

45. Clare

(1) Tell me about your background.

I was brought up in a very rural location. It was in Cornwall, and a very small hamlet with very few houses; quite isolated. My father was a teacher, my mother was a district nurse. I have siblings: two brothers and one sister. My sister's older than me and both my brothers are younger than me, but we're all quite close in age. I went to... the local village was about five... no, three miles away, and I went to the local village school. I enjoyed living where we lived, because I was very much, from a very early age, into horse riding and the sea, and we were very close to the beach.

How did your diagnosis with diabetes come about?

I was always quite ill as a child, in that I would fall asleep all over the place. I was very thin, and my family... we'd go for walks on a Sunday afternoon, and I used to hate it, because I always wanted to just sleep and drink. And one day, Mum walked over to the doctor's with me, which was about a three mile walk. And the doctor took a urine sample and said "no more sweets for you, young lady" - I always remember that - and that was my kind of introduction to being diabetic. He was an elderly Cornish village doctor, and I think most of his patients with diabetes were elderly, with type two diabetes. I obviously had type one diabetes, but I wasn't treated with insulin for a further four or five years. And so, I just really remember suddenly not being allowed to eat all these things. It was sort of long lists of things that I wasn't allowed to eat. There was never really any explanation - that I remember - at all, throughout my childhood, on it. It was things... it was done on a kind of fear, you know: if you eat more than half a banana, you're gonna die; if you eat more than two and a half slices of bread, you know, all sorts of terrible consequences were going to happen. And that was how it was treated, really.

How old were you when you were diagnosed?

I think I must have been about four or five. I can't remember, and I've asked my parents, and they can't remember either.

Now, this period when you were on diet only, how did you feel during those years?

It was awful. I had different food from everyone else in the family, and from... you know, my food was all weighed out, everything was very carefully weighed, and I was thirsty constantly. I remember this, you know, this terrible thirst. I remember that I was constantly wanting to go to the loo as well, and, you know, when you're sort of six or seven and you wet yourself, it's very embarrassing. I remember a few occasions like that, because I was so thirsty and I would drink so much. And basically I wasn't... you know, food was a real issue, because I wasn't allowed anything. Yeah, that's...

You mentioned this fear element. Was it your doctor who made these threats or

your parents?

It was mainly the doctor started it. I remember him saying... you know, it was from the very sort of first diagnosis, it was: I wasn't going to be allowed to have this, 'cause this would happen. And then, I think my parents just sort of carried on with it, because that was what he'd sort of started.

You mentioned that your mother was a nurse. Did she not suspect that more could be done for you?

I think that the only experience she had of diabetes was probably with elderly people, who controlled it quite successfully on diet and pills. And so, it wasn't until I was quite a bit older - about... must have been about nine, eight or nine - that I started going on insulin, and that was as a result of being so ill, really. My parents used to take in guests for bed and breakfast, and one of those was a doctor, and he said that I really needed to get to see a specialist. And that was when we went up to Plymouth, which was like a real long journey away - about ninety miles away - to the hospital. And I saw, for the first time, a diabetic specialist and was put on insulin.

(2) And what happened next?

I remember him - the diabetic specialist at the hospital - being very annoyed with the GP who had been treating me, and... so I was put on insulin. I wasn't put in hospital. Again, I still didn't have any kind of explanation as to why I needed insulin or anything. It was more, suddenly I was allowed... the thing I really remember was that I was allowed to eat ice-cream, whereas I'd never been allowed to eat ice-cream before. So, suddenly it was, I was allowed to eat all these different foods that I hadn't... Although it was still quite a strict diet - compared to the starvation diet I had been on, it was quite lax.

Can you remember anything about the diet? Were there diet sheets?

Oh, yeah, there was lots of exchange sheets and diet sheets. And, you know, you were allowed to have one apple, or, if you didn't have the apple you had a piece of bread or one Digestive and two Rich Tea - I don't know why I always remember that - but it was still quite controlled. And I was allowed so many units or portions for each meal. And I remember... because, I mean, I put on a lot of weight as soon as I went onto insulin. From being very underweight, I became overweight, and, I suppose, from going on this quite strict diet to suddenly being allowed different foods, I did kind of go a bit mad. And I remember eating things like Mars bars, and things I really shouldn't have eaten. And I tended to eat them when I was annoyed with my parents as well, like somehow that was going to get back at them.

Did your diabetes cause a lot of annoyance with your parents?

It caused an incredible amount of family strife. Because we were... where I was brought up was about twelve miles from the local grammar school, and there was a school bus that came and collected us. And I'd refuse to do my injection

until the bus had gone, I would refuse to do various things at school - activities - because everyone seemed to be petrified that I was going to go into a coma at any moment. I had a horse, and my parents would give me sugar cubes to carry around with me in case I had a hypo, and I'd feed them all to the horse, and fall off into a coma. It caused, I think, between my siblings and I, it caused problems, because I was always deman... you know, the one who was always getting attention, from their point of view. I was sent to see a child psychiatrist, which I really resented.

(3) And you say that you really had no education about diabetes. How were you taught to do injections?

I was never taught to do injections, and I didn't really ever have any education around diabetes. I would inject myself. It would take about half an hour, and I would put the needle in very, very slowly. The needles were generally... it was in the days of proper glass and metal syringes, and you were allowed - I don't know - about five needles, it seemed to be, a year, and you had to boil these up to sterilise them. And my needles, you know, they'd get little... you could feel at the end of a needle that it wasn't straight, and it would scratch your skin before you'd even got it in. And it was, you know, it was a big family trauma every time I had to do an injection. To start with, I was only on one injection, and then quite quickly I was moved onto two injections: morning and evening. And, you know, it was... I would just refuse to do it or I'd have a tantrum around it. And it was an extremely painful thing to do, or I would do it in the same spot so that it became inflamed. Yeah, and it was just very difficult.

Can you remember what insulin you were on at first?

I have no idea.

What about monitoring your sugar levels - were you taught about that?

Oh yes, we used to do a urine test. That was something else that was a bit of a trauma for my parents, because I'd refuse to do it. I just didn't like being diabetic. I didn't understand it, and it was just something that my parents made me do. And obviously, I was the kind of child who refused doing things, just because I was told to do them, and I would... I think I was only asked to do it every now and again. I remember we used to have to go up to Plymouth, to the hospital, every three or four months. And I was always told off when I went there, because I hadn't done enough urine tests and hadn't kept an account of what my sugar levels were. But again, no one ever... I don't remember anyone ever explaining to me what the point of it was. And then, for a long time, I was told that I had a low renal threshold, which apparently meant - this is how I understood it as a child - that they weren't ever very accurate anyway, so that just confirmed to me - what was the point of doing them?

