

100. Mushtaq

(1) Tell me about your background.

I was born in 1968, and lived in the area of Balsall Heath, with my parents. And my parents: my Dad was working in Lucas - he's worked there for twenty... most of his life - and my Mum was a housewife. I went to the usual school, there. And from there, I went to a secondary school, and educated there. Then, from there went to, a short while, to a college. And then, from there, I started my own business, and from there I, later in life, started... - past, about ten, twelve years - started looking after my parents.

Tell me about your business.

Right, business: I started early, when I was eighteen. I started a general corner shop, general store, and then I ran that for about five or six years. And then changed it to electrical repair; I've done electrical repair: TV, videos, and washing machines. And then, from that, I'd done a bit of debt adjusting. I've also done... I went into DIY and building, after that. And then I stopped my business ventures, and went on to caring for my parents.

When was that?

I was about thirty two, then. Ah, no, actually, I believe I was thirty years old, when I gave up my business and started looking after my parents. They both had diabetes and other illnesses.

Tell me about your earliest memories of your parents' diabetes.

As far as I can remember, my mother had diabetes, class 2, and she was on the tablets Glipizide and Metformin. And my father was on the same tablets, at that time, as far as I can remember, as well.

As far as you were concerned, then, they'd always had diabetes since you were born in 1968. But do you know when they were diagnosed?

As far as I know, my father had diabetes in the early 1960s, and my mother was diagnosed in the late 1960s.

And they managed on diet and then tablets. Any idea when they went onto insulin?

As far as I know, my father went onto insulin in the late 1990s, and my mother went on insulin about the year 2000.

And what was it like, when you were a little boy, having two parents with diabetes?

Obviously, it's like, when I had the sweets, they couldn't eat the sweets, and they were limited in what they could eat. And, obviously, when we went out together to restaurants and to the park, if I got an ice-cream, they didn't want an ice-cream. And my Mum had a sweet tooth, she used to love sweets, and sometimes she's been naughty and eaten sweets, but then she had to pay the

price when her sugars went high, obviously. So, yes, but generally they tried to be good with their sugar levels, as long as they could.

Did you understand anything about diabetes and sugar levels?

No, not at first; I didn't understand at all. I couldn't understand why they go up, why they go down, you know, nothing about it. Over a period of time, as I got older, obviously, I had to educate myself more about diabetes, and learned about diabetes: how it's affected, how exercise is a very important thing with diabetes as well, and also that keeping a sensible diet.

(2) So, when you were a child, was your parents' diabetes a big part of your life?

No, diabetes wasn't a big part of my life, because my parents kept their illness very private to themselves. They didn't want to disrupt my life, or things that I wanted to eat, or anything that I wanted to do. So, for a long period of time, I didn't even know they had, really, diabetes. They held it secret very, very well. It was a private thing; they never really used to advertise it.

If they went, say, to family weddings, and so on, did everybody know they had diabetes?

No, they didn't. Nobody knew, because they used to hide it quite well. And if there was something... they wouldn't eat the sweet things at the weddings. They could have the, obviously, rice and a bit of curry, but it'd be limited; they know their limitations. And, obviously, the sweets that they have at weddings, they wouldn't touch them. But nobody really questioned them. Generally, with the Asian community, I believe that every Asian person will keep their illnesses very private. They don't like to talk about it so much, because some of them may find it's an embarrassment, or they're limited to how they can socialise with other people. Example, eating with the diabetes: my father wouldn't be able to eat certain foods, and he might feel a bit out of circle, so... and same with my Mum, as well. So, that's why a lot of Asian community, I believe, are very private about their illnesses, and find it hard to come forward about it, and talk about it.

What are your memories of your parents' diabetes in your teens and twenties? This, I suppose, is kind of the 19... - you were born in 1968 - the 1980s and '90s?

