

My life with dementia – episode eight transcript

Food, routine and tailored care: how Admiral Nurses can provide culturally appropriate dementia support

Kola: [00:00:00] Welcome to My Life with Dementia, a podcast from Dementia UK. I'm Kola Bokinni. I'm here because in 2023, I lost my dad to vascular dementia, and now I want to help other families who are going through something similar. Admiral Nurses are specialist dementia Nurses who give families a space to talk to someone who understands.

No question is too big or small. In this episode, two Admiral Nurses, Hilda and Safia, are sharing their practical advice and insights on themes from Elene's story. If you want to listen to Elene's episode first, you'll find it right next to this one in your podcast feed. Coming up.

Safia: In my culture, for instance, there's no such thing as a carer.

Mm-hmm. You are the daughter of your father. Mm-hmm. The son of your mother. Mm-hmm. You are the uncle to someone. Yeah. The niece, the nephew. You're not a carer. In the [00:01:00] UK, we have the term carer for someone who- Yeah ... is supporting another person, but culturally, there's no such thing. Does that make a difference as to take-up of services?

It does because if I don't recognize myself as a carer- Yeah ... and there's no such term, and I see the word carer, I don't think it applies to me.

Kola: You'll hear Hilda and Safia explore things like how cultural beliefs can affect how someone responds to a dementia diagnosis, the guilt family members may experience when there are problems with their loved one's care, and more information on Safia's role as an Admiral Nurse of Black African and Caribbean communities.

If you'd like to speak to an Admiral Nurse, you can pause this episode at any time and follow the link in the show description to find out more.

Hilda: My name is Hilda Hayo, and I'm the Chief Admiral Nurse and CEO of Dementia UK.

Safia: And I'm Safia Seini, Admiral Nurse for the Black African and Caribbean communities. [00:02:00] I met with Elene, who is the volunteer ambassador for Dementia UK, where we discussed Elene's mum's diagnosis.

Hilda: So one of the things that Elene spoke about is how people in the community actually noticed some changes in her mother but hadn't thought to actually say to Elene ab- about what they'd noticed, and she felt quite cross about that.

Mm. Um, it can happen. It happens in, in lots of different situations. They say, "Oh, yeah, we noticed for the last few years that, uh, X, Y or Z started to behave in a different way."

Safia: Definitely. Yeah. And you would find that sometimes people don't think it's in their place- Yeah ... to come and tell someone that, oh, we're seeing A, B and C- Yeah In Elene's case, in Sis, in her mum.

And sometimes people don't like it to come across that they are gossiping about- Yeah ... someone they highly regard in their community, so very often they won't come out and say it. And I think in speaking to Elene, she was particularly heartbroken by [00:03:00] that. She was, yeah. Because she felt that she had a sense of community- Mm

and she felt that community members who were her friends and her loved ones would have told her about it. Yeah. And it was only when Sis had progressed to the extent that her symptoms were really noticeable- Mm ... and Elene herself had picked up on it, that people then came and said, "Oh, yes, we saw it too."

Yeah. And she felt, "So why didn't you tell me?" Very often people just don't want to say something negative. Yeah. And there's also the added layer of denial. Sometimes people see it- Yeah ... but they think, "Oh, if I close my eyes hard enough-" "... and if I pretend hard enough-" Yeah ... then it will all go away." Yeah. But unfortunately, it doesn't.

Hilda: Or they attribute it to something else. "Oh, they must've been having a off day. They were looking a bit stressed," or there's been a life change or they're not feeling well. So yeah, there's an attribution that tends to happen as well. Definitely. Yeah. So when we looked at what, um, Elene's actually was saying [00:04:00] about- Mm

the diagnosis with her mum, it was talking a little bit about some of the lack of cultural awareness for some of the health and social care professionals, which is why we've actually developed- Mm ... your post and, and another post within the charity. Can you tell us a little bit more about your role?

Safia: So my role as an Admiral Nurse for the Black African and Caribbean communities comes with the understanding that culture, um, affect health outcomes.

Culture shapes and frames the attitude that people have. So in a nutshell- The service exists to provide culturally sensitive dementia advice, support, and guidance primarily to people of Black African and Caribbean heritage or from those communities. For now, we have appointments- Mm-hmm ... um, that are bookable through the Dementia UK website.

