Michaela - Admiral Nurse ep

Marianne: [00:00:00] Welcome to My Life with Dementia, a podcast from Dementia UK. I'm Marianne Jones. I'm a journalist and podcaster, and an ambassador for the Charity. This is one of our dedicated episodes with two of Dementia UK's Admiral Nurses, Hilda and Vic. Admiral nurses are specialist dementia nurses who provide free advice and support to the whole family as well as the person with the diagnosis.

Both Hilda and Vic have years of experience working with people who are living with dementia as well as their family and friends. In this episode, they're going deeper on some of the themes from Michaela's story to give some extra advice and insight from their perspectives. So if you haven't heard Michaela's episode yet, go and give it a listen first.

You'll find it right next to this one in your [00:01:00] podcast feed.

Vic: Hello, my name is Vic Lyons. I'm one of the Admiral Nurses at Dementia UK.

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

Vic: We've just listened to Michaela and her family's story, and I think with this story you instantly got a sense of this very connected, very loving family unit who actually had supported each other over years, over whole generations.

And one of the things that stood out for me is in Michaela's words about it, taking a village to raise a child. And, and I, I love that sense that actually the whole family were involved in raising Michaela's child. But then also supporting Nanna Vanda as she advanced with her dementia. I think anybody listening to this wouldn’t question the real sense of love that came out of that podcast and that episode, this [00:02:00] head of the family and the impact that dementia had on the family.

One of the other really interesting things that came out listening to this for me was when Michaela spoke about this sense that stigma in Black communities is something that that is real. Of course it's real. We, we know that. It's not just in Black communities actually. We know that there is stigma around dementia in other communities too.

It can sometimes be seen as a normal part of ageing, as something that perhaps people might associate with shame or fear, or even spiritual beliefs actually, which can make families hide away. To quote Michaela, she talked about how keeping people hidden in a way or not acknowledging what's going on doesn't actually help the person.

It doesn't actually stop what's happening. It just sort of stops you being able to deal with it. And actually the way to tackle that is to, to go out there and talk about the fact that, [00:03:00] you know, yes, this is the changes that we're experiencing. These are the things that are going on. And this is so important because we know that people from Black, African, Caribbean families and backgrounds are potentially more likely to develop dementia, but also less likely to get a diagnosis and get access to services and support.

Hilda: You're quite right. There is a higher incidence of vascular dementia in particular within certain communities, the south Asian community and also the Black and Caribbean community. If it's a little bit more common, why aren't people talking about it? Well, yes, of course it's fear. Yes, of course. It's the stigma and what I'd like to see is people talking positively about the diagnosis and, and actually being upfront about the diagnosis and how it's affecting people and giving solutions and suggestions. And one of those excellent ideas was about the setting up of that community cafe. The Spring Bleau Dementia Cafe.

Vic: I think it's important to mention here as well, our [00:04:00] brand new service that we've just launched is a special admiral nurse who's going to be working with Black, African, and Caribbean communities.

And this is so important. This is such a, a fantastic new role that you think we would be silly not to mention here as well, wouldn't we really? Absolutely. And, and that role will be about actually understanding the culture, nuances around dementia in this community. Providing one-to-one support to families, and that might be emotional, practical support, clinical support and advice, and really helping to bridge that gap between the families and the healthcare systems and the support that's out there.

Hilda: One thing I thought was really great that Michaela did is she set up that group on a Saturday. So frequently you've got services and support that's functioning Monday through Friday. Not an awful lot happens at the weekend. So actually setting it up on a day when all the family can get together, where people can come and do activities, it helps people to then talk about what's happening to them.

[00:05:00] So all of those things, I think absolutely superb.

Vic: Dementia Cafes stop people being on their own. It helps to build communities and a sense of community. So you feel safe and included, and I think it's also giving you that sense of, we talked about that, that taking a village, but actually a cafe can become your village.

You might feel a bit nervous about that first step actually going in. I know there's a cafe that meets down the road, but actually is it for me, should I go. It's normal to feel those things. I think we all feel that way when we go to these things for the first time. But what many people tell us when we're working with them as an Admiral Nurse is actually, they feel a sense of relief.

They think, actually, do you know what? I'm not alone. I wish I'd gone to this earlier. I think that helps to break down that barrier as well, doesn't it? Michaela spoke as well about this idea that lots of families feel that sense that it needs to stay in the family, which then can of course lead to that kind of weight of caring, if you like, or the role of one, which Michaela also spoke [00:06:00] about.

