

(1) Tell me about your background.

My name's Emma. I have a mother who has diabetes, and a father. My Mum's had diabetes for around about forty years; I can't be precise on how many years it has been. She originally came from Uganda, came to this country in the late seventies, met my Dad. They went out for a short period of time, got married, and here I am!

And tell me what your parents do.

My Mum, she's a clerical worker for social services. My Dad, he used to work in the textile industry, but due to the business being in other countries, now, was made redundant, and now is a security guard.

And tell me about your earliest memories of your Mum's diabetes.

One of my first main memories of her is when me and my sister were at home, she passed out, fell to the floor in our old kitchen - which had, like, tiled flooring - so obviously she banged her head. She started to growl, and as we were children, and obviously you have a very... imagination, we thought it was a monster in the kitchen, so we wouldn't go in there; we hid behind the settee. She was going on, and she managed to call out our names. We went to the kitchen, and she told us to give her some ice-cream. So, we were giving her ice-cream, and sneakily we were having ice-cream ourselves as well. Yes, that's my earliest memory.

How old do you think you were?

I must have been around about four or five years of age... four or five, yeah.

Can you remember what your Mum told you about diabetes?

I can't really remember anything that she told us. She just said that she has an illness, and she needs... sometimes she needs sugar to make her feel better. That's the main thing, yeah.

So, did she give you any training in coping?

During primary school, I do remember that she took us to the doctor's - it was Dr Archer - and he actually showed us how to inject on a... I think it was an orange. My sister got the swing of it, but because I was quite scared of actually injecting someone, or actually hurting someone, I just couldn't do it. So, my sister was the main person who used to inject my Mum.

In what sort of circumstances?

Basically, when Mum would obviously pass out, and there was no way of her regaining consciousness, my sister was trained to do that. I was also trained, but because I was just too scared of hurting her, or just in case I got it wrong, I just wouldn't do it.

Would that have been injecting her with insulin?

Sorry, yes it would, yes.

- (2) So, tell me, from your earliest memories, kind of the range of options that were open to you, if anything went wrong.

First there would be, obviously, to phone my Dad, and we used to have the number of... my Dad's number by the phone. Also to call my grandma - my Mum's Mum. Also 999, as well - that was the main thing. I do remember calling 999 quite a few times. More often than not, it would be that.

And what did you say when you got through to the operator?

We would just say that basically "my Mum's diabetic. She's passed out, she's not coming round. We don't know what to do". And they would come round, inject her with insulin, and then she'd be okay.

What effect did these scares have on you, as a small child?

It didn't really affect... To me, it was normal, so there was no real effect on myself. Obviously you'd get worried thinking, you know, she's passed out, she's not come to. But it didn't really affect me. To me, it was just normal.

Was there any embarrassment for you associated with your mother's diabetes?

I don't think I ever did feel embarrassed. Living where we used to live before, when we used to call for the ambulance, a lot of neighbours used to come out of their house. And it wasn't embarrassment, it was more frustration, as in, they were very nosey and coming out. And obviously they knew my Mum was diabetic, and they knew she had passed out, but the fact they used to come out. And it wasn't a concerned thing they were coming out for, it was just basically "oh, what's going on now?" kind of thing. I think, as a teenager, going through the... when we used to go in shops, things like that, my Mum, when she's about to pass out, she tends to become very moody, and she could come across very rude to shop people. So, in that way, it would be embarrassing, as in "Mum", you know, "you need to eat something". And my Mum's very stubborn, when she gets to that point. She will not acknowledge you, she won't listen; it's just one of her signs. So, yeah, to that point it was a bit embarrassing, but other than that, you get over it. You know, you grow up, you become more mature, so...

- (3) Were there any embarrassments outside the house when you were younger than a teenager?

Me personally, no. But I do remember my sister - I think she was round about four or five, I can't be precise - but she was walking along one of the side streets from our house, and my Mum had passed out in the middle of the street. And what she had told me, obviously, she had passed out and a car had come, and a police car had come as well. And my sister was trying to explain to people that, you know, Mum's diabetic. My sister was more mortified, as in "oh my God, my Mum's in the middle of the road, and I can't help her", but yeah.

