

59. Husne Ara

(1) Tell me about your background.

Both of my parents are from the farming background, and I think my father is the, probably the first person who went to university, and he was a vet. My mother was always housewife.

How many brothers and sisters did you have?

We have three sisters and two brothers. And all my brothers and sister actually have education while... they finished their education, except me. I was married only when I was sixteen, so.

So, you stopped at sixteen?

Yes, I stopped at sixteen, but when I came into... I came into this country when I was seventeen plus, and I'm just did... not a sort of like education-wise to look at doing the degrees, or anything like that, but some sort of like English courses, and necessary courses, we needed to do in my job.

Why did you come to England?

As my husband went to Bangladesh looking for a bride, and my father, sort of... because it was arranged marriage. And this is the way, in our country; the culture: girls get married arranged. So, I had to come and join here my husband, because he was living in England.

Did you have any experience of diabetes before you came to England?

Yes. When I was ten, in 1963, my father was diagnosed diabetes. And it was diagnosed very unusually, because it was the day of my sister wedding. He actually collapsed in their wedding ceremony. And when he was taken to the hospital, and following day the doctor said "he's a diabetic". So, it was quite shock for us to know, which is quite horrendous. My elder sister was getting married that day. And first of all, we thought maybe the stress, in that he actually collapsed, but we later found out he was a diabetic. He was actually in hospital for nearly ten days, so it must have been very serious or severe that time.

And what was the reaction of the family?

My mother completely broke down. She sort of said... because, we were... although my father was a vet, I mean he did have some experience with medical, because to be qualified a vet, you do the same qualification as a medicine doctor. But I think we were not aware of what is diabetes, then, and my mother immediate reaction was "my God, your father going to die soon". And what I can remember, it was very frightening. For ten days, he was in hospital. It was sort of like, now how's something as seriously has happened. And I remember, sort of like, crying in the night time, crying, sort of, "my God, we're going to be fatherless in few months or few years' time". So, it was quite frightening to sort of like know he's a diabetic. And I think reason we're frightening, because way it

was found out. It was not, sort of like, a small something. He collapsed and he fainted, and he was taken to the hospital. And that was the frightening thing.

What would you say was the attitude to diabetes, of people in Bangladesh, at that time?

If I compare to now, I think that time, the diabetes... people... it's not with the diabetes. In Bangladesh, generally people with any illness, and people think you are very ill, you're seriously ill. Even if somebody has asthma, or similar kind of illness. And so, diabetes was, that time... I think, still now, people think this is a serious illness; they still have that kind of attitude.

- (2) The diabetes is... people doesn't feel shame, or people not afraid to tell you that they've got diabetes. And, it's like in Bangladesh, the attitude is: any illness is serious, doesn't matter what it is. And immediate reaction of what the family members try to do, sort of like: "oh, that person has got diabetes" or "that person has got asthma, we have to look after him, you know. He can't able to do anything, you know". So, it's like, every little job has to be done for them, because now it's actually like this person became disabled, now. So, I think the attitude is same what it was when I was younger, then.

What was your father's treatment?

What I can remember, I think he came home after ten days. And he sort of like told us that it's nothing to worry about. He says he's got sugar in his blood, his sugar is more than what should be, and from now on he just has to be careful what he eats. And he was actually quite overweight, that time, and my father used to love sweet food. So, he sort of said that "from now on, I cannot eat sweet any more, and I have to eat chapatti for the evening meal. And I have to take some medication, and I should be all right". So, he basically told all of us what it is. And I think, from that day, I sort of like wanted to learn about diabetes. Because, for ten days, when he was in hospital, a thing was going in my mind: "is he going to die? What is diabetes?", I mean. And after, he's sort of like gathering family together and explaining them "it's nothing to worry about, I'm going to be all right. These things I need to do, and I want all of your help to just help me to... if I can continue".

How did you help him?

At the beginning, I think - my mother is a very strong person - so, I think the first thing I remember what... At the beginning of his diagnosed diabetes, I actually... I started disliking my father. Reason was that the sweet thing was not coming into, any more, in our house, and my Mum was not cooking any sweet food any more. And plus, because we - Bengali people - we are... our staple diet is rice, rice. So, we eat rice twice a day. So, here goes the rice in the evening - everybody should have chapatti. 'Cause my mother idea was that, "I don't want to serve something on the dinner table which your father cannot have". So, I sort of like beginning disliking my husband... my - sorry -

- (3) disliking my father's, why he's got diabetes for. Because of him, we cannot have sweets now, and we cannot have rice in the evening - we have to have a chapatti. But, I think, because I was only ten. And then the later, I learn more about diabetes. My father was very good: he always used to talk to us, always used to explain to us things. And then I understood: yes, it is for the best for him, so. And it's probably best for us as well, so I think I did accept it at the sort of like... but it took me quite some time to accept it. And, soon after, it was one of my duty to see if the chapatti's ready in the evening meal time, and make sure he doesn't sneaks any sweet in between his meal, and he doesn't... He used to take lunch to his office, and we made sure that his lunch is enough for him, and he has a snack in between. So, I think I took, sort of like age ten, from that onward, I just took some responsibility for it.

And did he manage by diet and tablets alone?

I'm not very clear about his initial treatment, what it was. But I know he was taking some tablet, because he had blood pressure as well. So, he was taking... first few years he was taking his tablet, and I can't remember what tablet it was. And then, he moved in taking insulin, few years later. 'Cause he was a member of diabetic association in Dhaka, so... this only place, I think, that time, you used to get your annual reviews and your diabetes care. So, I used to remember my father's travelling to Dhaka every six months, because from where he was living and Dhaka - we used to live in Sylhet that time - so distance was quite a... it's nearly half a day travelling by train. So, I remember that he used to say "I got appointment with my doctor in Dhaka", and we used to think "why you have to go to Dhaka, you know, it's such a long way?". But, that time, it's only diabetic centre existed in Bangladesh.

- (4) When he started insulin, the frightening thing was most of all when I saw the needle. It was quite a long needle, and those needles - if I think about it now, compared to these days - I think just looking at those needles was horrific; silver colour long needles. And then, not even was thin. They were sort of quite chunky looking with the glass syringes. And what I... when my father took his first injection, I was actually standing there. And he didn't even say "oh"; he didn't even make a sound. And I thought "my God, how brave he is". So, I didn't... I don't take... care take... giving injection from... I think, not until I was twelve, thirteen. I think the reason: I was very close with my father, and he always tried to teach me things, because I was interested. And my other... my elder sister, actually, out of that, because she was married by then, and she was living with her husband. I'm probably... I was the only child who was there. Not adult, but aged twelve, thirteen, you know; I understand things a little bit better. So, probably first few months, I just watched how he was taking the insulin. And the insulin he used to take is the two cloudy and... the clear and the cloudy one. And I used to remember his mixing, how he was mixing the insulin in there. And I used to ask "Dad, what happened if you

take one more than other?”, because I don’t understand what the ratio is, what I do now. And he used to say “if I take one more than the other then I’ll probably have problem with my diabetes. My diabetes would be non good control”. Taking the insulin: funny thing is, I used to remember actually taking... he used to take his insulin his lower part of his leg. And this what I know that still some people - in Bangladesh - people doing that. But in here, we do not advise that, you see. But those days, the patients were told you can take any part of your leg, the insulin, as long as you’ve got a muscle. So, he actually used to take it in lower part of his leg. If I think back now, I say “my God, what was he doing?”!