In my teens, my memories of my parents with their diabetes is, they used to medicate themselves - they were on tablets, they weren't on insulin, at the time. My Mum used to look after herself, my Dad used to look after himself, and I was quite busy, at the time. I was involved in my business, and I was running that many long hours. I used to see them as and when I could, in the evenings, or give them a call. That's what I can remember from my teens.

And what about your twenties?

In my twenties and late twenties, I start... unfortunately my marriage broke down, and I started getting more involved in my parents' lives. I started to realise that they needed a lot more help and support than what I... I suppose I didn't give them the time and the place, as much as I should have. So, I got more involved in their lives, and start understanding more about diabetes, and more about their illness, and ways that I can support and help them, as well. 'Cause, I'm a bit old fashioned, in my ways, where I believe that parents were there for us when we needed... we were young children, and bringing us up, so we should be there for them now. Also, when I got more involved in their lives, I realised, through a period of time, Mum had illnesses that... later it was diagnosed she had Alzheimer's. It was just by accident, going to a surgery, seeing a poster, and it basically summed up Mum's symptoms of forgetfulness and asking questions. I got that investigated, and it turned out she had Alzheimer's. And Dad, unfortunately, went very low in himself, couldn't understand why he was low and depressed, and didn't want to do anything. And I found out he was diagnosed with manic depression. So, at this time, I decided to put my, well, business on hold, and give time and space to my parents, and help and support them, and be a full-time carer. So, that's what I did.

(3) Tell me first about looking after your mother.

One time, when I woke up to reality about my Mum, and Mum's state connected with diabetes, is she used to fast, which she shouldn't really do, 'cause she's on medication. And I went down to her home, and knocked on her door: nobody opened. I opened the door with the key I had, and she was lying in bed. And when she was lying in bed, I thought "Mum, get up", and she wouldn't get up. I thought the worst. So, eventually she got up, just about, and I gave her something to drink. And she was very confused, she wasn't making sense. And then, I realised that she'd never took her medication, and she hasn't been eating, 'cause she's been fasting. So, I gave her something to eat, and gave her some medication. And obviously, being Alzheimer's as well, she was very confused. And that's what really shook me, and woke me up, that my parents need my attention and my support. So, that was how I started to get involved more in Mum's life. And she was medicating herself incorrectly, as well. She was taking too much tablets, sometimes, and that's when I realised that: why does she forget? I didn't know the Alzheimer's till about a couple of months later, she had Alzheimer's as well. And she used to also go out during the night-time with confusion, so drastic action had to be taken. So, a member of the family had to... well, not had to - well, I wanted to look after my parents, because I suppose I'm old-fashioned in my ways. And also, my mother had other illnesses. She had a hip replacement, she was disabled, she had corrosion of the bone, but she's a very strong-spirited woman, and carried on. And also, my Mum was very... I believe what kept her going till the last days was her faith, and that's what kept her a very strong-spirited woman, and she was very kind hearted. So, then, from there, obviously, I took over and took care of her, and made sure... she'd a lot of things she'd never saw in life, I gave her the time and space and took her out. And simple little things, like going to a shopping store and seeing

a toy shop, she found it fun and exciting, and she was laughing. And simple things like that, she never saw in life. And obviously, she was limited, with her disability, to do her exercise and walking, so I had to find other ways to keep her active. But she was, like I says... she'll walk twenty minutes, or as much as she could, just to work up a sweat, which helped her diabetes.

(4) What sort of other things could you find for her to do, in terms of exercise?

She can walk a little bit up the hallway - I'll give her support, and with a walking stick. And I used to take her to the park. She used to like knitting, she used to like... she used to make excellent cardigans, by the way. I used to take her out and about visiting, keep her mentally motivated, as well. And generally, show her part of life that she'd missed out on.

Why had she missed out on these things earlier?