Can you remember how the urine tests were done?

Oh, yeah. You had to pee into a little receptacle of some sort, and then you had to put so many drops of water and so many drops of urine and a sort of a

test strip, and then you had to match them against a colour bar. But I don't remember it very clearly, 'cause I didn't do hardly any.

Were there any other children with diabetes at school?

No. My parents tried to get me involved in Balance, the magazine, and the British Diabetic Association, but I was never very interested in this. It always seemed to me... I always refused to have anything to do with it. Occasionally I was forced to go to these like Christmas parties for other diabetic children, and I really disliked it. And they did summer camps, and I just had this idea that we'd all be lining up for our injections, and I didn't want to have anything to do with it at all, so I didn't, really.

(4) What about at school - how did your fellow pupils react?

I don't really remember fellow pupils acting particularly differently or anything at junior school. I remember much more about it at secondary school. I don't have any clear memories of it at junior school.

What about the teachers - how did they treat you?

Again, I can't really say that I remember being treated any differently at junior school.

Tell me about secondary school then.

At secondary school, I was treated very differently. I had a different lunch from everybody. But, by the second or third year of secondary school, I took my own lunch in, but to start with it was a different lunch. And the school cooks did not understand diabetes. I remember having arguments with them when they gave me canned fruit in syrup, not because I didn't eat things like that - because I didn't do anything I was supposed to do - but I knew that they weren't supposed to give it to me. I remember the staff being very nervous. I remember not wanting to play hockey, so I said "oh, if do that, I'll have a hypo and go in a coma, and it will be all your fault". And that seemed to be kind of a common thing that I used to say. If there were exams, I'd say I'd forgotten my injection, and they'd have to drive me all the way home, until they sort of thought of the idea of keeping spare insulin and needles and a syringe in the school safe. I know I was the only child who had milk at break time, for some reason, because of my diabetes. I don't quite know why I was given that, looking back on it. And I don't really remember it being a problem with other children, but I do remember it being sort of seen as different by members of staff, and that they were slightly nervous of my medical condition.

And you mentioned that you were sent to an educational psychologist. Why was that?

Because I was still refusing to do... because I was difficult, I suppose - you know, not wanting to do my insulin. At the time, I didn't see why I should have to go, when my siblings... and I thought, particularly with me and my sister - we used to argue like anything - but I never really understood why I had to

go. I didn't like the man. I remember that they sent me to an adult one in a hospital, which was quite frightening. And then, after that, I was sent to the child psychologist, which was very close to the school, and so I used to have to go there once a week. And I carried on going there up until I was about fifteen.

Did the psychologist link your problems with your diabetes?

All I remember about the psychologist is that I found him a bit creepy. And I used to do things like draw sweets - 'cause he'd asked me to draw a picture. And I was very angry about having been sent there, so I'd think "oh well..." - and I'd draw loads of sweets, and then put a big cross across them made out of syringes and things. But I knew perfectly well what I was doing and why I was doing it - it was just to annoy him, because I always found him a bit creepy. And... well, I later found out that, a few years after I'd been seeing him, that he actually ran off with one of his child patients on her sixteenth birthday, which just kind of confirmed my idea that he was always rather creepy.

Can you talk about your teenage social life? Did you go in for smoking, drinking, drugs?

Yeah, that was me. Yeah, it was all of those things. I started smoking, drinking, drugs, any... you know, it was... Well, perhaps I should also mention before that, was that when I was seeing the child psychologist, they put me on Largactil, and I was - which is, as I understand it, a kind of liquid Valium - and I took Largactil for a long time. And I have very clear memories of reaching up into the cupboard where it was taken, and any time I got annoyed, I would just go and take a swig of this sort of thick brown liquid. So, I think, you know, my druggy years were kind of affected by having taken these things all along anyway! But yeah, no, as a teenager, I did everything that teenagers do. Didn't have it... because of where I was brought up, and it was so rural, we were always dependent on older people, really, to take you around in cars. And so, older people were into... you know, it was very much sort of surfing, hippy kind of scene.

(5) And how did you manage your diabetes during your teens?

I didn't. I just totally ignored it, and just ate anything I wanted to, injected without testing blood sugars, and just totally and utterly ignored it.

And how much contact did you have with the medical profession?

As little as I could. I would go up to the hospital... I can't really remember. I've got a feeling it was about once every four months, but if I could've avoided going for any reason, I would. And I don't really remember it having much of an impact, and I used to think people who talked about diabetes having a big impact on their life were just making a big deal over it. By now, it had become nothing for me, because I just ignored it.

And did you have many hypos?

I never had any controlled ones, that I've witnessed happening in hospitals now when people are first put on insulin; there was nothing like that. The first time I had a hypo was obviously when I was on insulin, and I didn't have anything like that before. And I think the first time - I can't honestly remember if it was the first time or one of the early times - I went into a coma, and I just went... just started feeling ill and went into a coma and didn't know what was happening. And then, after that, I went into quite a few comas - or it was unconscious, rather than comas, I suppose - as a child, usually by going out on horseback or being somewhere where I didn't have any glucose with me, and generally being irresponsible. Then, when I totally, you know, as a teenager, and I totally ignored my diabetes, I think my sugars were always probably rather high, and I didn't have hypos, or very occasionally. But when I left school and I moved to London and I went to college, I did have hypos, but I was always... I did spend quite a lot of time in hospital, whether it was because I'd broken my arms badly - horse riding accidents - or I got gastroenteritis very badly, and obviously these things really upset my diabetes. And I seemed to be admitted to hospital very easily, as far as I was concerned. Practically every time I had anything to do with the medical profession, they seemed to want to take me into hospital, where I would have lots of tests. As a teenager, I was also diagnosed with an under-active thyroid gland, and that took quite some time for people to diagnose, and I was told I would now lose weight. Throughout my teens I was overweight, and it was a sort of a problem for me, but I wasn't ever given any real help with it, from a diabetic point of view. But I was always constantly being told "now you'll lose weight", and I never did. But I do remember, like when I moved to London, that I again, I did spend... most London hospitals I've actually spent time in. I can't quite remember how I got admitted to them all, but I did spend quite a bit of time on various medical wards, which were always very, very depressing wards, and full of elderly people dying.