Did you get to know more about diabetes as you got older?

My Mum, obviously, she had Balance magazines that came on a regular basis, and we would obviously read it to begin with. However, as I used to get a bit older, I have to admit, I did become quite ignorant towards it. So, I'd only learn, basically, what my Mum would tell me. And as a child - it sounds quite rude to say - but when your mother's constantly telling you things, you don't really want to listen; you become defiant against it. So, in that sense, I did become quite ignorant, yes.

Has your Mum's response to diabetes changed, over the years?

She's got to the point where she knows the signs, however, in the past couple of years, she's quite stubborn. She has passed out quite a few times, and been oblivious to the signs, as if she's been ignoring the signs. It has affected her... to a point, it has affected her personality. My Mum has tended... she tends to forget a lot, and as a family, as a whole, we do tend to think it's part of the diabetes which has affected her in that sense. Her memory has got quite bad. And also, sometimes, it does affect your mood, because, obviously, if you're passing out and you feel drained, you are on a low, you know, for long periods of times.

And has the way her diabetes been treated - has that changed over the years?

Well, basically, as a teenager, and my Mum's obviously... When she passes out, she'll go to the relevant doctors, and things like that. And the only thing they ever come out with to tell her is, basically, to adjust her insulin levels. You can only adjust it every so often, and if you're constantly adjusting it, you're messing your body around. And they don't seem to understand that there's more to it, rather than just adjusting the insulin levels. And when they tell her "you need to make, you know, a higher dosage, a lower dosage", Mum - obviously she knows her own body - she knows what she can and can't take, 'cause she knows how it's going to affect her. And they... I have noticed, they do tend to ignore what she's saying. Just because they're qualified in the area, they assume they know, but they tend to disregard the person who's living with it for forty years, who knows how it's going to affect their body. I have been on phone calls to these, you know, relevant bodies, and they are quite rude. However, she's on new medication at the moment - it's to do with DEFNA - and I have to say it has improved. And with her diet has changed, she can eat a lot more things with this new medication. So, there are big changes in diabetes, especially in the last couple of years. Sorry, I do mean DAFNE. Basically, she went on the course, and they informed her of... basically, she can eat what she likes, but she has to monitor the level of insulin she takes. So, therefore, she can have more or, you know, reduced levels of insulin. So, it's better for her, in that way, and she does feel a lot more freer about her diet. You can actually eat chocolate, as well, so that's also an added bonus!

And does she seem to cope better with her diabetes since the course?

Since she's had the course, she hasn't passed out, so it's been very good. And she has a community-base with the people who actually attended the course as

well, so obviously they all communicate to each other. And after the course, nobody else has really passed out either. So, I mean, the other insulin trials that she's been on before, there's never been enough education. However, with this one, there's been a lot of education on it, and therefore it's helped her. It's like they've really paid an interest.

I think I'm getting some contradictory messages, so you can reflect on this. Now she hasn't passed out so much with all this education, but in the past, she was passing out a lot. Could you say that was her fault, in any way, that she'd perhaps ignored the doctor's advice?

I wouldn't say it was her fault. There was a lot of contradicting information. And my Mum is very in tune - she's very, you know, she's very, like, knowledgeable; she'll go out and research things. But then, if doctors and specialists are telling her one thing, and the other doctor is saying something else, it's very frustrating. I mean, the same specialist may tell her "well, increase your dosage". And then, a couple of months after she's done that, and it's still not working, "well, decrease it", or "increase it to this much". It's always contradicting on their part, rather than my Mum's part.

(4) And you say that you've had conversations with medical staff on the phone. Can you describe the circumstances?