And you actually did the injections for him, sometimes?

Sometime I did, yeah. Sometime I did it. And as I was getting better and better, and he used to say that if I give him the insulin, he feels much better by taking it himself. I don’t know why he used to say, but we actually tell patients now, that if you take it yourself, it hurts less than if somebody else does it for you,

- (5) when we encourage to take their own insulin now. But I think my father was more, sort of like, relying on me. And that... maybe that’s the way he was finding the comfort in it - his illness - and he’s probably sharing with somebody. Because my mother completely withdrew herself from that treatment side. Her side was just to look after his diet, and how he should be taken care of. But as soon as - I remember - as soon as she used to... my father used to take the syringes out, and she just used to close the door and just leave the room, you know - her attitude. And even until my father’s death, it was the same attitude. My mother’s attitude is that she’s not interested to see what he was doing with the insulin, you know. And, I tried so many times to tell my Mum, “Mum, what happens if we’re not here, you know?” And still I don’t understand. If my father was still alive, I could have asked him now, that why did he rely on other people to give his insulin? I mean, why was he not interested in taking it by himself? You know, I never asked him that questions, but I think it was because I felt like, as a daughter, I should look after my father. And I was the only one there who can do this; my younger sister was quite young, at that time. And maybe it’s a part of our culture is there, that parents sort of think the children should look after them.

So, how did he cope after you married and came to England?

Then, my younger sister, who was bit older then, and she was doing... helping him, as well. And then, when I used to go back to Bangladesh every two years, I used to encourage him to: “Dad, just do it yourself, because my sister will get married soon, and she will leave, and you will have no one. And Mum is not interested at all, so you just have to...”. And he used to smile, and sort of say “yes, I can do it, but it’s better if somebody else does it for me”. And I said, “really, Dad, can you just do it?” He said “yes, I can do it”. So, I think I sort of like teasing him, and telling him “all right, Dad, can you just take it

in front of me now? I'm just sitting here. Just do it, and see if you can do it". And he used to laugh, and used to say "listen, I'm just a vet, doing things, I can't take insulin myself". And so, I think, when my sister got married, when she left home, he was doing it himself - definitely was doing it himself. I hope so, because I was here, so I don't know!

What was the supply of insulin like, and also of needles?

The insulin wasn't... I think, that time, insulin - it was supplied from the diabetes centre, or the big pharmacies. But it used to be collected from Dhaka, I remember, or big city; not from smaller, sort of like, in a corner pharmacy, like that. And there wasn't any problem then. But few years... when I came into this country in 1970, and when I used to go after that, and my father used to say that... I think it's after the independence, because we had independence in 1972. And the country went to chaos, you know, and a different government came in too... And there was a problem of finding... problem to get insulin from the street, from the pharmacy. And at one point, I think father was buying insulin black market. And he actually once asked if I could send him some insulin from here, regular basis. And I just told him it's not possible, because I need to have a prescription from here, and to buy privately from the pharmacy is very expensive. But then, they managed. In our country, what happens: you manage everything, but it's with a difficulty, you see. But now, it's really good; everything is available. But I think, particularly last... soon after the country was independent - five, six years - it still quite difficult to get everything - what do they say - in order.

- (6) My father used to tell us that the centres - the diabetic centres - in Dhaka, that usually insulins are given free. But, I'm not sure if that was right or not. But he said those insulin used to... sold in black market - those insulin he used to buy in the black market, he used to say "these are the insulin should have been given free to us, but we had to buy it from the outside". But I'm actually not sure, myself, is the correct information or not. But, we definitely - I know now - we do get some medication free from European country for the third world countries, so maybe those are the medication was selling outside.

And what about the supply of needles?

He had a little box. I remember it was a silver colour; a stainless steel box. And he had two syringes and six needles in there. And, I think those six needles, he used for years and years, I think. So, what he used to do, he used to sharpen them in a bit of... it's like a knife sharpener thing, little gadget things, where you sharpens your knife. So, what he used to do, he used to sharpen every time, after the insulin - I used to do that, give the insulin - he just sharp the edge. And then, you sterilise it in boiling water, and just put it back into this cap again. And also, the syringe was a glass syringe with stainless steel tops, and you just pull at the bottom. And we used to sterilise those as well, after using, every times. So, there was quite extra work. I think that's what we were doing

for him: just helping with those sides. And also, I remember that he used to test his urine - not sugar - that time. And that was a bit of a job as well, to test the urine as well. And what you do is, this spirit lamp, he always used to use, and you just put urine in this tube - glass tube - and you used to put some solution in there. And then you heat this tube on the top of the spirit lamp. And, after few minutes, if it becomes like a reddish colour, then you know diabetes is not good, and if it is a blue colour, then your diabetes is good. But, I actually don't know what percentage of sugar, how do you work out that, then? Because I is not quite... understand how... So, what I used to do, I used to do it for my father, and take it to him, and say "Dad, this is the colour it is, you know". And then he used to say "yeah, my diabetes is good". But, these days we can actually tell the measurement - how much sugar you have there, you know. But I never understood how he used to understand that, himself.

Was he still testing urine, rather than blood, when you left in 1970?

Yeah, he was testing urine until 19... I would say 1977, '78. I think I was the first one to send him a meter from here. I remember, it's a Refolux meter. And then he was testing his blood from then on. Otherwise, he was using spirit lamp with the solution. Not even dye sticks, no!

(7) What effect did your father's diabetes have on the family?

When, initially, he was diagnosed, our immediate thought was "how long our father going to live?" I mean, that was obviously... anybody... because he was the breadwinner in the family. But once we sort of like established, you know, this diabetes is for him for the rest of life, but he can work, and normally there is no problem. But, in our country, I think, if you have got somebody, anyone who has got illness whose medication need to be bought all the time, there is a struggle with your financial side, because it's not free; treatments are not free there. And diabetes is one of the treatment is not only for couple of weeks. It's not like antibiotic - you just taking a two weeks' course, and it's finished. This is going to be the rest of your life. And, also, you sort of think the diet side, you always need to be careful, you know. Nutrition diet has to be provided for this person. It's not that we do not have nutrition diet, but I think people used to have this idea, before, that if you're a diabetic, you have to buy special diet, and special food. This person has to eat meat, fish, all the time, you know. And the diet was... diet-wise, we were not that worried about. But what my parents, both my parents found, struggling just keeping the... buying the medication, because you need the medication constantly, all the time. And we did... I wouldn't say we had very hardship, but some hardship we actually experienced, because part of my father's earning would go to buy his tablet, his insulin, and his urine testing kit, and all those things. And so, we had to sacrifice a few things in our own life. So, like the school outing - because we were five sisters and brothers - and it's sort of like, "all right, one of you can go this year, another one can go next year". You know, it sort of occurred like that. And I, especially, I remember that I wanted to go to this picnic. And my mother first asked how much it was going to cost, and I, sort of like, was in tears: "how

dare you ask me this”, you know. And when she heard this is... and it was a trip where you stay couple of night out as well, so she said “no, I can’t afford it. If it was a day out, then you could have gone, but I cannot afford it, because of this”. And, it wasn’t a very big deal, now, if you think about it. For me, that time, it was a big deal. So, you think, “because of this, I cannot go on my school trip”. So, it sort of like affected all of us, you know. We did accept it, at the end, because it was best for my father, you know, and we had to accept it. But it was hard; it was hard, yeah.