Did your diabetes affect your choice of what you did after you left school?

Absolutely no; that's, you know, end of it, really. I don't think it had any impact on what I did. I went to university, and then I went and lived abroad for about twelve (slip - since corrected to seven) years.

(6) Tell me about your time abroad.

I was in southern Europe: in Italy for a while, and then for a long time in Greece. I was under absolutely no medical supervision. Every now and again I'd come back to England and stock up on insulin, but any other drugs, like, you know, Thyroxine and things, you could just buy over the counter, so... And I would just sign on as a temporary patient with some GP and get loads of insulin, and then go back to where I was living, so absolutely no medical supervision. And really, again, I was just ignoring my diabetes, and it just sort of had to fit in with my lifestyle, and so it did.

What was your lifestyle while you were abroad?

Well, I was teaching English as a foreign language, and travelling to different

countries, and drinking and socialising, and just being on one long holiday, it felt, really, I suppose, for quite a few years.

And how old were you while you were abroad?

I suppose from the age of around about twenty one, twenty two to thirty five. I say that my diabetes didn't sort of have any impact on me, but there were things I didn't do, because I was diabetic. Like, a lot of people I knew were taking LSD, and I didn't think it would be... I didn't really understand how LSD worked, but I knew it worked on your sugars, and I didn't want to sort of have a bad time. But I did meet someone who I thought was very silly towards his diabetes, because he used to do all sorts of drugs, and say "oh, I would just make sure my sugars were really high before I took them, so that I wouldn't have a hypo". But I remember thinking he was silly, because he had all these enormous boils and blisters on his skin, and so I thought "oh, he obviously doesn't take care of himself". But I don't think I was particularly, but there were just certain things I didn't want to do, because I thought it might be irresponsible towards my friends, I think.

(7) Did your diabetes have any impact on your life while you were abroad?

Only in so far as that I had a very sort of strict understanding that I had to do my insulin at certain times, and then I had to eat at certain times. So, in some sense, you know, I was aware that I had to eat at... you know, I didn't just miss meals or miss doing my insulin. I always just carried on doing it, but I don't think I ever tested my sugars when I lived abroad, ever. And so, from that point of view, it had an impact. And then, in about 1982, I suppose it would be, I developed... well, what I experienced was just like a black line in my eye, and I thought that I had an eyelash stuck on my eye. And I kept getting up, asking people to see if there was something in my eye. And in the end, just by chance really, I happened to go to see this eye doctor, with my then Greek boyfriend who I was living with. And he just started like this whole sort of hysterical bit about how I had to get back to England and I was losing my sight, and blah, blah, blah. So, I came back to England the following day, and that was to Moorfields Eye Hospital I came back to. And they said I had diabetic retinopathy. And I then spent probably the next two years, really, in and out of Moorfields Hospital, going back and forth between Greece and England non-stop. And... well, I spent a long time in the hospital, and I had an awful lot of operations and I had an awful lot of lasering done to both eyes. And basically, I went in there with perfectly normal vision, with a slight black line on one eye, which turned out to be a haemorrhage. But as far as I... the way I experienced it was that I went into a hospital with full sight, and came out a year and a half later - well, obviously I wasn't in there continually, but - registered blind, and that was a bit of a shock. Although, you know, I... throughout my childhood I was worried that I would lose my sight, because that was one of the things that was always sort of said, that you'll lose your sight if you do this or do that. So, it was a bit... losing my sight was strange, because also, then, in my teens, if I did see a doctor, I'd ask about it. And they'd say "oh, well, there's no evidence

that says if your sugars are constantly high you're going to lose your sight or have any other complications. We just think it's better for you". So, I always just took this as "oh well, they don't really know, so I can do what I like". But it was a bit of a shock to lose my sight. And, well, obviously - well, not obviously if you haven't lived in Greece - but you don't want to live in Greece if you've got any kind of impairment, because they think you should be locked up! But, you know, when I was in Moorfields Hospital, for the whole time I was there, or going in and out, I really understood - and I'm not a stupid person - that they were going to cure me, because that's the kind of way they talked about it, and that they were going to make it okay. So, I wasn't particularly nervous - I really thought they were going to make things okay. And one day... I mean, I did have a lot of operations, and every time they looked at my eyes after the operation, they'd say "oh dear", you know, "the band's come off" or "this has happened, we'll have to try this next". But they always seemed to be: they were going to get it right. And then, one day, the doctor, just as... sort of as he was passing, more or less, said "oh, by the way, we've registered you blind today". And that was a complete and utter shock to me. And I think I swore, and, you know, and he said... and I said "what?", and he said "well, yes, it's about time you started facing some facts". And I was just... I mean, my initial reaction was just fury that they hadn't given me any facts to face. I mean, they'd been - to me - they'd been lying to me, and just... I mean, I just assumed that they were going to cure me, because that was the impression that they'd given me. And so, yeah, it was a real shock. And it was also a shock to me that there wasn't anybody... you know, they register you blind, give you a white stick and a radio - for some unknown reason - and you're on your way. And, you know, it's very much seen that "well, there's nothing more we can do. Off you go, don't bother us anymore". And that shocked me, and still shocks me, as, you know, as much as the whole sight thing. But you're very much seen as I was a failure in their eyes, and they didn't want to, you know, know anymore.

(8) You've mentioned a sense of failure, or of being blamed, all the way along. Is that true?

Yeah, I think... you know, from a young child, you know, up until I lost my sight, really, everything's seen as being your fault. If you go into a coma, if you... You know, anything that happens medically to you, it's because you haven't taken care of yourself, or that they have... well, I don't know... I've never liked... My experiences of the medical profession have never been positive. The most positive time, I suppose, was when I was initially in the eye hospital and they were trying out new techniques on me, and I was a very interesting subject. I mean, I've had eye students looking in my eyes - one doctor telling me to look one way, another doctor telling me to look another way. And they obviously, you know, just see you as an interesting eye or interesting eyes, rather than a human being. And once they were no longer able to do all their experiments or whatever on me, you know, they just didn't want to know anymore. And there was no kind of social help, really - you know, no one to talk to, no one to sort of und... so that I... you know, you understand what was happening to you



when you lose your sight.

(9) And how did you adjust to losing your sight?