When my Mum has spoken to specialists on the phone, and it will get a bit heated, as in, they're not listening to what she is saying. So, in that case, I do take the phone and say "look, my mother... you know, this is what's happening. I'm telling you from a point of view, as I've seen what's happened". Then they tend to listen. It's because... because she's diabetic, they just assume she doesn't know what she's talking about, because she may be passing out, or something. And because my Mum's... she gets very heated about it, which is understandable, they don't want to listen to what she's saying, but they'll want to listen to an outsider. It's very frustrating.

It sounds as though you've been quite involved in the management of your mother's diabetes. How has she coped when you haven't been there?

When I haven't been there, she's coped fairly fine with it. I mean, obviously when I was at college, she'd be more reliant on my father. At that time, he was actually working in London, during the week, so it was quite hard for her. She'd have to be more reliant on her mother, but, however, her mother is unable to travel, so she'd have to phone her brother. My Mum, she feels as if it's a burden, phoning other people. I mean, it is her family, but it's harder, she finds, because obviously there's that divide between the family, so she feels a bit of a burden, in that sense. A lot of the time, she will just, say, ring 999 instead, because she feels it's just the easier option, rather than ringing the family members. During university, my sister was here a lot of the time - and obviously myself - and my sister was mainly the main person who was, you know, helping my mother, in that case. After that, obviously, my sister's left home, it's just me and my Dad, and it will be myself who'll basically be here, who now injects. I mean,

sometimes I might get a bit scared, in case there's a couple of air bubbles in there, and I have to ring my Dad, and, say, just panic a little bit. And then he'll either tell me "just wait and I'll come home", or "ring 999". But more often than not, we tend to do it as a family, rather than ringing 999. You just feel like a nuisance, really, ringing 999 all the time. But other than that, she's done fairly well. I mean, she will manage it herself, and when she's home alone, she's very... she'll be checking her blood sugar level, she'll be constantly doing it, just to make sure she's okay. She's just more vigilant, in that sense, when she's home alone.

And what happens when you're at work?

When I'm at work, I mean, she's gave my telephone number to her work colleagues. So, therefore, when she's at work, I'm the first port of call, obviously, because my Dad does nights. So, they'll call myself or they'll call 999, but they'll always call me, just to inform me of what's happening. When she's at home, again, she'll phone myself at work or phone 999. I mean, if I can, I will always leave work. Work is very understanding, in that sense, so that's good, and at times when they've not, I've made it a point to them, saying "look", you know, "it's my Mum, I need to be there". So, they are understanding on their own backs, or by me, you know, telling them.

That's quite a responsibility for you.

Not really: it's my mother, so you are going to do it. I don't see it as a responsibility. It's how you would be with your children. If you have children, you'd do the same, so... Family's family.

(5) You mentioned phoning your mother's mother. How has your mother's family reacted to her diabetes?

Well, her Mum, she will tend to panic, if I do phone her; obviously, that's how a mother would be. The rest of the family have been fairly good, they will be attentive. However, as a child, I do remember, say if we couldn't go to functions because my Mum may have passed out, and therefore feeling tired, they would have always quizzed me and my sister afterwards. "Oh, so your Mum passed out, did she? When was that, what time was that?" It was more in the sense that they thought my Mum was using it as an excuse not to go here or go there. My Mum's very family orientated, and she'd never use things like that as an excuse. But you did have the feeling that they felt she was using it, you know, as an excuse not to go to places, which was, you know, not as supportive as they could have been.

What was your impression of your mother's family's attitude to her diabetes?

They were quite attentive. However, when I was talking to my Mum about the culture and things like that, the Asian culture is basically, if you have an illness or a disability in this lifetime, because, obviously, they believe in reincarnation, you must have done something bad in your previous life. So, when my Mum first developed diabetes, it was... she was shunned. She went to live with her

grandma, so she was shunned away from the family. And it was very much, “you’ve done something wrong”. Now, as a little child, it’s not very nice to do that, but obviously it’s the culture, it’s the way of life; they don’t know any better, in that sense. And obviously, until they come to this country, then, obviously, with the Western way of thinking, things change. But it was very much, you know, she’s done wrong. And also, it’s like... my Mum did used to tell us that, when it used to come to, you know, say, arranged marriages - so that’s the Asian way - they would always try and fix her up with somebody who had a disability. So, they could be in a wheelchair, but, “oh, you’re diabetic, so you should be with someone who also has a disability”. They didn’t see her as normal. So, it says a lot, that when it comes to the point of having your future with somebody, your own family don’t see you as normal. And, obviously, as a family, we do pick up on that.