- (8) Even now, finding money for the medication is hard for anybody diabetic in the family. So, my Mum is getting my father’s pension now, at the moment. And even... I don’t know how I put the ratio is there. The medication... if, for example, if I give an example: somebody’s monthly income, say, three hundred pounds - I’m just giving you just example - if somebody’s monthly income is three hundred pounds. If you’re a diabetic, a hundred pounds will just go on to the medication. So, medication is expensive. So, can you imagine this medication you always have to buy? And it is very stressful, that you have to actually economise in other way, on other things, you know. Spending - you need to be, sort of like... where you’re spending, you have to cut back in other things as well. And it’s really hard. And one of these... When I went, this year, into Bangladesh, my Mum was taking less than her medication. I asked her “why are you doing that?” She said “I’m sorry, I cannot afford it”, you know. And it’s really heart-breaking. ‘Cause we’re a middle-class family, and all of my Mum’s childrens are well off. And so, even she’s thinking that way, so what effect it happens people who are in even lower income than ourself?

When was your mother diagnosed with diabetes?

Fourteen years ago. Soon after my father died, she was diagnosed. I don’t know, maybe she was a diabetic before then. But I think she probably noticed herself, she’s not feeling well, because she looked after my father two years. My father was blinded last... partially blind two years before he died, and he was completely blind six months before he died. So, my Mum was constantly looking after him all the time, last two years of his life. So, maybe she was diabetic before that, but she was officially diagnosed fourteen years ago. I actually find very difficult to understand. If I talk my mother is... she - this medication - she knew... she knows that without her diabetic medication taken regularly, the diabetes will be not good control. And she actually was lying to us by saying that she’s taking the medication. And what I found at the end is not... reason she lied, because she cannot afford to buy full medication every month with her earning. And she’s very proud lady; she doesn’t want help from the others. But I think there’s thousands and thousands of stories like that, in Bangladesh: people who want to buy medication, and they can’t because of the income, low income.

- (9) Tell me about your life after you came to England in 1970.

I came in 1970, and... I think July 1970... July; 16th of July. I remember the day very clearly. And soon after I came here, I did some sort of like English classes, language classes, just to... preparing myself to go out for looking for a job. My first job was in - I don't know if anybody remember that - it's... they used to make TV, radio, records - called Decca. And it was very interesting work. I used to assemble things there. This was my first job. Then I left, then, when I was pregnant with my eldest son, in 1973. And my younger son was born within... a year after that; there were only fifteen months' gap between them. So, I didn't go back to work, because to give two young child keep in the nursery, it was very expensive, then. So, I decided to stay home, and I stayed until sixteen years, until my sons went... my youngest son finished his A level. Then I was looking for a job again. And, when I was looking for a job, and because I didn't have any qualification, I didn't know what I was supposed to be doing. But while I was actually staying home for sixteen years, I did lot of voluntary work with the Bengali people, who couldn't speak English. So, I used to like, sort of, helping them going to social security, or hospital appointment. It was just part of my voluntary work, I was doing. And it was very interesting; I found that I could help people in lot of way. And I did accompany couple of people in the hospital, as well, and hospital work's always interested me. I think the reason hospital work always interested me, because, when I was young, I was growing up, one of my ambition was to be either nurse or teacher. I never thought I going to be a doctor, but the nursing... because I always admired nursing profession - nursing and teaching profession - since I was young, and I used to admire. So, when I was doing the voluntary work, I accompanied a few people in the hospital, and I seen... when I was interpreting for them. And I found very interesting - sort of, people who can be helped health-wise. It's not only interpreting; teaching them, as well, with the health issues. So then, after I was looking for if I could find a suitable work, and then one of my friend 'phones me, says "somebody's on maternity leave". Would I like to work for six month in the child health centre, so working with health visitor? And immediately I took the offer. So, I went there. It was

- (10) in Tower Hamlet. And it was a very big clinic. Very interesting, fascinating work. Although some people will say it's only interpreting, but I found so fascinating, working with the young mothers, and talking about the health issues. And those mothers who wouldn't speak English at all, or doesn't read English. So, I worked there for six months, and that job was only for six months only. And during that work period, the job I'm currently doing became available. So, they was recruiting link workers for the Bengali population in Tower Hamlet, with the Royal London Hospital. And I applied for the job, and I got interview. So, when I went for the interview, and I was... I didn't know I was supposed to be working with the diabetes. They did not advertise that; they only advertised for the general link worker, who would be working with hospital doctors and nurses, and the community. So, when I went to the interview, and I was selected for one of the link workers. They were recruiting eleven of them,



and I was offered the job. And in my interview period, one of the nurse was there - she was a specialist nurse in diabetes - and she sort of says "congratulations, Neara. We actually can offer you one of the link worker posts, now. But would you mind to be trained as a diabetes link worker?" And I just couldn't believe myself, and I said "my God, this always I want, was interested in diabetes". And I said, immediately, said "yes". After, I sort of said "I don't know about anything about diabetes", and she said "yeah, we'll train you for six months on the job. And you'll be working with me and one other nurse, and couple of the consultant in the hospital as well". So, I was so thrilled about it, and I just couldn't believe myself. I came home, and I still remember my husband... "I got a job, but it's not only that. I'm going to work as a diabetes link worker".

What year was this?

It was 19... The year was 1990.

(11) Tell me about your job.

When I got the job... 'cause I think that, even these days, when you tell people "link workers"... We still have got about eight link workers in our... where I work, and they specialise in other areas. But I think with link worker, people doesn't know what link worker means. And so, even though these days, after seventeen years I've been in the... people in the post, and the link workers not defined the way it should be. What I understand link workers is that you actually link between the patients and the professional. And so, you are advocating patients' behalf, and also you are explaining what health issues should be explained to the patient. Because any treatment, if it not explained properly, people doesn't know why this treatment is given to them. So, that is a link worker's main job is. So, when I've started, it was difficult for me, at the beginning, because I was not... at first six months, I was trained. The training was just to familiar with the diabetes: what is actually diabetes, and the type of treatment they were given, and why the blood... I mean, those days, people rarely used to do the blood testing; it mostly it was urine testing. And blood testing didn't came four or five years after I was in the post. So, basically, this explaining people why the particular treatment was given to them, and why they have to take the tablets on right time, and the insulin - why they require insulin. So, first six months, I was trained. Trained meant I worked alongside the consultant and the specialist nurses and other health professional who had to do the diabetes.