Well, as I was saying before, I was living in Greece at the time, and I had a Greek partner who I was living with. We finished very quickly after I lost my sight, because he felt this was something that he was experiencing rather than me, and it was very unfortunate for him. So, that was that. I came back to England and decided to go back to university, because I wanted to be able to offer other people - who might be going through things that I was going through - some kind of help. So, rather strangely, I chose to do a psychology degree, but that's because I understood psychology would be about Freud and Yung and things like this. But, in fact, it wasn't, and it was far more about maths, and I changed and did sociology. And I developed a political understanding of impairment and disability, and that's what's helped me come to terms, if you want, with losing my sight.

What practical help did you get?

Very little. I came back to university, and I didn't know that I was entitled to anything, as someone who was registered blind, and I didn't ask for anything, so I didn't get any practical help at all. I had a white stick - I didn't have any training in mobility or in using it or anything. But after three years, I applied for a guide dog, because I've always liked animals and dogs, and it seemed a good reason, and so I've had a guide dog ever since.

How did you manage your university work?

Well, I think I was a typical mature student, where I was really into the work, but it was very difficult and I struggled to start with. I really didn't know that I was entitled to anything, so I didn't have any specialist equipment for the first two years. In the third year, I contacted the RNIB, who arranged for someone to come and see me. And I then got - it's quite a few years ago, so it wasn't exactly a computer - but it was a kind of computer, but again, I didn't have really any training in how to use it. And as my political understanding of disability increased, I realised, you know, that I was entitled to certain things. And, you know, I think I now have the support that I'm entitled to; certainly financial support. But I didn't... you know, people seemed to think that because... if you're a middle class educated person, then somehow, you know, you lose your sight and you're just somehow going to know all these things. But I knew absolutely nothing about what I was entitled to or not. And although I had a social worker, because - I don't know whether it's even still true - but, at the time, if you were registered blind - it's from a historical accident, really - you automatically got a social worker, who came to visit me once. And she just seemed to think that I knew everything, and I didn't. In fact, she asked me to come and meet this other woman who was losing her sight, because I'd, you know... be helpful for her to meet me. But then, when I met her, I learnt far more from it, because the social worker was telling her things that I didn't know - things I was entitled to, disability living allowance and things like that.

Did you have readers?

Nope. One of the lecturers was very good and he'd put things onto tape for me, but I didn't have anything like that. But it's also quite difficult, because, you know, if you're used to studying visually, I find - you know, you can make a funny story of it, but - listening to a tape can be quite difficult to assimilate information in that way, and I... things would put me to sleep. Listening to academic text on tape, I found extremely difficult. And I used to get things blown up for me. The library were quite good, once I'd got to know them. But it was always done on a 'who you know and what they can do for you'. None of it was done because it's your right to have this. It was always like thanking people endlessly for doing things for you. And the RNIB had a lot of books on tape and stuff, but again, you know, I found it very, very difficult listening to stuff on tape.

You said things blown up for you - you did have some sight then?

Yeah. Things were blown up, and then I had a magnification system as well. I mean, now I do it all on computer, but I still can read with a large magnifying glass.

(10) I think this lack of recognising your entitlements is of historical interest, so can you say which years this happened at university?

I went to university in 1986. I did an undergraduate degree - although I already had an undergraduate degree, I did another one. And then I did an MA and then I did a PhD, which I finished in 1996.

By 1996, had you recognised your entitlements?

Yes, I think after four years... when I was doing my MA, I think I started getting a bit 'on the ball', if you like, about what I was entitled to, and seeing my lack of sight as an issue around social equality as opposed to a medical issue. And that's really been a much more helpful way to understand impairment on a personal and political level.

And how was your diabetes controlled during the period of taking these various degrees?

Right, well, when I was in Moorfields Eye Hospital, my diabetes - which staggers me, really, looking back on it - but my diabetes was very badly controlled, because they were eye doctors, they weren't medical doctors. And they told me that I would have to have a district nurse coming round to see me twice a day, or however many injections I was having a day, to do my insulin. Well, you know, my mother was a district nurse - I know that they don't do things to a certain time. You could be waiting all day for them to come round. And, you know, this was a total lack of independence. And even now, as far as I'm aware, there are no syringes or pens, as they now are, that are designed specifically for diabetics with a visual impairment. The ones I use click, but the actual insulin doesn't particularly fit into that pen properly, but it's the only pen I can use 'cause it's

got the clicking sound, which I just think is horrendous, really. I'm sure there must be a human rights issue here, because, as far as I understand, the most common reason for people with sight impairments under sixty, is caused through diabetes type one.

- (11) But I think it was a kind of wake up call for me, personally, when I lost my sight, that if I didn't want to have all the other complications, I'd better start looking after my diabetes. And my diabetes has been well controlled, more or less - you know, I would call myself a stable diabetic - since losing my sight in 1984, or whenever it was.

And how have you kept it under control?

Well, I test my blood sugars very regularly now - about four or five, or even more times a day. I change my insulin according to my blood sugars. I'm very careful about what I eat. Up until relatively recently, I've done quite a lot exercise, which I'll be starting again, but I've got a heart condition, now, as well, so that sort of put that on hold. And, you know, although it is relatively much better controlled, this doesn't mean that I haven't had various hypos. Sometimes I've been on insulin that just doesn't suit me. I have at least six injections a day now. And when I was at university, I was under my first diabetic consultant who talked to me as an adult, rather than as some kind of wayward child. And he's had a big influence on my understanding of diabetes and on my treatment, although I understand, now, that not everything he told me is generally seen nowadays as correct. But he was the first person who helped me understand what it was all about, and what the complications are and why they arise.

You say that perhaps he taught you things which would not now be accepted. Can you remember what those were, just for the historical record?

Well, it's really more to do with having been on the course that I went on relatively recently. Things like, he would say "oh, well it doesn't really matter if you do, you know, one or two extra units, because, you know, every time you do an injection, a bit escapes. It's a bit... you know, it's never that exact a science". Well, from my understanding now, it is actually much more exact than that. So, that's the main thing I remember him telling me that sort of isn't necessarily correct.

And what did you do after you'd got your PhD?

I worked in the university sector for a few years, and then in 2000 - round about 2000 - I moved south. And since then, I've been the manager of a service user organisation, which works with disabled people and people who are long term users of health and social care.

- (12) And what kind of medical care did you get after you moved south in 2000?