(6) And what about the attitudes of your extended family on the other side?

Okay, well, with my sister’s family - as in her new family - they have been a bit weird, with my Mum, in the sense of baby-sitting. We have noticed that when they do ask for my Mum to baby-sit my little nephew, it’s always somebody else has to be in the house, or will never allow her to baby-sit on her own. I do find this a bit peculiar. I mean, obviously, yeah, my Mum may pass out, but then, she’s raised two children, there’s been no problems. She’s raised my elder nephew, with no problems. But, because of the younger nephew, there’s, you know, “oh, we don’t know, what if this may happen”. And again, it makes my Mum feel as if there’s something wrong with her, that she’s not normal, and that she may do something wrong. And it’s quite rude, and quite bad that people have that kind of mentality. I mean, with my Dad’s side of the family, they’ve been very accepting of it, because... it’s mainly because they’ve got people in the family who have diabetes. So, therefore, they’ve got the education there. And my Dad’s niece, who’s two years younger than my Dad, she also takes insulin as well. So, everyone’s well informed, there. My grandma had diabetes, my uncle’s got diabetes - well, theirs is the tablet form. But they’re very educated in that sense, and they don’t seem to see people as different from them, which is good. However, obviously, with the Asian side - my Mum’s side - it’s obviously a bit different to that. However, when it happens to their own - because one of our distant cousins, she also has diabetes, now - so, now it’s “oh, we accept it, it’s normal, you know, you can do this, you can do that”. But, because it happened to my Mum, and obviously it was, you know, a big generation gap, it’s quite different, the people’s perceptions.

So, you’ve got diabetes on both sides of the families. Do you have any concerns about getting it yourself?

No. I mean, if I, say, got it tomorrow, got it today, I have no concerns about it. You still can have a normal life; it doesn’t affect you. People think “oh, it’s one of the worst things that could ever happen”. No it doesn’t; you can have a normal life. It’s like having contact lenses. You can’t see, but you use a contact lens to see. So, what’s the problem? As long as you educate yourself, and know

how to take it, you know your limits, then there's no problem. At the end of the day, we live in a society where people just watch their diet. So, with diabetes, you have to watch your diet, so, to a point, it's normal. If anything, it just helps you have a healthy, well-balanced diet.

Has your mother's diabetes affected your own diet, as you've been growing up?

I think me and my sister have had an excellent diet. We're obviously... Bread-wise, you never have white bread, it's always been wholemeal. You can't have sugar. We're never allowed to have any fatty foods. If anything, we've had an excellent diet, and that is down to my Mum. Obviously, with my Mum, she's very wary about if we have sweet foods, and, you know, fatty foods, that we may develop it. So, we've obviously passed that... my sister's obviously passed that on to her children, and I think we're healthy individuals because of that. So, it's more of an advantage - sounds a bit peculiar - it's more of an advantage to have my Mum being a diabetic.

Did you all eat the same food as your mother?

Yep. There was no difference in our family. We were never thought to have any difference in our family, when it comes to food. Everything is the same: my Dad eats the same, we all eat the same, and everybody's happy with the food.

Did you experience any restrictions in either meal times or eating out?

No, no restrictions at all. There was nothing like that. I mean, my Mum, she'll obviously... say if we go out for a meal, she'll watch what kind of dessert she has, it wasn't too sugary, and things like that. But then, as a family, we don't really have a sweet tooth anyway, so it was normal for us.

(7) What would you say was the most frightening time for you, regarding your mother's diabetes?