So, this was all hospital-based?

It was hospital-based. My job was actually for the community, but the training took place in the hospital all the time, so I was mostly in the hospital all the time. And because I didn't have any medical background - qualification - they used to be very careful. So, I remember my manager, who was a specialist nurse, that time, and she was... not concerned - she sort of think, somebody who hasn't come from the medical background, how will I learn about the medication? And

I need to know how the medication works, and all those thing. And she was... I mean, I think what I am doing now, at the moment, I actually owe it to her - the way she taught me, and that made easier for me to learn. And I'm actually doing the work now. And what she used to do every week, end of the week, she used to have a five questionnaire for me. And she used to ask me these five questions, and see if I learned correctly. And that actually helped me quite a lot.

(12) And then, what did you do when your six months' training had finished?

When the six months' training finished: beginning, actually, I was not working myself. I was always working with somebody, either interpreting or advocating for the consultant diabetes clinic, or when the nurses were seeing one to one patients. Only time I was seeing my own patients, if somebody came for, say, urine testing sticks, or how to be shown to do urine testing; those sorts of things. But that's not in the hospital. Our first... we didn't have the centre then. We actually based in small office, in that area, near the hospital. And our... 95% of work was in the going to the people houses, visiting people in their house. So, that time, we actually... I starting people on insulin at home; insulin was never started in the hospital. So, when patient used to attend their diabetes clinic, and then doctor thought this patient need to go onto insulin, then the referral used to come to us. And then we used to go to the people houses to start insulin. So, I used to - accompanied by the nurses, obviously. I worked with two specialist nurses, that time - so my work was going with them to people houses, start insulin. And every visit, those nurses I stick to, go back, and I used to accompany them. Because I was never working alone, that time. It was always with the nurses or with the doctors.

And were you just interpreting?

It was... it sounds like just interpreting, but on the same time... For example, in particular one day, if we saw ten patients - nurses sees ten patients that day - probably four or five of them, I will take... they will refer to me, by saying this patient needs follow-up. So, for every day, or every other day, I used to 'phone them, and said "have you taken your insulin? What is your blood sugars? What is your urine testing now? What is the results? Have you taken the correct doses? How is your diet? Are you following the diet? Have you had any hypos?" So, basically, actually taking all those information and passing to the nurses. So, if anybody's having a hypo, or... are they taking their medication correctly? Are they all right with their insulin syringes, you know? So, those sort of issues, I used to relay to the nurses. And I used to go and see them, now and then, by myself, just to see if they're doing the insulin correctly. You know, are they... you know, those time, the syringe... it was not the pen, now, we are using now. Those were the orange colour insulin syringes, and you have to be careful. I mean, when we teach them at the beginning - we used to taught them the beginning - they make sure there's no air in there, you know, correctly to draw the insulin from the vial. So, initially, nurses used to go with me, and then I used to make few visit by myself, just to go back and see if they're drawing the insulin correctly, where are they taking the insulin, and are they doing the urine

testing, what are the results. And used to bring back to the nurses, and just... and then from... if anything was wrong, then nurses would say "no, the urine test is high, the results is high. They need two more units of insulin. Please go back and tell them to do more units". So, actually go in between... go between patients and the nurses.

(13) And then you mentioned that a clinic opened. When was that?

Clinic - diabetes clinic - was running before, but it was running in the main hospital, before. We used to run two clinic a week, I think - just Tuesday and Thursday afternoon; I actually can't remember which it was. The specialist nurses used to go there and help the consultant run the clinics. And I was never directly involved with the clinics, because my work was more in the community. So, we had two nurses: one used to be in the clinic, and another one, I used to accompany her to go and visit people in the house. So, our centre opened in 1993. When the centre was open, the clinic moved into our centre, so... But I was based in the centre. So, from that on, I was more involved in the clinics than before. And slowly, slowly, we actually stopped going in the community - community visit was more sort of like 50% reduced. We started to insulin start in the centre, as well. Other than doctor clinics - there was four... I think, three diabetes clinic was running in the week - and remaining time we used to run our own clinic. We used to call it "link workers and nurses' clinic". And what we used to do there, instead of going to people houses, we used to ask people to come into the centre, and insulin is started then. And also the follow-up one as well. Only people we visited, very rarely, the people who were house-bound, who cannot come by themselves to the centre. But even those ones, now reduced. We actually now, at this current moment, we totally stopped home visiting. Everything happens in the centre.

And what do you feel about home visiting having stopped?

Personally, I feel it's good, because I think that diabetes is one of these condition where people are not disabled. Why do you have to go and visit them at home? And, why we actually encouraging people to go about, every day, go out and do, sort of like, physical activities? So, if you go and see somebody who is thirty-plus or forty-plus, that person, you are actually making that person a little bit disabled. And, you actually giving this message "diabetes is such a bad condition, you can't even go out". So personally, I believe it is very good. You're encouraging people to come out. And another reason, I think, coming out in the centre, they actually see there's hundreds of other people who has diabetes as well. It's not only them who is suffering this condition. So, they actually can see. And another things, we've got all of the resources available to us, all the time. So, whatever the patients require, instantly we can give it to them. I mean, I remember when we used to visit people at home, we had to carry everything with us, and if you forgot anything, they would say "oh, I'll come back again tomorrow to give you this". But when they come in the centre, it's always there, so we don't have to sort of like "sorry, I haven't got it with me. I'll come back tomorrow, or day after", let's say. So, the benefits are, people are... I think the

major benefit is, people actually see this is a centre of diabetes - a lot of people are with the diabetes - and also they are all out and about, you see, so it's good for them, isn't it?

(14) Will you describe the patients that you see?

My job title was Bengali Link Worker, so I was only seeing Bengali patients, Bangladeshi patients. The area I worked, the patients, majority of them from Sylhet district - from Bangladesh, in the district Sylhet. And their education... I mean, their English is... Then - I mean, I'm not talking about now - when I started in my job, the patients we were seeing, I would say 70% of them didn't speak any English at all, and other 30%, although they spoke English, but their understanding was not that brilliant. So, it was very hard for me to... I mean, to explain to them about the diabetes - the treatment - was very hard. And the same time... and reason my part was very difficult, at the beginning: they couldn't understand this person - because I'm not a doctor or I'm not a nurse - here I am giving them advice on this condition and this treatment. And, at the beginning, they actually were not accepting me. They sort of saying... as soon as they heard... Funny thing is, when I used to introduce myself to them, "I'm Husnara, and I'm the link worker", they say "Are you a doctor? Are you a nurse?". When I used to say "I'm not a doctor, not a nurse", they'd say "Hmm". But I have to convince to them that, although I'm not a doctor or I'm not a nurse, but I actually know a lot about diabetes, and I can help them. And they did accept in me, in the end, because I was their mouthpiece, so they used to be open with me. But a few things I found difficult to convince people that their insulin - especially when doctors used to say "yes, so and so needs to go onto insulin, you know, so could you just start them as soon as possible?" And 75% time, we used to get rejection, but saying "I don't want insulin", and "no way I'm going to take insulin". I think the people used to think the insulin is a medication, other than, sort of thing, this is a part of the body you use to put this insulin. So that my part was to make them understand what the insulin is. And that was very difficult for me; it was very difficult, you know. I still find it difficult, but I can do it easily now, because I'm more experienced now. And, I think people are more knowledgeable, now, on diabetes, than when I started my job nearly sixteen years ago. People see more media, newspaper, all this about diabetes and other illness, and the health promotions, you know; all those thing. So, people accept it more. But that time, it was to be very difficult.