Well, to start with, I wasn't at all happy with it, because I went to a large hospital. And I didn't see the same doctor, I saw them very infrequently, and I didn't feel I had any kind of personal relationship with the consultant, which,

for me, is very important. I then moved, because I live on the sort of edge of the county, so I come under... it would appear two sort of catchment areas, if you like, so I moved to the other catchment area. But it was very difficult for me to get there. As someone with a visual impairment, obviously I don't drive, and the only means really open to me was on hospital transport, which I just found so sort of humiliating that I just couldn't do it. So, I went back to the original hospital, but this time I went back sort of armed with insisting what I wanted, and insisted that I saw the chief consultant each time. And now I see him each time, and I have a good relationship with him and I find him extremely helpful.

What about diabetic specialist nurses - have you had anything to do with them?

Yes. I have never... up until I moved here, I've never had anything to do with diabetic specialist nurses, because I always felt that I knew as much about it as they did, because I'd lived with it. And, you know, it just seemed to me that things came into fashion and out of fashion around diabetes. But when I came here, the consultant asked me if I wanted to go on a course, which was called Insight. This was a course that was run by a dietician and the diabetic specialist nurse, and I had to say I was quite pessimistic. I thought it might all end up being rather a waste of my time, but I thought I'd give it a go. And I was very pleased with the course and I've learnt an awful lot from it, and it's resulted in my diabetes being far better controlled, I think, than it's ever been in my entire life.

Can you say when the course was and how it was organised?

It was in autumn 2003. It was for three half days and one full day, over four weeks. And we... there was a group of five of us, who were all long-term diabetics of ranging sort of years - I think I was the longest identified diabetic. We were all insulin-dependent, and we... I think most of us had just gone onto the relatively new insulin called Lantus, which, as I understand it, allows for sort of twenty four hour background cover without really peaking. And we started the course really looking at all the assumptions that we had around diabetes. And I hadn't realised how much of the stuff that I had been... that had been drummed into me as a child, I really still carried with me - things like the exchange ratios between foods.

- (13) I think one of the main things was that before... well, all my life it has been that you do a certain amount of insulin and then you eat according to the insulin that you've done, which is a real pain if, you know, if you're not hungry or whatever. Whereas suddenly it was the completely different way round, and nothing was barred. You could eat anything you wanted to, and you did the insulin... the insulin was adjusted according to that, which doesn't sound like a very big deal, but in practice, it's a huge and revolutionary way of thinking about food. I've always hated the fact that you have to eat, even if you're not hungry, and you have to eat so much carbohydrate at certain times. And it's not a hundred per cent fluid, obviously, and you still want to eat healthily and stuff, but if you don't feel

like eating much, you don't eat much, which is, you know, a huge change.

And what about if you feel like eating a lot?

If you feel like eating a lot, you can eat a lot, and you can eat anything. I mean, you know, the idea of being able to go into a restaurant and having a dessert, if I wanted to... I think for the first sort of week I kind of did eat desserts, but I don't actually have a sweet tooth at all, so it hasn't really made much difference to me, but... although I did have a very large box of chocolates given to me for Christmas. And I still felt guilty when I ate them, because like chocolate is like - you feel guilty, if you're diabetic for forty odd years and you're suddenly allowed to eat chocolate, you... But I don't actually like it that much, but, you know, I am allowed to eat these things if I want to.

And how do you work out how much insulin to take?

Well, I'm not very good at maths, and it's... Basically, you just count the carbohydrates, and you have a particular ratio - which is unique to you, depending on the overall amount of insulin that you normally take - a ratio of carbohydrate to insulin.

And how did everybody on this course find this maths?

Well, I don't think I was the worst, but I certainly wasn't the best! It's quite... if you're taking one unit of insulin to ten grams of carbohydrate, obviously that's quite straightforward. But now I'm taking one unit of insulin to fifteen grams of carbohydrate, which is less straightforward. And I think my maths is improving, but I still have to sort of look things up in my carbohydrate book and weigh quite a few things. I think, because of my sight, it is more difficult for me to sort of think "oh, this is about the same size of portion that I had yesterday of pasta" or whatever, because I can't actually see it like that, so I think there are issues around my visual impairment and working it out. But I do... I mean, if I'm at home I tend to weigh things, which I don't think I would have gone on the course if I'd known that, but actually, I don't find it an issue at all, and, you know, it just frees things up incredibly.

Did the course address the difficulties you might have with visual impairment?

Not really. I think they tried to, but I don't think it really did address it, no. I mean, they did very good things and put a lot of stuff into large print for me, and they did the best they could, but I think there were actually sort of more deeper issues, if you like, than just accessing the material. I mean, for one thing, the carbohydrate counting book is bloody... I mean, it's tiny, the print in that. And I rely very heavily on my partner to do a lot of the maths for me.

(14) Did you find it worked well to have three separate half days and a full day?

Yes, I thought it was excellent, because you had a week in between each session to try out how things were. And we had to keep a food diary and write down the carbohydrates of the food we ate and then the insulin we took, and whether or not we had to take a correction dose. So, you had a whole week's kind of

information to look at the following week with the tutors, which was really good. And you could see what was working for you and for others, because we all looked at each others as well, and, you know, what mistakes were made by us and things like that. And it also brought home to me, things that I had always known through my own experience, but which had never been recognised by anyone in the medical profession before. And I found that... well, it gave me a lot more trust in the two people who were running the course than I've ever had for the medical profession, to be honest, because usually, if it's not been proven scientifically, then what you know through your own experience is just... they don't treat it as valid knowledge at all. I've always known that stress affects my diabetes; always known that. And I've always been told, up until recently, that that's just rubbish. Now I understand why it affects it now, but, you know... And the course also, we had this little board that had... oh, I don't know, because, again, it was a bit of a sight thing for me, but it was a very visual way of understanding how diabetes and the hormones and, you know, what was happening, and how things - cells - were unlocked and all this kind of stuff. But it was a very easy way of understanding diabetes, and the different impacts of alcohol on diabetes, and stress, etcetera. I thought it was a very good course.

You said it was a revolution for you - almost reversing what you'd known before. Was that true for the other people on the course?