Mum missed out a lot in life because all she knew is, really, is stay in the house, be a good mother to the children, and cook, clean. Simple things: she hasn't even been to a Safari park, which we take for a liberty, in a way, now. I took her out, and she enjoyed that. I took her to a shopping centre, she loved that. Just the general out and about, which she didn't have, where normally her day-to-day life was just cook, clean and stay in the house. And she was very, very limited. And that was most of her life, and I wanted to give her the opposite.

By the time you were doing that, she was beginning to have Alzheimer's, but she still enjoyed it?

Yes, she had Alzheimer's, but she still enjoyed it. I had to also educate myself how to understand somebody with Alzheimer's, as well. Because there's ways of, like, touching and talking and understanding, so they do not get stressed, in order that... then they believe that they've got... why are they making the mistake of not... of repeating themselves. You've got to make them feel calm and comfortable within themselves, which also does affect sugar levels, as well. Because, if you're stressed and you've got an illness like Alzheimer's, it does affect the sugar levels to go high and low as well. You have to be calm and collective within yourself. I should explain, also, while I was caring for my mother, she was in a warden-controlled place, in a flat, because, obviously, she was unsafe for herself at the bungalow she used to stay in before, because she had a habit of leaving gas on, and going out at different hours, thinking it's still daylight, and it isn't. So, because of those reasons, she had to be somewhere safe and secure, so that's where she was.

And who controlled her medication?

The medication was then, at the last three or four years, was helped and controlled by... the insulin was given by a district nurse, and the medication was given by the actual place where she was staying. So, they gave her the medication, then I would go in and see to her, the needs: taking her out, seeing to her bills, et cetera, and food and shopping, and general hygiene, as well. So, then, I took care of those needs.

And how was her diabetes, for the last few years of her life?

Generally, her diabetes was fine; it was under control. But the odd occasion when it was high, I found out she was naughty: she had sweets under her pillow that she shouldn't have. But she had a sweet tooth, and she used to love her sweets, and she used to, you know, be a bit naughty, like a naughty child, at times. But, generally, her sugars were under control.

And how do you think you helped?

Generally, giving my Mum the life she should have had many years ago. Her last, I would say, four to five years that I've given her the time and space, I believe she enjoyed very well. And I'm glad I had those moments with her, which meant a lot.

- (5) Meanwhile, as you were visiting your Mum in the sheltered accommodation, you were living at home as a carer for your Dad. Can you tell me the history of his illnesses?

Yes, also - balancing out Mum and Dad - Dad was also diagnosed with manic depression, which, how I connect that with diabetes is, there was times when his sugars were very, very low, or up and down. And he used to go, unnecessarily, very, very low in himself, and very depressed, which didn't help his sugar levels. And then he refuses to eat, which didn't help his sugar levels again. So, the further it... obviously, he'd seen the doctors, we found out he suffered with manic depression, as well. So, we had two matters to balance out. Dad, unfortunately, had to go into hospital for a while, for about at least nine months, because he refused to eat, he refused to take his medication, which led him to, like, more or less, suicidal thoughts. So, obviously, under the mental health, he had to go to the hospital. And the doctors helped a lot, there. He was there for about eight months. And when he came back out, he was fine. He was fine for about six months, then he had to go back in again for another five. And when they gave him the medication for the manic depressive, his sugar levels were also up and low, as well. It came to the point where they were considering giving him ECT. Now, ECT is a last resort. There isn't a medical reason why they can say why it works, they just say it either works or it doesn't. So, I was at a point, now, where the medication was failing with him, on the manic depression side of things, which was affecting his diabetes. And then, I had to literally shook my Dad, and put a lot of hours and time into him, and make him walk, make him do things he didn't want to do. And, thank God, he did come out of it, and he did come home. Got his sugars under control, and he was fine for about six or seven years, after that. Unfortunately, now, at the present moment, he's back in hospital. He went low, back in himself, and he refused to eat. He's affected his diet, he's lost weight, so he's affected his sugar levels again, and he's in hospital, now, having treatment. If all goes well, and they're considering the ECT, which is still negotiable, because I've tried all my best, tried all my efforts, and if that's the right path to go down, I have to seriously consider that. But saying that, at the moment, while he's in hospital, the hospital don't have to just fight against