(15) You say that 70%, when you started in 1990, didn't speak English. Would they have had any education?

No education, especially the women, the ladies. Maybe they went to school for couple of years in their lifetime, but they may probably have not learned... And the difficult thing, what I found most difficult part, was if we were sort of like writing something for them, that your insulin will be twelve units BD. And if somebody doesn't know what the twelve is, how do you make them understand? And also, the same time, we used to do the urine testing. People used to record in their book, and how do somebody sort of say they're recording if they cannot

write? So, is it negative? Or, what colour is it? What's percentage of the...? Those part was very difficult. And, I actually found quite a few method to teach them to write. Sort of say... What I used to do, there were some dye sticks, or there were colours there, you know, the blue, green, and then it goes that colour. So, what I used to do, ask the patients "do you recognise... although you cannot write the colour, but do you recognise the number?" They used to say "yes, I can write... I can recognise one, two, three, four". So, what I used to do in the report, also in their diary, I used to write "if it is blue, just put one, and if it is darker colour, then put number ten". So, that's the way I found to say... because they cannot write the blue or red or green, but they can recognise one, two, three. So, those were the few easy method I used to find. 'Cause what is the point of somebody... And also the same thing with the number writing: sort of, how many tablet they should be taking. So, if you say "you take two Gliclazide in the morning and you take two Gliclazide in the evening", so it's no point of writing in their diary by saying "two Gliclazide", because they cannot read their medication packet either, so it should be two. So, majority of time we're finding that they're taking one tablet instead of two: Metformin or Gliclazide; sulphonylurea or the other... And what I used to do, sort of like, make sort of like a shape of the tablet, and sort of say... and put number two beside it. So, the large one - Metformin is always the large one - so you take two, or you take one. And what I used to do, sort of like, if it was the morning, I used to put a sun symbol there - the sun is the morning - and the moon is in the evening. So, you take one in the morning sun, and you take one in the evening. And those used to work. Because, it's very difficult, as patient who cannot read or write, but they can understand the symbols.

(16) So, that's how you helped with tablets. How did you help with injections?

The people who used to be frightened taking insulin: way I helped them is just injecting just empty syringe, just taking into my body. What I used to do, I sort of say "just watch". So, we always used to have, sort of like, empty syringes with us, and I just used to say "look, I'm just putting in my leg", or, at those time, we used to advise people to take in the arm as well - what you don't do now. And I just used to take in my arm, in my leg, or in my tummy. And I think people who at least is looking... watching me, and they used to think "yeah, she didn't say anything". My face never showed that it is painful. And that method actually worked 90% of time. Then they sort of say... or I used to say "all right, can I just do it for you? Can I just do the first one for you? Just don't look at me, look somewhere else, or just close your eyes". And I think what used to be the first... what I used to do, not to give them the first insulin - syringes with the insulin - was to just, sort of, let's just try... I remember one particular lady, as soon as she used to see you taking the syringes out, she used to scream. So, that particular lady took me nearly two weeks to convince her, insulin syringes doesn't hurt that much. So, first what I did with her, I sort of said "just close your eyes, just close it. Let me just do something to you". She said "what are you going to do?" I said "just close your eyes". So, she closed her eyes, and I just actually put the empty, just a needle into her tummy, and

just took it out. She didn't say anything. So, when she opened her eyes, she said "what did you do?" I said "I just, you know, put this needle in your tummy. Did you feel anything?" She said "no", you know. So, I think this the way just take the fear out of it. Just, don't just go into the insulin at the start. Just play with them a little bit, you know.

(17) Are there any differences in the ways you behave with men and with women?

When I'm doing group education, the men and women, I always mix their classes. But we do insulin group start as well. So, when I do group start insulin, our Bengali groups, I'll - that time, only time - I'll probably separate women then the men. I'll take the women to the next room. But, for myself, if I have to show somebody... to me, if I see a patient individually - man or women - doesn't make any difference to me; I always treat them the same. And, only thing will be different, the making them understand and giving them example, because I always give advice with the example. And the women will be slightly different way, to make the example, than the men. So, I mean, reason what I'm saying - so if I said exercise, you know, physical activities, there's so many way you can do physical activities. So, the men, I'll probably say "you go to mosque five times a day. Instead of using your car, just walk to the mosque". And the women, I'll probably say "rather than asking window cleaner to go and clean your windows, just do it yourself. And it'll be better cleaned and you'll have exercise", or cleaning the floor, you know, just... That way, I'll probably use different example. Other then, I treat them the same.

How have things changed over the years, over the fourteen years, since the clinic opened in 1993?

At the beginning, as I said, we started seeing patient in the clinic, as a nurses and link worker clinics. Then we started separating the clinics - sort of link workers' clinic. I was seeing patient for the blood testing purpose only, to teach patients how to do blood test. At that time, we are... lots of new machines was coming out. People were... we were encouraging people to do the blood test and the urine testing. And so, sort of like, we were actually running blood testing sessions, so people used to come to this. And we used to do the group session, that time - just show the patient how to test blood with the meters. And what I remember, ten years ago - ten, twelve years ago, soon after the centre was open - we were actually given five meters from this meter company; I can't remember who they were. Anyway, we were sort of given five meters, and we were told we can give this meter - loan - to the people who will be only on insulin, but not on tablet; they still have to do urine testing. And my job was to keep those people's name, so they could have this meter - one meter for three months - and then somebody else will take that meter. And if they do not return within the three months, you just 'phone back and write to them saying "please could you bring our meters back, 'cause somebody else is waiting for that". And, I mean, if I think about now, how funny it was... it sounds very funny. But people used to bring it back. I never found anybody say "oh, can

I keep the meter?”, you know. I think the auto meter was nearly forty to fifty pound each, those meters were, at that time. As I said, we was given five meters from the company, and these five meter used to go people to people. So, you prioritise people who are newly start on insulin, so they can have it for three months. Then, when somebody elses starts. . . And we have this waiting list, waiting people, who waiting to get the meters.

(18) What other changes have there been?

