Safia and Elene - storyteller ep transcript

Kola: [00:00:00] Welcome to My Life with Dementia, a podcast from Dementia UK. I'm Kola Bokinni. After losing my dad to vascular dementia, I wanted to share stories of other families who are facing dementia and finding a way through it. So in this series, you'll hear how people are adjusting to life with dementia or the loss of a loved one.

And how Dementia UK Specialist Admiral Nurses can be there for you in the toughest moments. If this is your first time listening, welcome, you can find a link to Dementia UK's Helpline in the show description and a wealth of information in every episode. If you're joining us again, welcome back. Coming up in this episode.

Elene: I would like my legacy to be. I've helped everyone that possibly came and knock on my door or phone my number and asked for help that I didn't say no, that I tried to open a door for [00:01:00] them because that door was not open for my mum.

Kola: You might already know about dementia. UK's Admiral Nurses. Specialist Dementia nurses who offer free advice and support to people living with dementia and their families and carers. In March, 2025, Safia Seini joined Dementia UK as one of the charity's first Admiral Nurses for Black African and Caribbean communities.

Safia recently sat down for a conversation with Dementia UK Ambassador Elene. They talked about Elene's experience caring for her mum. Who had mixed dementia and died in September, 2023. And why? Cultural awareness, which is often overlooked, is actually really important to provide compassionate person-centered dementia care.

Elene: Elene, can you tell me a little about your mum? What can I say about my mum? Um, for number one, I'll just [00:02:00] give you a joke about her name. When my mum was born, there's one boy, four girls. So my uncle was the eldest. So when he saw my mum, he called her, oh, look at my little SISs. So the name SISs got stuck.

At her funeral, my son said he was 38 years old before he knew what my mum proper name was. Her name is actually pronounced Medling, so that's why people prefer to call her Sis. But my mum was um, quiet, very straightforward, very hardworking. Yeah, strict. Although she didn't raise me, my grandmother's Sister raised me.

I used to live in Birmingham. She lived in Redding.

Safia: Yes.

Elene: I used to go up on my holidays and then eventually I moved to Redding when I was about 12, but I still didn't live with her. I used to see her every day. I didn't have anything in my mind what my mum's supposed to be like. I just accepted as I got on with her, we had jokes.

She took me out to places, but sometimes, [00:03:00] like later in life, I felt that I was missing out. Eventually I lost my dad 2010, and then is when my relationship really kicked off with my mum. She used to call me like two, three times a day. We'd talk about any and everything. We start going to reading light once a month or every other week.

Take her shopping, making sure she's all right. Sometimes I wish that relationship was earlier on in my life, but I don't hold anything against them. My mum did what she thought was best with the tools that she had. My mum, everyone would say the same thing. Sis was quiet, very straightforward, walk very upright, stand for no nonsense.

Safia: Was she, was she a good disciplinarian then?

Elene: I had to be careful 'cause don't forget, I live with my aunt, so the last thing I wanted was to be disciplined by two people. Definitely. [00:04:00] Um, yeah. But yeah, she was amazing. One thing I'm really grateful for is even although I didn't have a hundred percent of a relationship in my younger life, my children had a thousand in one relationship with her.

Okay. Yeah. She used to roll around the floor, especially with the twins, and she did everything she could possibly do for them. She would do for them. They were the apple of her eyes.

Kola: Elene thinks her mum's dementia symptoms probably started as far back as 2017. But at the time, Elene was still living in Birmingham and her mum was down in reading.

Elene: I think that I miss so much because not living with my mum. Yes. Or not living in the same area as my mum and just going to see her like once a month or every other week. The signs were there. Yeah. But my mum always had a story to tell mum, why is the curtain at 10 o'clock in the lounge drawn? And it's like, oh.

I couldn't be bothered to [00:05:00] pull them, that kind of thing.

Kola: Small changes in a loved one, like not opening the curtains in the morning or losing their keys, those things don't necessarily mean something serious is wrong. But in June, 2019, it became clear that cysts needed help. One morning she called Alina and the police saying someone had broken into her house.