I think particularly for one of the other women, who had had it for a very long time. There was some... a younger woman, who hadn't had it quite as long - I don't think it was particularly for her, and I think her understanding of diabetes was quite different from ours. I think, for me, it was really... things that you've just been told as a child but no explanation, but it's just been sort of drummed into you what you must and mustn't do - those sort of things, it was very difficult not... you know, if I didn't want to have lunch, not to eat lunch. I still find... I mean, I couldn't not eat lunch, because you have to eat lunch. And it's still very difficult, that kind of not worrying that... you know, normally, I must have it by a certain time, and not worrying about it.

(15) If you don't want to eat it, you don't have to; it's... yeah. You don't realise how engrained these things are, until you try and stop doing them.

Can you talk more about the effects of stress, in your own experience throughout your life, and what you learnt on the course?

Well, I've always felt that a small amount of stress and your sugar levels go lower. A large amount of stress and your sugar levels really soar high. Now, I've kind of known this... I've known it as long as I've been aware of being stressed, and I have to say that my awareness of stress levels has certainly increased since I've got a visual impairment, and I do get stressed. Particularly, I travel an awful lot, and I don't enjoy travelling. And, you know, our train services are rubbish, and I have to rely on booking assistance ahead of time, and quite often it's not there, and then suddenly you have, you know, an unannounced stop and you've got to all change trains. Things like this, I find extremely stressful, and

my sugar levels just soar after that, and it takes quite a while to get them back down again. And as I understand it, it's a bit like the sort of fight or flight thing, and adrenaline is produced if you're that stressed, and that pushes your sugars up... yeah, basically.

Had you mentioned this to medical staff before you went on the Insight course?

Yeah, but it had never really been... people didn't seem to regard it as an issue. Some of the things that I've found... you know, it's like I have neuropathy in my feet, I have a sight impairment in my eyes, I have a heart condition, and I'm diabetic, but that means you have four different medical people looking at you. And I've been, at times, where different... you know, it's not just that they're in different hospitals, they're in different parts of the country, and even, at times, when they're in different countries. You know, you're never seen holistically. And for the first time, during this course, I understood... you know, I was talking to people who seemed to understand you as an entire person, and they were looking at all aspects of you, and that, for me, was, well, very positive.

Has that continued since the course ended?

Well, not quite, because since the course ended, I had to go and see a heart specialist. Now, I... you know, you end up feeling that you're kind of stupid, because you don't know the connections between heart problems and diabetes. But I've not had them ever explained to me. They weren't explained on the course either, particularly, but I do think that people on the course perhaps didn't like going down the "what are the complications?" road, because I was sitting there with a guide dog. And I think other diabetics find that a bit nervous - they get a bit nervous about it - so we didn't really talk that much about complications. And so, going to see the heart specialist, you know, more or less the first thing he said to me was "well, someone your age, who's had diabetes that length, well, this is what we'd expect". And, you know, he was very nice, etcetera, but, you know, that seemed to be the kind of... and suddenly it's like "oh god, what else is going to go wrong? And why haven't I had this explained to me - why don't I know this?". And, you know, again, he's not really... he was seeing everything from a heart specialist's point of view. So, whereas if I get cramp in my legs, the neuropathy guy sees it from a nerve point of view, he sees it from a heart point of view. And no one's actually... you know, I'm just looking... everyone's looking at it from their specialist point of view, rather than from me as an entire person. I mean, as it turns out, the heart condition isn't particularly much - it's just brought on by stress - but, you know, and there we go on.

(16) So, can you go back to the people who ran the Insight course for this holistic approach?

I can go back to the diabetic specialist nurse, and I've gone back to her since the course. I've seen her at the clinic - I arranged to see her once before I saw the consultant - and I phoned her a couple of times. And it's very good to talk things through with her; things like changing... you know, if suddenly your...

I mean, for my example, I suppose, was my sugars were always high in the morning. And it didn't matter how much long-acting I did in the evening, my sugars were high in the morning. So, we worked out a way of dealing with that over the phone, and now they're fine. And it's obvious, once I started talking to her, what I should be doing, but it's good to have someone who knows about it who you're talking it through with.

What would be your ideal way for a diabetic patient to be treated?

Well, I'd like to be able... you know, if I... I now have quite a few complications, having had diabetes for so long, and I would like to be able to go to one place and see a specialist who could... you know, who saw me holistically. And I would like - like I can with the diabetic specialist nurse - to, you know, phone up and discuss it with her. But I think she, personally, is an exception, because I have had contact with other diabetic specialist nurses in the past, and I have always felt that I know more about it than they do, and, in fact, they've often said that I know more about it than they do. And that, I don't feel, really fills me with much confidence.

Can you describe a typical day in your life now?

Well, I suppose I'd have to give two typical days, because one would be where I'm working at home and one would be when I was travelling. If I'm working at home, a typical day is to get up about six thirty or seven, test my sugars, do twenty four units of Lantus, eat a bowl of All Bran with half a banana and skimmed milk and a cup of coffee, and do the appropriate amount of NovoRapid insulin. Take a whole load of pills: I take... oh, I take some for heart, some for blood pressure, some for kidneys. I take a lot of pills - some for thyroids, Amitriptyline for my legs, Simastav... oh, I can't remember all the names of the pills. Anyway, then I have breakfast, have a shower, go out with my guide dog. Because I know where I am, I need to work my guide dog when I'm in crowds of people more than when I'm in the rural area, so I take him for a walk in the mornings. Come back. And then, for most of the day, I'm sort of answering telephones and writing reports, so I'm very much at the computer. I go out for the... At lunchtime, I'll probably have a piece of bread, hummus, something like that; do insulin - NovoRapid insulin again. And then, in the evening, take the dog out again, have food - something like a bowl of pasta. I don't eat meat, and try not to eat too much dairy products, but eat quite a bit of fish, pasta, rice, and do insulin accordingly. Have a few glasses of wine, and then do more insulin, last thing at night, of Lantus.

(17) And what about a travelling day?

Well, usually I'm travelling from here into London, and that involves... can be quite an early start. And so, it's the same sort of routine, to do with my insulin, but my sugars can - or do - have a tendency to go very high in the mornings, if the journey hasn't gone well or if I've got a very stressful meeting, or something that... you know, I'm going somewhere I haven't been before. I find that quite stressful, from a visual impairment point of view. And so, I quite often just have



to do insulin to bring my sugars down, and not really bother with lunch. And then the same for the train coming home. Yeah, that's the only difference, really, in terms of the insulin I take - my sugars tend to be higher on those days.

Do you need to have emergency rations with you?