I think the major changes has been, it’s sort of like patients’ understanding of diabetes. Although, when we were seeing patient one to one, we found that this patient had been seen for last five years, six years, and nothing has been changed, their HbA1c’s still high, and they’re still having a problem managing their own diabetes. And then we sort of concentrate more on education, so make the people understand about the diabetes, and take their. . . let them take some responsibility themself. And education: for my part, it was very difficult, because leaflets - there was plenty of leaflets that was available there in English, and in Bengali, but the. . . if someone cannot read, what is the point of producing a leaflet, hundreds of leaflet? So, I just gave them idea: how about just putting this in a video, in Bengali? So, my department sort of say “yeah, this a very good idea”. Because I was always against the leaflet, because leaflet is. . . you take the leaflet with you and go home, and then throw it in the bin. And, if you cannot read, then it’s no use of that leaflet. And the leaflet, also, when people who are translating that leaflet, they were translating in proper Bengali. And this group of people, we were seeing, actually speaks Sylheti dialect. So, for them to understand, too difficult. So, I came with idea of producing a video in Bengali, and it will be video of all about diabetes. So, that first video I produce, it was in 1994. And we produced ten video, and each video was in only three to four minutes. And it was introduction to diabetes, so: what is diabetes, and why you need to do blood testing, why you need to do, and how to do the urine testing and blood testing, insulin injections, hypo, travelling. So, all those subjects were the ten, was there. And then what we found that when people was borrowing those video from us, we had to give them ten video, you know, so you have to give full carrier bag of video. And when they bringing back the videos and two or three were missing from them, you see. And so. . . The idea was actually working. People were interested to borrow the video, and we found people learned more than one to one advice. And then, few years later, what we did - what I sort of like proposed to the department, again - I said “instead of ten two minutes video, why don’t you just compress the whole ten video into one for twenty minutes?” And luckily, actually, we have a video department, which. . . that do health promotional videos. They were also very good with me, and then we produced the next video,

(19) which was twenty minutes, all about diabetes. And that video was quite brilliant, and still we are using that one.

Was that in the Sylheti dialect?

It was Bengali and Sylheti. Because, I sort of... It is English, Bengali and Sylheti. The reason I proposed that, because there's so many younger generation of people who probably not understand Bengali, but they need to see English one. And Bengali people who are not Sylheti, they cannot understand Sylheti people. And good thing about it, we actually... I came out the idea, because when we sort of said that video will be made, and the department sort of said "oh, to hire an actor and actress, we need lot of money to produce this video, and we've got only five hundred pounds to produce this video", you know. So, I sort of came about, I said "how about using our own patient, you know?" And they said "no, the patient will not". And I actually made convince them. I said... made them, you know, sort of say "would you like...?" They said "yes, yes", and people actually queuing up to star in the video, now. So, we used five, sort of, patients, and all are real patient from the people who come here. And we used our consultant chiropodist, and our own dietitian all took in part, you know.

- (20) So, we started, the education... we started, sort of, improving education. First of all, we sort of say, we'll do education one day a week. So, we used to do the group start - I started that in 1995 - and the English classes and the Bengali classes. And the first initial idea was that we'll do the group session, mixed group session, with the Bengali and English people, and I would interpret there. So, the nurse will say it in English, then I will say it in Bengali. And I sort of said, "no, that's not going to work", because the English... the session will take double the time, and English people will find bit irritating. I would find irritating, you know. And Bengali people will lose interest, and they will not come and stay in the room, you know. So, our lead nurse sort of said, "what do you suggest?" And I sort of said "if it is okay from the department, I will do the session myself". So, at the beginning, they were not very confident, because they said the education should be done by the professional person who is a nurse, but I am a link worker. So, you know, the confidence, is it going to be questioned by the PCT? Sort of like a unprofessional doing the professional job. And then, sort of, they got okay, they said, "yeah, Husne Ara has got enough background knowledge on diabetes, she can do it". So, I started with one day - six hour session, for whole about diabetes, everything in six hours. And found very difficult to bring the group together, starting the group session. But it was working; people were attending. And people were attending - our lead nurse was quite impressed by attendance. The English classes were not attended that good, but my class... because the reason, I was explaining to patient, people think "is a Bengali person going to be there?", you know, so. And then it moved to like a two days. We couldn't do it... one day is not sufficient enough time to give enough... So, we started four hour session for two days - went to eight hours. Then it moved into three day sessions. And now, what we are doing now, we are doing structured education. It's equivalent to DESMOND in Type 2, so we call it, actually, HAMLET. We given our own... because we work in Tower Hamlet. And it's a structured... it's called expert programme,



so it's structured education. So, people will come for five weeks, in five day sessions, each day for five hours. So, they have to come for twenty five hours altogether, and this education is government approved. And the people who are running the session - I'm doing the Bengali one - we have to go... we actually were trained by the expert programme for two days. And it's all being audited - going to be audited - end of the year.

How does this fit in with people's work, or are they mostly retired or unemployed?

- (21) Majority of time, attendance not too bad. If I invite, say, forty patient, I'll get, probably, good twenty, twenty two people attending the courses. And these courses are... yeah, people who are working full-time, it's difficult for them to attend. But we have... if anybody says that "I cannot attend because of my working. I'm really interested", we're actually keeping name for those people. And I'm thinking of... may run courses in the weekend or late evening, if enough people say "yeah, we want you to run these courses to be run in the evening". We're always flexible there, in our centre; especially my centre, we are flexible. But, because this... majority of Type 2 diabetic patient are... they are forty-plus, fifty-plus patients, so majority of them are retired, or they're actually unemployed in Tower Hamlet; lot of unemployment. Yes, it is difficult. People who are working, it is difficult them. So, you find, out of five... four... My course is actually four days - I take longer hours to finish in four days. And what I tell the patient, if they sort of say "it's not possible for me to attend four session in a row", so I sort of say "at least attend two this time, and whichever you have missed, you can come next month", so they are actually splitting it. So, many patients are doing that, so they're... like the course I've finished this month, quite a few people only attended two, and they're going to attend the following one. We actually give the letter to the patient to take to their employer, by saying "this is a government drive for education sessions. People with the diabetes need to attend these sessions", and they should give them time off. And they do give time off, yeah.

How complicated is the course you run?

The course is not complicated at all. The course is, basically, learn about diabetes. Our structure of our course is: we talk about what is diabetes, you know, how it is diagnosed, and why are the medication required. And the diet is... we take, actually, two day just to talk about diet. It's not only diet. We talk about, you know, the balance of good health. So, balance of good health - we teach patients their portion of carbohydrate, what is carbohydrate. I think that the main problem with the diet, especially the Bengali patient - because even someone who's educ... When you finish education in Bangladesh, the nutrition side is not given that priority, in our education.

- (22) I don't know about the English here - you know, education-wise - how much nutritional information is given. But, in our country, somebody finish the secondary school, nutrition knowledge will be, say, ten... out of

ten: three, two? So, I don't know about in this country. So, that's why I actually put more emphasis on our Bengali patients' diet and physical exercise. That is where they're lacking of the knowledge. So, delivering the course, whole education is not difficult, but how you are delivering to this group of people is most important, you see. And, as I said, so our courses: what is diabetes, diet, medication, why the insulin is required, why the blood testing, and the complication. And another part I touch in, extra in my education, is the cultural issues there, like Ramadan and fasting and praying. Because most of our days - a Muslim person's - in their life is revolving your praying and all the religious ritual you have to do. So, I try to teach patient how they can still keep a good control of the diabetes, when maintaining all the cultural belief in the same time, which is extra in my education.