The police visited and found nothing had happened.

Elene: So the next morning I went up and I took her to her gp. He knows her quite well 'cause that's been her GP for like 40 odd years. He told me he would get the mental health team to come in and do a proper assessment on her. So probably about three weeks later they came to the house.

They were there for about two and a half hours and you know, they went through a lot, a lot of things with her to see like on a day-to-day how she was, was she cooking, paying bills, this, that and the other.

Kola: After a [00:06:00] few different assessments, SIS was diagnosed with a common form of mixed dementia, Alzheimer's and vascular dementia.

That was in the summer of 2019 when her mum was 85 years old. And her GP helped deliver news.

Elene: It says, well, the report's come back. Have you heard of the word dementia? And she says, I think I've heard it on the tv. And it says, well, um, it's come back that, you know, you've been diagnosed with dementia. My mum shot out coverture dementia.

I ain't got dementia. The only body got dementia is you And the doctor face went so red, you know, and he just sat back there and I thought, he must have think God, this room should open up and take me anyway. I sort of say to him, I think I sorta. Take her now, and he says, please, on the way home. I says, mum, did you understand what the doctor was telling you?

I don't wanna talk about it. Nothing wrong with me. So I [00:07:00] took her home and over the weeks trying to gently bring around the conversation,

Kola: it was hard for Sis to accept. In fact, it wasn't something she wants to acknowledge or talk about. So Ilene just focused on looking after her mum. And now she transitions into this new carer role.

Elene began to witness the barriers that people from black, African, and Caribbean communities particularly face when it comes to getting care or support. They need

Elene: a lot of Afro-Caribbean fight, even today. Still find it a struggle. Of going to the gp if they can get an appointment nowadays, getting a proper diagnosis or getting the preliminary diagnosis and followed up by a proper assessment, that is a barrier for them.

I can remember as a child where people was, say that the lady up the road is senile, she's. And I think a lot of Afro-Caribbean people thinks of dementia of [00:08:00] someone that's mad that's gonna go outside and shout and raise their hands. That is the stigma that's coming from dementia.

Safia: That's the thing about cultural perceptions.

Even though when we talk obviously of black African Caribbean people, we know that they're not a homogenous community. So it's not. All of us are the same, but cultural perception sort of permeate.

Elene: You know, we have a lot of family where my mum lived. My mum cannot go on the road and don't see someone that is either family or someone that's known her, but yet all of them chose not to say anything.

And that's what hurt me. 'cause when I go to Reading and I start doing things for mum in this. Seen me?

Kola: Mm-hmm.

Elene: Oh, you, you moved back to Reading And I said, yeah, I'm sort of looking after my mum. Then they were telling me the story. Yes. I wanted to hear that story when it started. Right. And I started to get defensive.

It's like you didn't tell me when it was there, so I don't wanna know now. That was me. 'cause there's no [00:09:00] point in me knowing now I already know what the situation is.

Safia: I have seen and practice very often. The stigma that you mention. Families don't want to come forward. It isn't necessarily that they don't want the support, it's because they are sort of afraid of being discriminated against.

They are also afraid of being ostracised in a way, like shunned by their community should they come forward and what's more, sometimes people just fear that their loved one would be put into some sort of institution if they were to come forward with saying that this is what's happening. So you find people don't really want to do that.

Like I said, it's not because they don't need the support. They very desperately need it. When we talk about people being diagnosed with senile dementia and the perceptions of madness, we know that very often when someone is living with dementia, they may exhibit some [00:10:00] sort of behaviors that might not be appropriate or be deemed appropriate, whether socially or societally, as what we would expect.

So very often people will label them as being, you know, mad. And the other issue is we have very often. Attached a lot of stigma to mental health in general, regardless of what mental health condition someone is living with, as long as it's mental health, we are going to stigmatize it. And because dementia, even though it's a neurological condition, has lightly been deemed as part of the mental health umbrella, people are very, very hesitant to come forward.