his depression, they now have got a mobile number of a doctor, who deals in diabetes, as and when they can ring him to sometimes to adjust his insulin, even. Because, there's a problem with insulin is that when a patient goes into hospital, the nurses and doctors can't decrease and increase insulin without authorisation, and without somebody who is an expert on diabetes. And there seems to be this barrier of bad contact between doctors on diabetes, and if the patient is being treated for something else. I think that barrier needs to come down; there needs to be a better communication level there.

(6) Do you think it's working at the moment?

It's working now, because I've been very persistent. And before Dad went into hospital, there was this big debate and argument about the mental health saying "it's a mental health issue, he's not eating", the diabetes saying "no, it's not our problem". They were passing the buck onto each other. And eventually, I had to fight the case, and say "listen, I know it's mental health. If he was fine mentally, he would eat, and his diabetes would be fine". I had to, as a carer, put my ground rules down firmly, and for them to accept. Now they've accepted. Then there was this problem of communication with the diabetes, again, because Dad's sugars were out of control. He's had hypos during the night, and he's got a habit of eating during the night, as well; he gets sort of a hunger pang. And when he gets up during the night, he doesn't eat, his sugar levels go very low in the morning, and his sugar levels have even been two. And the nurses don't know what to do; they have to just quickly give him some kind of liquid. Now, if they have a direct number that they can talk to a doctor who's on the diabetes... a doctor who can help them, then at least they can adjust the insulin, and know what to do. I believe they need to communicate; there's a lack of communication. So, I made his appointment with the diabetes clinic, and explained the situation to the doctor. And now he's given his personal mobile number to the GPs at the hospital, if there's any problems. So, that's how I've balanced it.

Your sister told me that your Dad had been very good at keeping to a healthy diet, and controlling his levels of sugar.

Well, generally, when he's mentally fine, he's got his manic depression under control, yes, he's fine; he can control his own sugar levels. He knows what he's eating, and he's sensible, and everything's balanced fine. It's just that, when you've got... when you're fighting against another illness, and you're trying to balance the two, that's where you need the help and support.

What support did your Mum and Dad give to each other, before they had mental health problems?

My mother and father always supported each other, and always been there for each other, for many, many years. But unfortunately, when we had two separate illnesses - somebody who's got Alzheimer's, who forgets, and my father's got manic depression - it's very hard to keep the two together all the time. And that's, especially with the Asian community, it's hard to understand, where you've got to take drastic measures to separate them. They were together during

the day, and then, obviously, in the evening, they need their space. My mother would keep repeating herself to my father, “have you got this, have you got this?”, and when he has, then he was suffering with manic depression, so he’s getting depressed. So, it was a hard balance, between the two. But generally, they were fine. They were brilliant as a couple, and they’ve been through a lot together. And they would have been a lot supportive with each other, if they didn’t have these illnesses. And there again, us, as children, didn’t discover these illnesses, especially my Mum having Alzheimer’s, like I says, through sheer accident, on a poster in a surgery I saw. And with Dad, through further investigation. As I was an adult, I insisted on, you know, “this ain’t Dad’s usual nature, to be low in himself”, and we diagnosed manic depression. Sometimes you need to look behind the scenes, why somebody’s acting not normally to what you’re used to, because there’s usually a reason behind it, and that’s what needs to be found out.

- (7) You’ve obviously been to a lot of appointments with your Mum and Dad. Did you find that health professionals understood the interaction between mental health difficulties and diabetes?