How do they cope with Ramadan?

If you are a diet control, there's no problem; and if you are on Metformin, there's no problem with Ramadan. But the problem is, because the Ramadan is a fasting month, is one of the month which is very sacred in our religion, in Islam, and every adult Muslim has to fast. But then again, the teaching of Qur'an... because our lives - everyday life - it's all instructed in Qur'an, how you should go about every day. So, Qur'an sort of said, if adult Muslim... healthy adult Muslim should fast thirty days a year. But then again, some instruction is there: who should be fasting, who should not be fasting, who been exempt from the fasting. And that's... some of the people actually not aware of, and this what I actually put emphasis on, then. And people do understand. So, I just give you the simpler version of rules of the fasting is, and there's couple of people... few people are exempt from... couple of people are exempt from the fasting. The people who are... Exemption from fasting is that if you are pregnant,

- (23) you don't need to fast. But when the baby is born, after... when you're no longer breast feeding, you have to make up those days you have missed. And also, there's the illness: that, if you are ill, then you don't need to fast. So, if you are ill for a few days, you don't fast, but you have to make up those fasting you have missed. But, if your illness due... if your illness is a life condition - you will never recover from that - then you do not fast, but you actually have to give some money to the poor people, you know. But, I always say to the patient that, just think of your... how it going to affect your diabetes, if you're fasting; you decide. And these are the rules; you decide what you have to do. But, again, just go and ask somebody who knows about it. Just don't decide yourself. And also, in our Islam say that, if you're fasting, if you're... you'll make worse to your illness, then you should not be fasting, because your life is more sacred than the fasting.

And do people accept that from you, or do they need to check it at the Mosque? Sometime they accept it. Sometime they'll sort of say "we will go and ask

somebody". Sometime they know themselves. But I always sort of say "what I'm going to talk about fast... I'm going to talk about fasting, now. And please, if you do not agree with me, go and ask somebody". The imams at the Mosques are very good. They are actually advising people according to what we say. They should be, because this is in the Qur'an. This... nobody is making it up, you know. What is the instruction in the Qur'an, exactly, is explained to them.

Have you had to do diabetes education with the imams?

I haven't done it, but it's a very good idea. I think I'll just take your idea and just will probably...

- (24) You've talked about fasting. What other cultural attitudes or experiences are there that might affect people's diabetes?

I think the diet is very important. As always, sort of said, diet and the Type 2, you know, that body weight is very important there. Because you find majority of our Asian people, we are... our waist is much bigger than the average people. And so that diet plays probably big part in there, and also the physical activities is there as well. And physical activities, we are not used to in our country. I don't know the European country, how they're used to it, but definitely our mothers or our aunt, we never go out, you know, walking in the park, or just going to the gym, or just have a swimming, you know. And the diet is another issue that, because our staple diet is rice, fish and vegetable. And because we actually grow lots of rice in our country, and the rice is very cheap form of carbohydrate you can buy, and fills... it fills you quickly, isn't it? So that's... maybe that's the reason we eat quite a lot of rice. And when our dietitian gets amazed by hearing that average person - Bengali person - will eat two plate of rice with their dinner. And my part is actually making health professional, instead of criticising the Bengali patient, sort of saying "why are they eating it?" Because, this is the way a person in... When a person comes in this country, aged twenty, twenty five, and for last fifteen years of their life, or twenty years of their life, they've eaten two plate of rice. All they know that, isn't it - the brain is understood that you have two plate of rice. And when you suddenly sort of see this patient for the... For example, if I give an example. Fifty year old woman come to you, with the diabetes. And you just checking the diet history, and she sort of say "I eat two plate of rice at lunch, two plate of rice in the evening", and you sort of say "my God, you cannot. Just go and have only six tablespoon of rice", and she'll not going to do it. So, what you need to understand: you just tell them, but do it slowly, so that your body doesn't require more than that. Because you've been eating it, you know, that's why you think you cannot do it. So, you just make them slowly understand the diet. And another one is fruits. We do not eat fruit as you should be eating, as the dietitian are saying that five pieces of fruit and vegetables a day - minimum of five.

- (25) Because fruit is only seasonal in our country - it's only come in the season. Like this country, you get pear, apple, banana, all round the year. In Bangladesh, it's not like that. It's every season, two to three months, you

have one particular fruit. Like, mango season will last only two months. After the mango season finish, you do not get any mangos. Orange season will last for a month. So, we need to understand that, because it's not been available in their... in this... like this country, so that's why not they're doing it. So, we can change their habit by just... by education, you see? And also with the exercise. The women doesn't go out. They don't do shopping in Bangladesh, and anything, anything be done, it will be the man who'll do it for them. So, how do you encourage this sixty-plus woman to go and do some sort of exercise outside? Then again, you need to understand, how do you make her to do it, you know. You sort of say "fine, if you're scared to go out, just do walking in your balcony for twenty minutes," you know, or "just go up and down in the stair. Everybody has a stair in their house, so if you find it difficult to go out, just go ten times up and ten times down. And just clean your kitchen four, five times a week, instead of one day a week". So, you just trying to find the way it will be culturally accepted by that person, because, if I tell a sixty year old woman "you have to go swimming twice a week", she will not accept it. She will reject it, straight away.

It sounds as though you've had to educate the health professionals as well.

Yes, that is part of my job as well. Because, I mean, the half part of my job to educate patients, and half part of my job to educate the health professional as well - especially the cultural issue. I remember when I started in 1990, and the dietitian, she was particularly talking to me about the diet, the Bangladeshi diet - not Bangladeshi diet... Asian. She said "Husne Ara, I think we need to concentrate to tell people not to use ghee in their cooking", you know. And I sort of said "we do not use ghee". She said "oh, but you use ghee in the curry". I said "yeah, the ghee is used... Bengali people, we do not, because we are fish eater. So fish, you cannot cook fish with the ghee". The ghee is a butter, you know. So, we use always cooking oil, you know, vegetable oil. So, I think those, and also the chapatti. We do not eat chapatti, we are rice eater. And our staple diet is fish, rice and vegetable, and lentils, even, very small amount, you know. So, because I think the people have this idea that you're Asian, everybody's eating rice and curry. No, it doesn't... everybody rice and curry... And also, another... I think this idea's actually changing - people are now aware of it more. So, what you go and see in the Indian restaurant, when you are going out in the Indian restaurant, the rice... the curry they are giving you on the... you are ordering, it's not the same curry when you eat at home. So, you need to understand that, as well. So, I think... And the dietitians actually do acknowledge that, by saying that they have learned so much from people like us working in the health authority, on cultural side, which they are not aware of before, you see.

How's the curry that people eat in their homes different from the curry I would eat in a restaurant?

I think the restaurant curry, you'll be more oil floating on the top, and the curry we cook in the home, it will be less oil. That's only difference, probably, because

I think you use more fat to make things tasty, and also it's cheaper to produce, because if you put more oil or fat, people doesn't eat that much, isn't it.

(26) Have there been any other changes in your work?