As a community, we are very, very resilient and we are incredibly adaptable, and because of this resilience, we sort of like to depend on our own selves. So you would rather depend on yourself and on your family than go outside and seek for support. There's a lot of mistrust there. And because of this mistrust that exists, [00:11:00] discrimination and what have you, people very often don't want to do that.

So I, I think that sums up our cultural perceptions and how that might, at the very base of things, influence how we go out and we receive the sort of support that we need.

Elene: You touch on something there when you say about in putting an institution.

Safia: Mm-hmm.

Elene: And I was just thinking if that's why a lot of Afro-Caribbean do not want to put a low horn in a home because they feel that they are going against everything what they were raised.

Because we were raised to look after the older people.

Safia: Yes, of course.

Elene: Right. So to put someone in a

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Safia: home, it's available.

Elene: Yes. It's a failure on that family. But I didn't look it like that. I mean, if my house was durable for my mum, I would've had my mum at home. Yeah.

Kola: Some people with dementia, especially Alzheimer's disease and frontal temporal dementia, can experience symptoms that seem to change their personality. [00:12:00] The person with dementia may not realize they're acting out of character, and occasionally they might even become aggressive verbally or physically.

With the people around them

Elene: looking after her for the year. It was only in the December for the first time that my mum showed me what aggression was like. Mm-hmm. And it frightened me.

Safia: Yeah.

Elene: Because, you know, this person in front of me was not my mother. You know, she, it sorta sort of brought me down with a, a, a thump like, what's happening?

Where's my mum? Mm-hmm.

Kola: When this happened, Alene rang the dementia UK Helpline to ask for advice.

Elene: Explain it to me like, you know, because it's your mum, you need to pull yourself away, that that is your mother. Just pretend it's someone you don't know. Yes. Because when they calmed down then and everything started to go back on track.

That person will come back.

Safia: Mm-hmm.

Elene: But it, it is a very difficult, difficult road.

Kola: In late 2019, Elene [00:13:00] made a decision to move her mum into residential care, and so Sis moved into a care home in January, 2020. Although Elene knew this was the right choice for her family, the move came with new and unexpected challenges.

Elene discovered that the care home mostly planned things around what worked for the majority of the residents, whether that was personal care, routines, food, or activities, but that approach can leave some people behind.

Elene: When my mum went in the home, I was told that they have a duty of care.

Safia: Mm-hmm.

Elene: To keep her in the way that she was brought up as much as they can.

It was important to me that my mums still identify some of the food that she was grown upon.

Safia: Absolutely.

Elene: And also to keep up her stamina and her nutrition.

Kola: For people living with dementia, changes to their routine can be detrimental to their overall wellbeing, and food is a huge part of all our daily [00:14:00] routines.

Helene's mum was used to eating meals like rice and peas with veg and curry mu, and the food she was given in the care home was nothing like her usual diet.

Elene: This particular day when I went in, they put a plate in front of my mum and I'm like, what's that? And I thought, you're joking. It was like. A garlic bread, a piece of garlic bread, and it looked like I gave you one side and I had one side and we played tug of war, you know, and it was like, looked like half raw chips.

So I said to them, my mum wouldn't eat it. Eventually I asked for a meeting with the care home manager and they taught the talk and I had a meeting with the chef or the cook over what you call them. Nothing was changed. I see Mum was getting things that she wouldn't eat. Turn its par. Its my mum's never at those in her life.

So then I made a decision.

Kola: Elene decided to bring in food [00:15:00] for her mum for at least two or three meals each week. Elene would make food in her own kitchen and deliver it to the care home, and she supplied ingredients they could use on the other days.

Elene: I was buying pumpkin and sweet potato for the days I couldn't cook for my mum.

I was providing them and the cook was cooking them and putting it with the rest of my mum food, and that was throughout. Her time in the home. And then the later it got, the more longer she was in the home, the more that I would cook.

Kola: Mm-hmm.