I don’t believe they understood, and the reason why I don’t believe they understood is, because I’ll give you one example with my Mum. We went to a dentist, and she had to make a decision to have a tooth pulled out. Now, with her diabetes and Alzheimer’s, she can’t exactly make that decision. Now, the hospital can’t pull the tooth out without the consent and permission of the person they’re pulling the tooth out for, although I reassured them I am quite capable of making that decision. I could see my Mum in pain. Now, because we had that barrier, and they could not pull her tooth out, I had to, with great difficulty, hold my Mum’s hand, give her reassurance, and convince her, from her own mouth, to say that she would have this tooth pulled out. So, through... it was quite emotional, quite hard. And for my Mum... My Mum just held my hand, and says to me that “for you, son, I’ll do it”. So, she gave the permission, and she done it. That was one time.

And what about when you saw specialist diabetes staff, did they understand about mental health issues?

When I went to see the diabetes specialist, obviously, all their main concern was the diabetes. They weren’t really interested about the other medication, or the mental health issues that my parents had. And the same on the other side. If I went to the hospital regarding their mental issues, they didn’t really want to know much about the diabetes, because their focus, their job is to sort out the mental issue problems. Where the two should compromise and combine the two, because the two do meet, and do cause... The diabetes causes the mental health problems, and the mental health causes the diabetes problems, so there needs to be an understanding between the two.

How far do health professionals allow you to make decisions, on behalf of your parents?

If they needed a consent... consent is a problem, because they need the consent to come from the patient. Although I've got full authorisation to consent for them - by signature, by decisions, I'm their next of kin, I'm their full-time carer - it's, at times, not good enough, it has to come from them. Well, it's not fair, if they're not mentally there to make that decision, which is very hard.

Are you able to show the professionals the forms that you've signed that give you the authority?

They don't want to know. I've told them, they don't want to know. They says it has to come from the patient; the consent still has to come from the patient. And in my Dad's situation, where I can't make a... If my Dad had to make a very important decision medically, with his mental health, it will have to go down... it's called sectioning. They will section my father, and then make the decisions for him, but I can't make it for him.

Can you talk about the financial aspects of being a carer?

The financial aspects: I will say, if you love caring, it's more, yourself, an emotional... the financial side you can forget. The reason you can forget that, 'cause it's a very low amount. It's not like a wage. You can just about get by, if that, at times. You're doing it more out of love than the money, and, if anything, I would say carers should have more support, financially. It's like, for my father, now, he's in hospital, they've cut his... the high attendance allowance, obviously, because they feel as if... although I'm still going there, twice a day, I still got to do his laundry, I still got to do his running about. They don't understand what we do, as carers, and what's involved. And because my Dad's got mental health issues, I've got to do a lot more than I can find time to even get a job. And compared to what I used to earn in my business, it's not even a fraction, what they give me now.

So, you mean, now he's in hospital, you've lost your Carer's Allowance, but, in fact, you're working as a full-time carer, still?

Yes, that's what's going on, at the moment. But I'm still going to carry on the best I can, for my father. And so, at the end of the day, I'm doing it out of love, not for the money.

(8) What would you like to have happened that hasn't happened?

I believe, as a carer, we should be more recognised, if we're supporting our loved ones. For example, we should have our national insurance paid for; we should have a fair income. I'm not asking a lot, just a fair income. Because, the government are saving something like four hundred pound a week on a person that I'm caring for. If I'm caring for my father, I'm saving the government four hundred pound a week. And if they gave a fraction of that towards my national insurance contribution, and a fair wage that I can live on, that would be very supporting, very grateful, as carers.

And what about practical help?



Practical help: there is practical help out there, but, unfortunately, to get that practical help, you need, as a carer, it's called a care assessment. Now, to get the care assessment comes from the social services, and they should assess a carer every year. Now, unfortunately, they've got a backlog, and last time I had my assessment was about, ooh, four years ago; four or five years ago. And now, I could do with some help and support with my father. It's called a drop-in service, where they'll come and sit with my father, so I can actually go out and have a bit of a social life myself, which, unfortunately, I'm limited, because of my father's situation. Now, I don't know as and when this assessment will happen, but I just hope it happens soon.

How has being a carer affected your own life?