Until two years ago, I was seeing mostly patient with the nurses, and I was doing little group education - starting insulins, group of insulin starts with the nurses, or follow-up insulin starts, or meter training. And since last two years, I'm actually fully doing the education. My job role has changed now; my job title is Lay Educator. And I'm just training patients to understand more about diabetes. The education is structured, now, than the education we used to do before. The programme, for four days - patient need to attend for four days - and we have... each day we talk about certain things. And end of the four days, the patient should be aware all about diabetes and their control, and everything. So, when you start... before you start the class, you have to have a baseline blood test done for all the patient. It's like the creatine in the liver function, their HbA1c, their waist measurement, their blood pressures, their cholesterol. So, all those should be done before they start the course. And when the course is finished, for four days, they go away, and they come back again after six months. And what you do... try to do in this four days course: lifestyle changes; you encourage people to change their lifestyles. You're not changing any medications. So, you actually encouraging people to do more exercise, carbohydrate awareness, to eat more fruit and vegetables, and not snacking all the time. So, those are training you're giving. So, after six months, those same people comes back, and you do their blood pressures and all those tests again - profiles - and see what the advice has made any changes in there. And we're actually finding people are. Their HbA1cs are dropping, and their waist measure... they're losing weight. But not by changing their medication; just by advising. And again, year time, the patient comes back again, will come back. We won't completed a year now. We've completed few groups at six months, and the signs are very encouraging. So, we have to see what happens in year time. So, my job is now full, 100%, now, on education. And this education, my role - especially my roles, because I'm only seeing Bengali patients - I try to do... all the materials which are used for the education, I try to make them simpler version to understand, for the Bengali patients. So, the CDs... so, we have this... whichever the CDs or video use in English, and I change them into Bengali translation, so you have to redo the video again. I'm given that permission to do from the department. And I'm actually translating quite a few video and DVD into Bengali.

And do you voice them yourself?

I don't voice them. I do the translation, and we actually just finished one last week, last Friday. They asked me to voice, and they tested my voice. My voice doesn't come right in the video, you know. I sort of said I didn't want to...

(27) Are the four days once a week, so that there are several days between each session?

It is once a week, so a patient will come one... four hours one week. If it is...

sometime we do it, sort of like, two in a week, and two in next week. It actually depends the times of the... when our room is available. But, it's supposed to be four weeks, because you're actually giving enough time that person to make the change. Because, what they do the first day of the session, they'll have their goals. They'll give you their goals, so you have to say what action they should be taking. So, if you do not give four weeks, it's not enough time for that person to reach to their goals, so.

It's a concern of health professionals all over the country, how to help people to lose weight. What would you say were the main elements of success in your programme?

Exercise. With the Bengali patient - I can only talk about the Bengali, I think - our Bengali patient, we do not do enough physical exercise. Whatever we do, we do not do properly. So like, a lot of people say "we are walking", but how fast are they walking? So, you sort of like limit them, sort of say "if you are walking one mile, then you have to have it done in, sort of like, fifteen, twenty minutes. It's no point of walking one mile in half an hour". And another thing I'm finding, sort of like, a lot of people are interested in swimming, so the ladies - even the ladies are interested in swimming. And I try to find out where the ladies' swimings are available in that area, so you just give information: "there's a ladies' swimming only classes done in those areas". So, losing weight, and another thing is fat. Because, earlier, as I said, Asian cooking, we use lot of fat, you know, oil, to do the curry. So, I think the fat intake is another, in my opinion, important issue in the losing weight. So, just make them aware that how much fat should be using in cooking curry for six people, you know. So, you know, it's sort of like hands-on advice. You just have to tell them every single thing: how should they be doing, you know. And this is how our whole... HAMLET is for... stands for hands-on advice in a, sort of like, everyday... how far should be walking, how you should be walking, how you should be cooking, you know. And maybe reason is, this group of people who basic... because they - education-wise, you know - they haven't, you know, they didn't get much... I don't know how to explain that. And some people, sort of... One of my colleague once sort of said "it will be offensive to say somebody how should be their cooking. How to make a stew, you know". But, to me, it's not offensive to tell a Bengali person how to cook curry in healthy way. I don't think this is offensive, you know.

(28) How do you think that your work has been affected by your own family experience of diabetes?

I think, because my father was a diabetic, and so is my mother, since last fourteen years, and... I was very... what the word I want to use is... I think I was very lucky that I knew about diabetes, you know. And I think, although people sort of say diabetes is very easy to understand, it actually not that easy to understand. But I had this opportunity, because my parents were diabetic, and my father was - since my younger age - my father was a diabetic. If I was sixteen and father was a diabetic, I don't say I'd be that much interested. Because I was a little girl, then, and then that made me interested. And also,

I am a diabetic now, as well. Since last one year I... I was diagnosed a year ago; I'm diabetic. And funny thing is, all these years I've been working in the diabetes, and diabetes actually means different to me now, because I am diabetic, because I am actually on the same road as those people I see every day. So, I can understand the problem people going to face in more deeper than what I used to. I mean, until a year ago, it was my job. I just stand there, give a lecture for four hours, you know, and tell patient "you mustn't eat sweet, you mustn't do that". And now I understand, if I tell somebody not to have two plate of rice, what kind of feeling that person will go through, you know. How difficult it will be that person to resist two plate of rice, every time they're going to eat dinner. And I think by understanding that, my job is actually easier, now, than it was a year ago.

Do you follow your own advice?

98% time, yes.

(29) And just as a postscript, you said there was one thing you forgot to tell me about.

Our education programme, we are taking more in the community now - this and other big changes happening. It's actually good, because, if you have one central point, the people find difficulty to come from far away. So, we are doing... this way, we are doing more and more this educational programme into the GP surgery. And that giving opportunity to the patient to attend; easier for to access the services. And this, and other changes, is happening.

Do you mean group sessions and your four weekly sessions - are those taking place in surgeries?

Yes, group session, yeah. The group weekly sessions, yeah.

Do surgeries have room?

Most surgeries are have rooms. And what we are doing... what we are going to do in the futures, the surgeries which haven't got space available - so, for example, if you have a radius of two miles, you got three surgeries, four surgeries in that area. So, one of them, which has got a room, they'll probably do it together. So, this one we are planning for the next year.

And one more postscript about the labelling of food?

Labelling of the... One of our structured education programme is to teach patient label reading, to find out the what type of fat, or carbohydrate ratio - how much is there - and sugar contents. And with the group side and the Bengali patients, it's very difficult to teach them to find out, because the majority of them cannot read English, or they cannot read at all. So, what I try to do, to make them understand - it was, at the beginning, it was very hard for me, but I actually found a easier way to tell the patients - so what I do, I tell them to... the ingredients; this the way our dietitian actually taught us, says this the easier way to teach them. The first four ingredients, whatever the first four ingredients

is, the contents of that ingredients will be more than the other. So, the way I teach the patient is tell them, if they're taking their daughter or son with them to the supermarket, or buying any food, just read them the ingredients loud to them. And if they say the first ingredients is sugar or salt or fat, then they'll realise the ratio is more than the others.