Mm-hmm. Our landing page is Black African and Caribbean communities. Mm-hmm. We have appointment on Tuesdays and Thursdays. Mm-hmm. It's 45 minutes. It's free and confidential. Whatever is discussed [00:05:00] stays between the Admiral Nurse- Yeah ... and the person who books that appointment. We want to support people who may be facing cultural stigma- Mm-hmm

and sometimes might not even know it. We also want to support people who are supporting a loved one who's living with dementia. Yeah. Whether they term that as dementia or not, because in a lot of communities, they may know the signs and symptoms of dementia- Yeah ... but might not know that it's actually dementia.

Yeah.

Or they may very well think that it's due to old age or it's a normal part of aging- Yeah ... when we very well know that it isn't. Mm-hmm. So we provide a range of support and, yes, we really want to make an impact within Black African and Caribbean communities here in the UK.

Hilda: Super. Have you got an example of the sort of person that might come along and the issue that might be presenting in the clinic?

Sometimes it's

Safia: aside from having that understanding of the signs and symptoms, it's also, well, we want meaningful engagement for our loved one who's living with dementia. I've had, um, an example where family came in and they said, [00:06:00] "Well, our loved one has been very difficult. We've sent the person to A and B, um, dementia cafe."

Mm-hmm. "And they went there and they won't do anything. Very, very stubborn." And so we had to try and unravel that and understand. And lo and behold, we made that discovery. Mm. Their loved one was an older gentleman, and he had come from a community in Africa where art was

something that children did. Ah. So in his older years, he was then told, "Well, you need to go and do artwork."

And in this person's mind, artwork is something for children. And so the person said, "No, I'm not doing this." Mm-hmm. And that was what was then termed as being resistant and being stubborn. Mm-hmm. So it's having that understanding of culture.

Yeah.

And, um, another example that I can share is supporting someone who came in and who said, "Well, we want our loved one to go into a care home, [00:07:00] but, um-" The community that we have back home probably won't understand.

Mm.

Right? So it's about, okay, how do we support this person- Mm ... to reframe it? How do we support this person to, in a way, either educate the people who are back home about- Yeah ... what's happening, and why there's a need for this decision. Because very often what you will find is, um, whoever comes into clinic sometimes is not the final decision-maker.

Yeah. Mm. The person is merely gathering information, as it were. Mm. So it's about making sure that that person is also equipped. And then it's, again, building confidence in people so that they are able to access services. And when there is some sort of dissatisfaction, that they are empowered enough that they can gently challenge inequalities- Yeah

or inequities when they see it. Yeah.

Hilda: I found it really interesting when Helene was saying about being a carer. Mm-hmm. It's not something that, that is so accepted as a term. It

Safia: isn't. Yeah. Um, [00:08:00] in my culture, for instance, there's no such thing as a carer. Mm-hmm. You are the daughter of your father- Mm-hmm

the son of your mother. Mm-hmm. You are the uncle to someone- Yeah ... the niece, the nephew. You're not a carer. Mm. So when you are supporting an older person, there's a strong emphasis on respect, obedience, and seniority. Mm. And this means that older people are more or less revered. So if you are supporting an older person, it's what you should do.

Mm-hmm.

In the UK, we have the term carer for someone who is supporting another person, but culturally, there's no such thing. So a lot of people think that a carer is someone who is professionally paid, so they can't- Mm ... identify themselves as carers- Mm ... simply because it, it doesn't really exist.

Hilda: Right.

Safia: Does that make a difference as to take-up of services? It does, because if I don't recognize myself as a carer- Mm ... and there's no such term, and I see the word carer, I don't think it applies to me.

Mm-hmm. [00:09:00] So

if I s-hear that there's a program, for instance, for carers, I'm thinking, "Oh, it's for those people who are paid to go there.

I'm not going to go there." Yeah. So if there's a service, I'm really not going to access it. And it's quite saddening that it's for a mere terminology. Yeah. And if that was changed, people would think that, "Oh, this is for me too-" Ah, yeah ... "and I would be able to access this service."

Hilda: Yeah. So there's, there's, there's a bit of work to do around that, obviously.

Um, so we need to be able to change the public perception, but also, I would say our health and social care, um, professionals as well.

Safia: Definitely- Mm ... because there's a need to develop cultural competence and cultural humility Obviously in the UK, we live in a multicultural environment and multicultural society.

Mm. So we're all coming from very different cultures. Yeah. And if we aren't exposed to a particular culture, we may never actually know about it. So when we are supporting people, we won't know the nuances- Mm ... that's involved in that particular culture. [00:10:00] So for instance, communication styles. For some people, direct communication is how best to communicate with them.

Mm. And for people from other cultures, it's indirect communication. Mm-hmm. So w- we really need to know all of this so that we can build trust with- Yeah ... the population or with the people that we are supporting,

and when we are able to promote trust, there's a high likelihood that when we recommend that they do something, they'll be able to follow that up.