Elene: Cook for her. I was buying bananas. I was, it was like, I was shopping for my mum every week and taking it in, and I was saying to them, why, because, you know, you assess my mum, you said all of these things would be here, but yet you are failing her.

Safia: She's under your care.

Elene: Right. And you have a duty towards her. I can remember as a young person when my children was at school, I can remember loads of people starting up petition to sign for [00:16:00] Afro-Caribbean food in schools, in hospitals, and this is 2025 and we haven't moved very far.

Safia: Yeah,

Elene: on that. Why?

Safia: If you're going to take someone and lay your care, food, nutrition and hydration is one of the very essential things.

It's fundamental. So a human being's life, it's quite heartbreaking. There's obviously the need to tailor people's care to the culture that they come from. You know that their cultural background. Yeah. What do they eat? What are the beliefs that they hold about themselves that are fundamental to them?

What are the considerations that institutions have to put in place to ensure that they deliver that care and they deliver it well? Those are the essential questions that you have to be asking. But what I've found is that very often we look at things in systems and we look at major provisions that we have to make for the majority of people.

And very often what this means is we let the people who don't quite fit into those systems, [00:17:00] they sort of fall back unless we make a plan and we provide for them. Making plans for those people who don't quite fit. Sometimes it's not practical, and so we, we, we don't do that. But when it comes to dementia, you really can't look at things from a practical lens.

You have to look at things from a person centered lens. Who is this person before me? What's your story to date? What do they eat? What music do they like to listen to? What makes them happy? What's their daily habit like? If I wake up in the morning and I have breakfast before brushing my teeth, and you come to me, you know I've been doing this for 50, 60 years, you know, and then you come to me one day and you're like, no, that's no good.

When you get up in the morning, you must brush your teeth. Why would you do that to me, that's not what I like. That's not what I do. So you have to fit what's happening to shoot at the person, regardless of whether they are African Caribbean. Whether they're black, whether they're self Asian, whether they're Chinese, whether they're even white.

Regardless [00:18:00] of it, you really need to look at who the person is. You cannot just assume that what, what works for one person works for all. There's no one size fits all approach when it comes to dementia.

Kola: It wasn't just food where a lack of cultural knowledge impacted life at the care home for Sis.

Elene: My mum had court.

A lot of hair afro or whatever, what you wanna call it. Anyway, I provided the shampoo, everything. Mm-hmm. For, so one morning I went in and this carer said to me, oh, your mum, we've washed her hair, da, da, da. So I said, you have to comb me. So I said, that's all right. I'm here. I'll comb my mum's hair. So I got the comb and I went like that and put my hand.

It was a big dollar per something in my mum's head. So I said, what have you, what have you put in my mum's hair? She said, oh, the moisturizer, lotion. So I said, well, how, what have you done? She just hold the bottle and squirt it in the top of her head. So I had to sort of say to her, we don't [00:19:00] do our hair like that.

We put it in our hands, rub it up, massage it in her head. Right? So I went to the manager and I said, look, I said from now on, anything to do with my mum's hair when I come in. I will deal with it, right? Because your carers just don't know how to do it, to just stop any problems. I can understand why a lot of people have doubts of putting a loved one in a home because the stories that are circulating about, it's like, no, my mum's not going in a home.

Kola: Over the past six years, Elene has regularly called up dementia, UK's Helpline. She says The advice and support has been invaluable. It would've been even more impactful if Safia's role had existed when it all started. Today though, Dementia UK has specialist clinics for people from Black, African, and Caribbean communities.

Anyone can call and speak to a nurse like Safia, who [00:20:00] understands the experiences and challenges they may be facing.

Safia: It's with the understanding that culture affects people in different ways. Mm-hmm. You know, I mean, dementia doesn't discriminate, don't get me wrong. But we all understand how cultural perceptions can affect how we receive and respond to services.

So my role essentially is to support people from these communities by providing culturally informed or culturally sensitive dementia advice, support, and guidance. And. Just with the understanding of cultural nuances really, and it's an opportunity to come out and to talk about what exactly it is that's happening with you, be it in an emotional psychological sense, and you need that sort of support, or you just need advice and guidance.