I always carry glucose on me and some biscuits.

What have been the main changes in technology that you've seen over the time you've had diabetes?

The blood monitoring equipment is very good. I've just received a new one, which only takes five seconds to measure your blood. I've got all sorts of equipment, so I can do diabetes management software on my computer. So, from the monitor, you know, it can give you graphs of various descriptions to see how your diabetes is, and the patterns of your bloods sugars, and what have you. So, I think that's been a huge change. Obviously, there's also been a huge change in the delivery of insulin. I used to have to... you know, as a child, there always seemed to be pans of things boiling to keep syringes and needles clean, and... Whereas now... one of the things I learnt on the course was that I should change my needle far more than I do. And I still don't do it enough, because I was brought up that needles were these really, you know, scarce things that you... and you used about five needles a year, and you just circulated them round, sort of boiling them all the time. And I was using a far too big a needle, apparently, when I got on the course, and I'm now using a much finer one. And, you know, I said I changed them when I changed the insulin cartridge, and this sort of shocked everybody, because apparently you can change them every time if you want. But I still have... because, then, I had to buy them. The only time you... at first, when you got needles - the sort of new plastic things - you had to buy them, and it was only when they changed the law, so that junkies could get needles if they had HIV and things, that we got needles free as well. So, in my life, it's been relatively new to be able to sort of be so free with needles. So, anyway, that's been a big change. But the actual syringes - these pens - are very, very different from the old way of drawing up. It makes, actually, quite a big difference in your life, because I can be in a restaurant - I don't even have to go to the loo to do an injection, they're so small and discreet. You can even do it through your clothes if you have to. And that's a huge difference from sort of, you know, knocking a glass and metal syringe to get the air bubbles out, et cetera.

(18) And have you observed any differences in the way medical staff treat patients over the years?

I don't know whether it's a way... because, if I think about the times that I've been in hospital - and I have spent quite a lot of time in hospital, for various reasons - I can't say that I've really noticed a huge change. I think some medical staff have really changed the way they treat patients, but others haven't, and that's all I can say on that, really.

What about changes in the National Health Service?

Well, there weren't, as far as I'm aware, diabetic specialist nurses when I was younger, so that's been quite a change. I don't know how much of it is a change from the actual medical staff, or how much of it is a change from me in what I expect. I'm much more demanding than I used to be, and I expect people to treat me as an equal. My title is Doctor, and I use it a lot in a medical situation - not a medical doctor - because it gets me respect in a hospital, which I think is rubbish - I think every patient should have respect! But I do think it really makes a difference on whether or... on who you are, whether people treat you with respect or not. I think, as a white middle class woman with the title Doctor, I get a lot more respect than an elderly Asian woman would get.

What about changes in organisation - things like waiting times?

Well, sometimes... well, no, not real... generally, you still wait a long time, and you always have done. Hospitals are places where you sit and wait.

And have you noticed any changes in attitudes to diabetes in society over the years?

Well, I think, because I never felt... as a diabetic, I never really felt particularly discriminated against, or that people had sort of strange attitudes about me because I was diabetic. But then, I quite... I do a lot of training around disability equality issues, and sometimes, some of the things that people say around diabetes - I mean, now - really staggers me. I mean, one group - and they were actually health... they worked for a health authority - said that if they had somebody with diabetes working with them, they would want somebody shadowing them all the time, in case they went into a coma. And this was only recently. So, although I feel that, you know, generally, as a diabetic, it's a hidden impairment, and it is very, very common. I suppose, because diabetes is more and more common - and it's common, as I understand it... it's more common in type two... sorry, that type two diabetes is increasingly common because people lead unhealthy lives. Now, this is very, very different from type one, and I really resent the fact that all the time we hear about type two diabetes, and people think I'm diabetic, and do they see me as leading a very unhealthy life and it's my own fault? That really bugs me. Also, it bugs me, because type one diabetics is also... there's more of us around. But that's because, in a way, it's because we're a success story, and there's more of us having children, and there's obviously a genetic factor, as I understand it, in type one diabetes. But all the sort of the general public's understanding of diabetes - and the more that we hear - is generally about type two diabetes, which I think should have a completely different name.

(19) Do you think people discriminate, at all, against people with diabetes?

I think they do. I think there's a general level of ignorance around all impairments, and diabetes isn't an exception. I think people have a lack of understanding of the barriers that people experience, whether they're organisational barriers... One of the things I used to find very difficult was always being the one having to say "I need to eat", and people automatically think it's because you're greedy.

I think, examples in... work I've had as a student, where it was important that I had my lunch breaks within a normal - what's seen as a normal - lunch break time, whereas, as the newest student, you should have your lunch break either very, very early or very, very late. And people not understanding that it's actually, you know, a real issue. People wanting to have... now, you know, there are a lot of things like people wanting to have breakfast meetings, people wanting to have lunchtime meetings. I was invited to a lunchtime meeting where there wasn't food provided. And these things... you know, okay, now I'm on this new diet I don't need to, but, you know, a) I think it's not just diabetics who need to eat at certain times, but these kind of... You know, food is increasingly an issue for everybody in our society, and for diabetics, you can be made to feel that you're just some kind of greedy person. I know I was witnessed eating something the other day in the town, and I was hypoing, and I just went into the shop and just bought the first thing, because I didn't have any glucose. And I felt terrible eating it in public, because, you know, you're not suppose to be seen to be eating these bad, unhealthy things, but, you know. And people don't... there's just a lack of... there's just sort of an ignorance around.

And what about discrimination surrounding visual impairment?

Well, I think people don't understand that diabetes can cause other issues. I mean, they might have some kind of vague idea that it can cause blindness, but most people seem to think that you're born blind. And I think, you know, there is a huge ignorance around people with an obvious impairment. People assume that you're not working, people assume you don't have children because of your impairment, and that it's a good thing, people assume that you're stupid. As a visually impaired person, people seem to think I'm deaf as well, because quite often they shout at me. And yeah, just general level of, again, not understanding the kind of barriers that you encounter on a daily basis, that can be through other people's ignorance, through sort of real physical barriers - like steps with no clear sort of notice that they're coming, road works, where you suddenly find yourself... the pavement stops and you have to go into roads - and, you know, transport is a huge issue.

(20) How do you think your life would have been different if you hadn't had diabetes?

