, and then he would end up sitting in the car. Then, of course, it basically - saying 'spoilt' is the wrong word - but it did, because we were anxious about him, and we didn't feel like going off and leaving him, you know, sitting in the car, kind of thing. It was very strange, actually: it wasn't until he ended up in hospital that - in 2006 - and then he did an about turn, and he said... I don't know; he suddenly seemed to accept the fact. I think a lot of it was that he didn't want to accept the fact that he couldn't walk properly, and he kept trying. And it was quite... really,

it was very difficult to watch him, because you knew he was in pain when he was walking, and he tried not to give up. But when he sort of... the final time, when he ended up in hospital, then he said "when I come out", he said "then we'll buy a mobility scooter". But, up till then, he kept making excuses.

I think, there again, it was just he felt that would be the kind of final admission, you know, that... and I think he just couldn't face that, somehow. I think he found it very difficult to come to terms with the seriousness of his illness, so... He found it difficult to accept and to come to terms with it, in terms of altering, perhaps, you know, the way his life had to be. So, he seemed to be just giving up. And I felt, perhaps... I mean, I used to try and sort of - because he would sit and he would sleep a lot. I think that was partly due to the medication, but also the nature of the illness, the fact that his heart was obviously not functioning properly - and I think I often used to try and chivvy him into, you know, some kind of activity. And I thought - thinking about it, with hindsight - I felt a bit guilty about that, because I think he was just so tired, you know, that he really hadn't got the energy anyway, but yeah.

(13) Did he suffer from many hypos?

Initially he didn't, but then, as time progressed, he had patches where he kept having them, and obviously, you know, there were difficulties in adjusting the insulin. In fact, he ended up having four insulin injections a day. So, yes, he did have patches where he had a lot of hypos, and, of course, this caused him to be irritable; that's one of the, you know, effects. And basically, all he wanted to do, if this happened, was just sit quietly and recover from it, and that took me, I suppose, time to get used to what was happening, but...

Did you do anything?

Well, in terms of, I always made sure that... I used to remind him... I mean, he checked his sugar level every time he went out - I reminded him to do that and he always carried his glucose tablets with him. But as soon as, you know, I was aware that it was happening, I would give him - you know, if I was there -I'd give him his glucose tablets. And the only thing, really, you could do was just let him sit, because he would be very tired after it happened. And I had to accept, really, that he would be irritable, which sometimes it was hard to... even, because I think with the best will in the world, even though you know that illness, you know, does change people - it does change people's personality, there's no doubt about it, particularly, you know, if there's depression involved it's not always easy, you know, to, even though you know what's happening, but just to put up with it becomes difficult, sometimes. I think, overall... sometimes I used to feel very resentful. Not... I didn't feel angry or resentful with him, because, you know, I felt that he couldn't help it, but I felt very resentful about the situation that we found ourselves in. And I'm sure that's true for a lot of people, having spoken to different people about it, and particularly if you have a health problem yourself, you know, you just get so tired, sometimes.

(14) You said that you couldn't really think what anyone could have done to

help, but obviously doctors, nurses and other people would like to feel that there was something they could do to help, so can I push you a bit on that one?

Yes, the only thing is that he did actually become involved in an education, if that's the right word, education programme. It was sort of 2000/2006. It was really done through the dietitians, I think, but it was a series of talks, getting together a group of patients, and they looked at all sorts of things, not just nutrition, but other aspects of diabetes. And I think he found that quite helpful, not only for the information, although it probably came too late - it came too late, I think, for him - but the fact of being in a group where other people were talking about their experiences. In a way, it provided some kind of support, and he did actually go to all of the sessions that he was able to go to.

The other thing that - there again, it would need to have been started much earlier on - I know of someone who, although not diabetic, because they'd developed angina, was enrolled into an exercise programme at a hospital, which meant probably a couple of sessions, maybe even three a week. This was a rehabilitation programme for those cardiac patients. But, if there'd been some kind of exercise programme that my husband could have joined, when he was able to still do that, I think that would have helped him, because he was always willing to try things. And I think the support that he would have got from a group of other people, even, you know, in terms of sharing experiences, and I think also it would have focussed him. I think he would have done that, if it had been available. In fact, when he was doing the other education programme, I think he kept asking the nurses involved whether there was any possibility of some kind of exercise sessions. But obviously, all this hinges on resources being available, and, you know, this kind of thing. But I think he was very impressed - it was actually a friend of his who was involved, you know, with the cardiac rehabilitation, but at a different hospital. So, I think that would have helped him; I'm sure it would, in fact.

What would have helped you?

Well, I think if he... I think if there'd been that kind of thing available for him, that would have helped me, because I would have felt that, you know, he was doing something positive. That was the thing.

Also, I think what would have helped me, perhaps, as a carer - I mean, I was aware that there is a network of carers, associations, but, for one reason or another, I never really investigated. Maybe because I was just so involved, you know, with what was going on at home. Strangely enough, I did become involved in a six-week programme, which was aimed at carers, but my caring role had finished then. But I went along to it, on the grounds that it was suggested to me that, perhaps, whatever I'd learnt in the role of carer, you know, I might have some input, although the course was actually aimed at people who were still in a caring role. I'd enrolled on it, actually, I think it was summer 2006, and it ran in the autumn. It was a PCT course, and it was quite good, and a

lot of information was given out to people, which I think would have steered them, perhaps, in the direction of looking for support from carers... and, of course, now there is the new carers' centre, which really wasn't there. You know, perhaps if that had been there, I think I would have investigated that.

And I think just having support, you know, it would have helped, because I think a feature, really - not only for diabetic patients and carers, but for any chronic sort of health condition - is the fact that you can end up feeling very isolated: physically, because of the limitations that are placed on you - things you can't do, can't be involved in - and also, you know, psychologically, really.