It feels very isolating and lonely, but sometimes when you speak to other people, you find out that there are so many people. Who are facing the same things as you [00:21:00] are, and in a sense that can bring a sense of comfort because you know that you may be living alone, but you're not truly alone in your journey.

And there are people who can always come in and support you. If you go to them, but again, I recognise and I appreciate that it's not as simple as just saying, pick up the phone. There are complex emotions because some people feel like by seeking support, I am failing my family. You know, I need to keep it in.

I can't just come out and tell people I'm not, you know, I'm not doing what I'm supposed to do, that I'm failing my family, that I'm struggling with care, that sometimes I wake up in the morning and I don't even know how the day is going to be. Like or look like, and that hour to hour, I'm scared. Nobody wants to say that.

Elene: Yeah. I, I, I agree with a lot of that because being a carer myself, you know, at my church I run, like alongside the outreach, a carer can come in and some of them just want to come and [00:22:00] talk.

Safia: Yes.

Elene: Right. Just someone's come for an hour or so to look after that person, so they just come out Can. Talk. Some of them need advice or some of them just want somewhere where they can come and have a cup of tea.

I think the carers are always getting left behind because they feel that all the everything is going into that person that has been diagnosed, and they're the ones that are looking after them, and no one think about how they feel, but it's important that we recognize them because. A lot of them, sometimes they're feeding the person that is has dementia, but sometimes they don't have enough time to eat properly themself.

Or if they have a pain problem to make an appointment at the doctors to go and get themselves medically checked out.

Safia: You know, some people don't even identify themselves as carer as

Elene: terror.

Safia: I'm a daughter. Yes. This person who is living with dementia, who has been diagnosed with, I'm the wife of this. I am the husband of this. I am the Sister, I'm the brother, I'm the lithium, the [00:23:00] niece sometimes, and I want to just put this out there.

Some people don't even know that carer means someone who supports a person. Yes. They think a carer is someone who is professionally paid to care for someone. So when we say carer, I think it's really important we define who a carer is. Because someone might be listening to this and think, oh, but no one pays me, so am I a carer?

Elene: Yes. As long as you are looking after someone that is depending on you to put food on in front of them, to to wash them, to give them, make sure that they take their medication on time, you know, that is, that is caring. Like when you become a mother, you are a carer because that baby. It's depending on you.

And the same thing you know in the Caribbean all over. There's a saying, once a man, twice a child. Yes.

Kola: As an ambassador for Dementia UK Elene has found purpose in supporting [00:24:00] other people from black, African, and Caribbean communities sharing what she's learned and providing space for people to talk.

Elene: I would like my legacy to be, I've helped everyone. Possibly came a knock on my door or phone my number and asked for help that I didn't say no, that I tried to open a door for them because that door was not open for my mum, right?

So as many doors as I can open for another family to stop them going through the doors that were shutting my face, that is what I would like to leave as a legacy, that I was there to help those, that there was no help for them or signpost, those that think there was no help there. I was able to open that door for them, and that is what I would like to carry on to do.

Kola: Thank you Elene for meeting with Safia and sharing your story. If you're in a similar situation to Elene, you may find this next episode, [00:25:00] especially useful Dementia UK Admiral Nurses, Hilda and Safia. Dive deeper into some of the themes that came out in the episode. Offering advice from their perspectives as specialist Dementia Nurses.

Hilda and Safia's episode will be out two days after this one, so look out for it in your podcast feed.

This has been an episode of My Life With Dementia, a podcast from Dementia UK. Please subscribe in your podcast app to get new episodes as soon as they come out. And if you've enjoyed this episode, why not share it with someone you think might find it useful? You can take a look at the show notes for a link to our support services, which include online resources, ways to contact Dementia UK Helpline, and information about Admiral Nurse Clinics.

Thank you so much for [00:26:00] listening.