Hilda: Yeah. Yeah. Elene was saying about her mother in the care home as well. Mm-hmm. And although the care home was selected because it, it felt like the right place for mother, in reality, there were still some issues there. Definitely.

Safia: Um, Elene's story was quite heartbreaking- Yeah ... to be honest. Yeah. We are all very, very different- Mm-hmm

and a one size fit all approach- Mm ... doesn't work. Mm. So it means that people have accommodation to eat food, for instance- Mm ... that is resonative of their [00:11:00] culture in however they want to eat that food. Mm-hmm. You know, Helena, I come from a culture where we don't have cutlery, or let me put it this way, we have cutlery, but we have our natural cutlery, which is we use our hands to eat.

Yeah,

yeah.

But if I were eating with my hands in a care home where someone probably had never seen that, the person would be shocked. Mm. So it's making allowance and giving provision for people to have expressions of their culture. So things- Yeah ... such as food, their religious practices, for instance, the way that they like to pray- Mm-hmm

and their daily rituals- Mm-hmm ... whether that's ingrained in culture or not.

Hilda: Yeah, absolutely agree, and I think that, um, if people did individualised care and they did the care plans properly, we shouldn't have these sort of situations occurring. It shouldn't be that a relative has to bring in the food Um, because the, the care home isn't actually providing that.

Safia: Yes.

Hilda: So I think that there's still a lot of work that we need to do within those settings. [00:12:00] Absolutely. Yeah. And I think when you, you've selected somewhere that's going to be for, for long-term- Mm ... so long-term care, you can feel very guilty if that doesn't go quite as well

as you anticipated. Um, and people will probably feel that personally rather than thinking actually it's the care home that's in the wrong.

They feel that personally. Definitely, Hilda.

Safia: Um, again, if we were looking at cultural beliefs- Mm ... because they play a huge part in ability to cope- Mm ... expression of pain, expression and handling of emotion. Culture is very, very often- Very ... found in there. Yeah. So what you will find is that from a cultural perspective, there is usually an unspoken expectation that you would care for an older one- Yeah

a duty of care. So very often, if there's a point in time that people have to make the decision that a loved one has to go into a care home, in itself, there is that feeling of failure- Mm ... of having [00:13:00] failed that person. So there's a lot of guilt as well.

Mm.

And then when they finally have the courage, and the loved one goes into a care home, and then they find that things aren't going so well-

Mm.

Mm ... there

is heightened sense of both failure, of guilt- Yeah ... anxiety, and shame. Yeah. So people have complex emotions that they are going through.

Mm-hmm.

The way I look at things, it's how best do we support people, one, in terms of communicating with them- Mm-hmm ... and supporting people to, as it were, unravel the different layers of cultural beliefs that may be impacting them and impacting

Hilda: them negatively.

Some of the things that we've been talking about is why we've got your post as an Admiral Nurse working with health inequalities, in particular the Black African and Caribbean community. So going forward, we will obviously extend that [00:14:00] service as much as we can. But what would be your callout so that people will contact you on the Tuesdays and Thursdays?

So first off would

Safia: be that if you're supporting a loved one, you are a carer, and this service is for you Right from when you suspect a loved one is living with dementia, you're not quite sure what the signs and symptoms are, and you need support with knowing what to do and what the next steps are. We offer support if your loved one has been diagnosed and you need emotional and psychosocial support.

We offer support in managing some of the behaviors that come about when someone is living with dementia. Obviously, not everyone has these behaviors, but sometimes some carers can struggle with how to manage those.

Mm-hmm. We

offer advice about entitlement- Mm-hmm ... about benefits, and about the legalities of supporting someone.

So what is a lasting power of attorney, for instance, and what do you do if you don't have a lasting power of attorney- Yeah ... [00:15:00] but your loved one now requires support?

Yeah.

We go all the way to post-bereavement support- Mm-hmm ... helping families so that they understand what end of life is all about. Yeah.

Death sometimes is still very much a taboo topic.

Yeah.

So we want to ensure that people have information about death and what a good death looks like.

Mm-hmm.

So right from the beginning until the very end, we want to make sure that we're there and we're supporting families.

Kola: If you'd like to speak to an Admiral Nurse like Hilda or Safia yourself, you can contact Dementia UK's helpline. Just click on the link in the show description or visit dementiauk.org. The helpline is open every

day of the year, except for the 25th of December. 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 [00:16:00] 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 listening.