We know that often in families it, it might be one daughter or one son, or one sibling or one grandchild, that picks up the kind of emotional, physical load, if you like, of, of caring, which can actually lead to that person experiencing burnout. Taking it outside of your family walls and saying, this is what we're dealing with enables more families to step forward as well. And say, 'Actually yes, this is something that resonates with us.' And it's those kind of open, honest conversations with your community that are going to help, and can encourage more people to accept the support that is out there.

Or if it isn't out there for us to kind of go, well, okay, what support do we need?

Hilda: That sense of community is really important. And that came across clearly and what Michaela was saying, the community that's actually all around that individual, not just the family, the whole of the community.

And I absolutely, I will say the [00:07:00] same thing as aou, Vic. It often does fall to one member of the family. Sometimes that's self-selected and sometimes it's somebody that's kind of thrusting that onto you because you are, are perceived at, at a certain time of life not to have so many commitments, for instance.

So therefore you can look after mum or your dad or whoever else. Yeah. That kind of puts on that load of, yeah, but I've now got to care for her. And you feel guilty if you want some time for yourself or, well, she used to do that for me, so therefore I should be doing it. So sometimes guilt is, is internal, is what you feel.

Vic: One of the other things that came through for me listening to Michaela's story was that that sense of grief and end of life, she talks very [00:08:00] poignantly about, about actually the end of life. We know that grief's a big part of the dementia journey and you know, actually it doesn't actually just happen at end of life either.

There's a term called anticipatory grief, which is the kind of grieving those small losses along the way. Grieving the change in the person. Perhaps you know, the person when they stop recognising you or they stop being the person who, who you think about as, as mum or whoever that person is for you, might even be grieving that shared routines, the conversations, the things you, you did together.

And so we know that that happens. That's something that all families, when you're living with someone with dementia, you kind of have to experience anticipatory grief. But you also of course, have that grief towards the end of somebody's life and, and actually how you acknowledge that and what that looks like for, for you as a family, and how do you prepare for that?

You know, how do you recognise somebody is getting to the end of their life? Who do we [00:09:00] need to see? Who do we need to connect with them around this time? It's a normal part of life, isn't it? Where you know, everybody listening is going to one day have to face this, but yet we don't often do a lot of preparation around those, those last parts of our life.

Hilda: And I think for some of the families that we support, it's about recognising when it is the latter part of a person's life. So we have something that's called palliative care. And palliative care is where we have an expectation that the person's probably got about a year left of their life and it's not an exact science.So it's not, it's not going to be an exact year. It might be longer, it might be less, but at that point, you've got a team of people called palliative care team that will go in and will be able to guide what the next stages are for that person that's living with the diagnosis. So in some circumstances it might be that they can suggest a certain amount of medication, or it might be that [00:10:00] they suggest a certain approach, or it might suggest there's more hospice care involved.

It depends on what the condition is really. I think it's recognising those early symptoms and often the symptoms that you would notice. Where you're getting towards the latter end of life is when the person starts to have problems with swallowing, when they start to lose weight or they don't want to eat or to drink.

I think family frequently, particularly if a person's in an institution or in a long stay bed, will think, oh, they're being neglected. Nobody's encouraging them to eat a drink, and the person's losing weight, when in reality that's part and parcel of the body checking out in effect. I know Vanda started to have some problems with swallowing. Started to withdraw from food and fluids and at that point, that's when there was a suggestion we might need to start thinking this is a person that's approaching the end of their life. We are there as well as nurses [00:11:00] and as palliative care teams to support the family. If you don't support the family well, at that point of the process, often the grieving process is much more prolonged after the person does pass away, the nurses specialist, dementia nurses in particular that we have in Dementia UK, we are on the end of a phone, so we can actually guide around that with the helpline.

You can book a clinic appointment and we can talk about some of those aspects.

Marianne: If you'd like to speak to an Admiral nurse yourself, you can contact the Dementia UK Admiral Nurse Helpline. It's open every day of the year, except for the 25th of December. And there's a link to more information about opening hours and how to contact the helpline in the show notes for this episode.

This [00:12:00] has been an episode of My Life With Dementia, a podcast from Dementia UK. Please do subscribe in your podcast app, and you'll get new episodes as soon as they come out. You can find lots more information about the things we've talked about in this episode. By visiting the Dementia UK website, it's dementia UK.org.

Thank you so much for listening.