Diabetes is kind of central to who I am, because I don't remember not being diabetic. To talk about not being diabetic would be to say to somebody "how do you think it would be if you weren't white, or if you were black, or if you were a man or a woman?". And, you know, it's part of who I am.

What keeps you going?

Well, I think... you know, as I've been trying to sort of say, I do have a political understanding of my position, and I think that's very helpful for anybody who has any kind of impairment. I don't think... I don't blame myself for my impairment; I blame society for the barriers that I have to overcome, because people don't treat you equally. But, on the other hand, you know, this is my life,

and, you know, it's a lot easier than some people's lives, and, you know, what keeps anyone going?

Can you spell out a bit more what you mean by a political understanding?

Well, I suppose I mean that, you know, we all use words like disability and impairment, but historically, they have a very different meaning in different times and in different societies. Our understanding of disability, from Ancient Greeks right through to the Middle Ages, was very much from a religious concept, and that disability was something that happened to you if you were evil; if, you know, you were the spawn of the devil or something. And then, from the Industrial Revolution times, it was very much a medical understanding, where the body was the focus of attention, because there were huge, huge changes in medical understandings of disability. For various reasons, disabled people became separate from non-disabled people. People with epilepsy were put in special homes. People - you know, cripples, etcetera, etcetera - we became very separate from non-disabled people. And it was really only in the 1960s that disabled people started arguing that we should be changing society, rather than changing disabled people and concentrating on some kind of quick fix cure. You know, if you look at the history of the human race, people have altered and changed their environments to suit themselves, you know, since time began. You know, we don't walk through rivers - we build bridges, etcetera; we can't see in the dark - we put street lights up. But when it comes to disabled people, we're constantly trying to change them to fit into society. And a social and political understanding of disability would mean that, instead of trying to change the people all the time, we would be trying to change the society, so that they didn't have to feel different, and that they were accepted for who they are, rather than for what they can't do. So, for myself, as a woman with a visual impairment, it's about making sure that everything is in an accessible format for me. That hospitals... the local eye hospital, I stopped going to it, because it was so badly signed, you got lost every time you went there. You know, they could have done a lot of things for people with visual impairment, to make it easier to move around the hospital. This isn't my fault, because I've got a visual impairment. It's the hospital fault for not addressing their access policies.

(21) Is there anything else you'd like to say about your experience of diabetes?

I think one of the things I learnt from doing the course was that I have always thought that diabetes is no big deal. Okay, I lost my sight through it, but, you know, it's like it hasn't had a huge impact on my life in some way. But then you start thinking about the amount of time I spend every single day thinking about it: thinking about, you know, what my blood sugars are, how they're going to be affected by doing certain things - if I go swimming, will, you know, where will I have lunch? Will my sugars go too low? Have I got glucose on me? - how to work out the certain amount of carbohydrate if we go out for a meal. You know, you do spend an awful lot of your time thinking about it, and it's so much part of you, though, that you're not even aware. Until I did the course, I wasn't really aware of how much time I actually spent thinking about my diabetes, because I

don't remember not think... you know, it's just part of my life.

Have you got any message to someone newly diagnosed with diabetes?

Just try and find out about it as much as you can, so that it fits into the way that you want to live your life. It doesn't have to be the end of the world, but you do need to be able to manage it so that it doesn't take over your life.

And can you talk a bit more about the emotional effects of having diabetes?

Well, I think there's two ways of looking at that, really. I think, as a child, it was... I think I was always seen - and, in fact, I was talking to my sister about this the other day - I was always seen as the difficult one, even though, when you look at it objectively, I actually did everything pretty normally and straightforwardly, as a child, compared to some of my siblings. But I was always the sort of difficult one - the one, as I said before, you know, not wanting to do injections and things. And I don't think I have a very good... a healthy attitude towards food, in terms of, I eat what's on my plate, I don't think "am I still hungry?". I was always very much... everything was weighed out, and I had to eat everything that was on my plate. And I still have this kind of like, whatever size portion's put in front of me, I eat it all! And I think that's from, you know, years of having done this. And then, as a teenager, being overweight - I think for teenagers, particularly, there's issues there. But, I think the most sort of emotional stuff for me is how you don't know whether you're actually feeling in a bad temper and uptight about something, or whether or not it's because your sugars are high. Because, when your sugars are high - or for me anyway - I feel very irritable and uptight, and feel like screaming, quite often. And so, you're not really sure whether it's... you know, how you make that distinction between whether it's you, because it's still you with your sugars high, or whether it's an actual sort of physiological reason that's making you feel like this. And I think that's very difficult. And I think for partners of people with diabetes, that can be very difficult as well. I know, if my partner says to me "oh, are your sugars high?" after I've just snapped, then I just snap even more. And I think it can make you, you know, a pretty difficult person to live with, because, as I say - or low sugars can make you feel irritable as well - so, you're not always sure why you react in a... you know, is it for an emotional reason or, you know, is there a sort of a physiological reason behind it?

(22) And do you talk to doctors and nurses about the emotional effects?

On the course that I did, we did slightly touch on the emotional effects, but it was really about the difficulties, as I said before, about doing things that you'd all your life not been able to do. But generally speaking, certainly throughout my childhood and up until my sight problems, really, I would say that the majority of the times I had anything to do with anyone from the medical profession, it was lying to them, because even when you were an adult, you're treated... if your sugars... I mean, even last year, when I was having an operation that was nothing to do with my diabetes. I was in the hospital, and the anaesthetist came to see me, and there was a packet of Dextro glucose on my bedside table, because

my experience is that if you're in a general medical ward, they'll know nothing about - no, sorry, I was in an orthopaedic ward - and they would know nothing about diabetes, as they didn't. So, I took glucose in in case I hypo'd. Anyway, this anaesthetist came in and said to me that he hoped I wasn't eating glucose, because, as a diabetic, I shouldn't eat it. Now, this is like, you know, after forty odd years of being diabetic, and they still treat you like you're a child. And, you know, if your sugars go high in hospital when you're very stressed, they say "have you been eating Mars bars?" or whatever. And so, that kind of... you lie to the medical profession. You lie because you don't want to be told off, you lie because you've been forced to act like a child, because they're treating you like a child. And I just think the majority of people with diabetes, I would say, lie to the medical profession, because they're not being honest with you, they're not treating you like an adult, if anything goes wrong, you're the first one to be blamed - must be something that you are doing that is wrong. So, you know, it kind of fosters this distrust, if you like, between the medical profession and diabetics.