Well, your life is on hold, and you put your loved one's life first. Obviously, the social life, I don't go out as much as I used to, don't do the things that I... do as much as I used to, as well. Even my friends, I have to, when my father's here, you know, just work around a couple of hours, or if I can get the odd relative just to sit in with my father, while I go out. Because, also, my father gets very insecure. If I'm not around in more than an hour, he starts panicking, and he's got to ring me to get back, and he thinks the worst is going to happen to him. So, it's stressful, at times. So, my life is very limited, unfortunately.

(9) Is there any advice you'd like to give to other carers?

Yes, I believe everybody - even the Asian community - you need to be more open with yourselves. And if you have any experiences like I've had, I hope my interview can help others as well, and perhaps you can share your stories and experiences that may help other people in difficult situations. Because we're not all... we don't need to all hold it in, and keep it a secret to our hearts. I think, if you take that load off your shoulders, and share it with others, you'll feel a lot better yourself.

Are there any other things that you'd like to share that you think might help other people?

One very important point is, one time my father went in a hypo, he was shaking, and I knew straightaway what to do. I believe his sugar levels were low. I got water and sugar, mixed it in, because, obviously, he needed sugar in his body straight away. So, that goes straight into the blood straight away, so I made him drink that. And also, I advise diabetic people to keep a diabetes pen, and to check their blood, when you give the blood and you can check the BP; that's very important as well. So, when I checked Dad's, obviously, the sugar levels went up, and he was starting to come around, and he was a lot better. There's other methods: you can give a sweet, you can keep Lucozade tablets, and they also say a Coca-Cola tin. Not a diet Coca-Cola tin, but it's got to be a full proper Coca-Cola tin. Things like that will help. Main aim is to get sugar straight into the bloodstream.

How did you know what to do?

Well, one is from, I had a DVD, which I watched, and it explained about exercise and diabetes, so that educated me. And also, thanks, I've got a sister that's diabetes specialist (Shanaz.56), and so, if I was stuck, I'd ask her and she'd advise me. And through experience with both parents having diabetes, I've got used to how to adjust the insulin pen. You, obviously, if their sugar levels are low, you give less insulin, and if they're high, you give a bit more insulin. It depends on how much they eat during the day, as well. I've had an incident, also, where my Dad has decided... I've given him his usual insulin in the morning, and he's decided, in the day, not to eat, so his sugar levels went low. I had to check his BP, and, straight away, I gave him the liquid and sugar, into his bloodstream. It's always advisable for people's sugar levels to be high; it's best to be a bit high. If they're not controlling it right, then they'll be low. And that's it. Another thing about diabetes is foot care. Now, foot care is their nails. As their nails grow, they become very thick, very off-colour, and you must not force cut it yourself. It's advisable to see a chiropody, and go to your regular appointments for your foot care. You can clip your finger nails yourself, but toenails I don't recommend, because easily, you can crack them all the way up. I'll never forget the time, once, I tried to cut my father's toenails. They were so thick, that normal clippers were impossible. I worked my way up to my pliers, and I was going to even try considering the fine little hacksaw. And then, just by chance, my sister rang me, and she says "what are you doing?" And I was telling her, and she says, you know, "you're being a bit silly". She says "don't cut it, whatever you do. You go to see a chiropody". And if you want to maintain your feet, you can get a special file that you can file your toenails with. And it's always best to file them after you've had a shower, because the toenails are quite soft, then, and then you can file it down. She says "whatever you do, don't cut them".

And how do you keep your own spirits up, as a carer?

I try and keep my spirits up. What I do is, I'm proud of what I've achieved with my father, and I'm proud to have achieved what I achieved with my Mum. And also, I've been learning to play guitar, so that keeps my spirits up. It's just my few moments alone, and I have an hour or two, wherever I can fit it in.

Mushtaq remembered afterwards that he'd wanted to emphasise that stress affected his parents' blood sugars.