Well, when my sister had moved out, and my Dad was at work, it was my first time ever injecting my Mum. And I knew how to do it; I'd read the instructions and I'd practiced before. And it was my first time ever doing it. And I was always told, always be careful there's no air bubbles in there, because if there was a massive amount of air bubbles, and it's going into her bloodstream, obviously she can die with that. And I panicked like no-one's business. I was very, very scared. I was, with the syringe, flicking the syringe every five minutes, flicking, flicking, flicking, flicking. And I just couldn't take it. So, I rang my Dad, and said "look, I can't do this", you know, "there's too many air bubbles in there". He goes "look, I'm about five minutes away from home." He came home, he looked at the syringe, and he goes "no, no no, you're fine with that". And I just couldn't do it, but he did it for me. So, to me, that was the most scariest moment. Obviously, when I thought my Mum was a monster, as a young child... But when I've had to do it myself, that was very, very nerve-racking, because it was... her life is in your hands, to a point.

So, you've described some events that could be called traumatic, and yet, you've

also used the word normal, normal, over and over again. Would you like to reflect on those two?

Well, everybody has traumatic parts in their life. Yes, it was scary, but again, because it's all I know, so to me it is normal. I wouldn't change anything. If anything, that moment has made me more aware. And, obviously, I've educated myself more - I know what to do more, I've taken more of an interest. So, it's helped me get more close to my Mum within the diabetes side of her life.

Can you reflect on what could, perhaps, have helped you, as a child, coping with your mother's diabetes?

Well, obviously, when I was younger, I had the brief training, as in a ten, fifteen minutes session with the doctor with the orange. I think, for young children, there should be like a child-friendly training session for children. A child-friendly book to help children as well. There is no information out there for that. And for... obviously, if your mother is diabetic, who's the main person around the mother? It's the children. So, there needs to be more of a child-friendly focus, with the children, on the training segment. Also, people like the specialists, they need to take more of an interest with the children. Yes, they talk to the mother, but then, obviously, if the children are there at appointments, they should take more interest with the children as well. There is no education out there for children, full stop.

(8) What are your memories of going to the hospital clinic with your mother, as a child?

Waiting in the waiting room, obviously, for long periods of time. Playing on the toys; getting very, very, very bored. People coming out, and speaking to my Mum, but there was no communication towards me and my sister; it was as if we weren't really there. Nobody acknowledged us. It was just, me and my sister had to entertain ourselves. And they were basically the memories: just waiting in waiting rooms.

What are your feelings about your mother's diabetes now?

I'm very happy with the way she's managing it. The only other concerns that myself and the family ever have is obviously her driving. There have been quite a few occasions where I've have been in the car with her, and she has started to pass out a little bit - she's... you know, her blood sugar level's going down - and she does become very stubborn. And it was more nerve-racking when I didn't know how to drive, so, therefore, if we stopped or we needed to, you know, take control of the car, I didn't know what to do. However, obviously, passing my test, I feel more, you know, confident now. Where I feel that she's not ready to drive, I myself will drive. However, she has got a lot more better - she will always test herself before she drives. With this new medication, it has helped her, again. Yeah, but that's one of the main concerns, because, obviously, if she has an accident on the road, what's going to happen? Another car's going to go into her, and who's going to be the one at fault? Obviously it's going to be her,



isn't it?

Has she ever had an accident?

She's had accidents - not due to diabetes; just other accidents, yes.

Do you have the impression that it's any easier, nowadays, for a child to cope with their mother's diabetes?

I do think there's a little bit more education out there for children. I mean, for example, say you watch these TV programmes, and... where children win awards: "oh, my child did this when I passed out". And you think, well, sorry, that's an every day occurrence for me, what's so special about it? And there is a lot more information out there, which is good, but I do think it can get better. I mean, I have never seen any child-friendly books out there, again, for children, concerning, you know, the illness. And I'm sure that's with any other illness out there; there is no child-friendly information out there. People feel that they need to protect the children by not informing them, but then they're not protecting the children, because, if something happens, as a child, the first thing you ever do is blame yourself. You don't think it... "oh, well, it's a normal thing", you blame yourself. So, to protect the child, they should educate the child.