Michaela - storyteller 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. Last year I lost my mum, Maria to dementia. I've written a lot about the condition over the last few years. Because I felt that it was something often hidden behind closed doors and not really spoken about.

In this series though, you'll hear directly from people whose lives have been impacted by dementia.

Michaela grew up in a close family, a multi-generational home, and a community where dementia wasn't really talked about. So when her Nan, Vanda was diagnosed with dementia in 2022, [00:01:00] it was a big learning curve for everyone.

Michaela became Vanda's primary carer and started a new dementia cafe to support not just her own family, but her local community too.

Michaela: I was born and bred in Luton. If you read the news, you see things that say Luton's the worst place to possibly live ever. But what I've realised is Luton is a little community that helps people. We are there for each other when we need each other, and there's some great talent that's come out of Luton and there's some great things that go on there.

I am Michaela Williams. I have two brothers and two sisters. I'm the oldest child and I'm also the oldest grandchild. Mum always used to say to me when I was first born, she was [00:02:00] like, although you was my first child, you wasn't my first child, because grandma always looked after you and you was literally like her last baby.

So she was like, I never got a chance to look after you until I moved out of home. She's like, I only really become a mum when I had my second child, which was my brother, because Nanna always looked after me. Nanna was the centre of the whole family. If I remember my childhood, it was sleepovers with Nanna and your cousins and this big massive family dinner on a Sunday where everybody would come and it was, it was the heart of the family.

Like even if people were popping by for a few hours, we would all be there. Grandad would take the kids to the park and we'd have lollipops or penny sweets from the corner shop. Grandma was family and the heart of the family. So that's what growing up was for me. It was being surrounded by family.

When I had Tiana, I was [00:03:00] up early in the morning 'cause I was working in Canary Wharf at the time. Out of the door for half past seven, back in at six, and I had this amazing support unit. So I was lucky and fortunate enough to do that and not worry about, oh my God, how am I going to provide for my child and how am I going to be able to work and do that?

Because they took care of her. She's 11 now. It takes a village to raise a child. I look at this kid and I'm like, wow, you're actually pretty amazing. And that's from all the people who have helped build her up.

Marianne: For Michaela, her Nan was one of the most important of those people. Her name was Vanda.

Michaela: If I was describing Nan to someone... loyal, loving, a woman full of integrity and grace and the heart of gold. She would literally do anything for anyone.

And also she's got a bit of a filthy mouth. She was a woman of love and a woman who loved to feed people, [00:04:00] feed, feed, and feed. No one would ever leave her house hungry. That is how I would think of Nanna and almost with a smile. Always. She was a magnetic force that just drew people to her, and you just naturally fell in love with her.

Marianne: Vanda grew up on the Caribbean island of St. Vincent and moved to the UK when she was 16.

Michaela: She had this thing that every grandchild was going to go home to St. Vincent because it was important that we all knew our roots and where we came from. Nanna and Granddad took every single grandchild throughout her life back to St. Vincent in her last few years with dementia. When we took her back there for like the first time post-diagnosis, she was so much more settled than she was in England, and it was like she felt back at home. I think St. Vincent was kind of a calming place for [00:05:00] her. She knew where everything was and she talked about her family and it, it was beautiful.

It was beautiful.

Marianne: The early signs of dementia can be subtle at first. With my Mum, it was the constant losing of her keys, her coat, her handbag, forgetting appointments, things that could easily be put down to getting a bit older and absent-minded. And that's what it was like with Michaela's Nan too.

Michaela: It was when she started losing her keys and purse quite frequently.

I think if I'm honest, there was a part of us that was like maybe naive to it because was like, course, technically it could be old age. I lose my bank card all the time, so I'm not going to say Nanna's got something and like kind of label her with an illness because she's doing what we all do every day.

Then it was the way that she started to dress. Nanna was so [00:06:00] prideful in how she went out. Looking good was a key factor for her. She always took pride in how she carried herself. She was just mixed and matching various things of her outfits and not really having that same self love of care and how she looked.

Or it wasn't even that. Maybe it was, she thought she looked great in her head, which she really didn't, and you couldn't really tell her that either at the time, just like, now, do you want to maybe change your outfit? But still at that point there was the denial part. No, I'm not labelling her with having. An illness like dementia.

She's just changing on how she wants to look. She's getting older. And then it was the cooking and there was random things going into the cooking pot that she never used to put in before. And I used to be have to be like, do we normally put that in there? Like, I don't think we do. And she's like, what? You don't want it in this time? You want to change it? And I was like, yeah, maybe let's change it this time Nanna.

Nan had a [00:07:00] stroke in 2022, and she was literally called up one day and was like, ‘Come Michaela, I, I can't move. I really don't feel great.’ I said to my dad, something is seriously wrong. I was like, I need to go to Nan's right now.

She was literally on the bathroom floor behind the door, so I, I had to kick the door open because she couldn't get herself up. We called the ambulance who came out pretty quickly.

Marianne: Michaela insisted on staying with Vanda. She was afraid her Nan would become more disoriented if she was left alone in the hospital.

Michaela: I said to her doctors, I really need to get her home. How do I do that? Like, what's the best way for us to get home? What do we need to do? They were like, oh, well, we're worried about her taking her medication and. How is she going to cope being at home by herself. And at that point, she was still able to go out and about and do what she was doing.

So I was like, to be honest, I've got no concerns and she's with me most of the time during the day. My uncle [00:08:00] stays there at night, so I think she'll be fine. We can keep an eye her.

Marianne: The hospital agreed that Michaela could take Vanda home. But one of the conditions was that she had to go to a memory clinic and be assessed for possible dementia.

It took over six months, but Vanda eventually had an appointment.

Michaela: I got a phone call from the memory clinic and she said to me, I've had a look at some old medical tests from your nan's scans and stuff, and from the conversation that we had, I, I think it's likely that your nan's got vascular dementia.

There's no medication that you can take for that. The lifespan’s like three to five years with vascular dementia. But like, don't be sad or don't worry about it. Like just create lots of memories. I sat there and there was a like a thousand thoughts going through my head at the time. [00:09:00] I just cried. I couldn't grasp it.

It felt like it was too much to take in and it was so overwhelming and I was like, oh my God, am I going to lose her? Like, she's not that bad. She can't be dying. I kind of had to like slap myself. I was like, I'm crying because I'm worried about Nan and of the person who she was before of this happened. The person who she is now, and the person who she's potentially going to be and what it's going to be like.

And then I have to remind myself, this woman's had 80 odd years in life. You've had her in your life for 40 years. You've had her meet your daughter. You've had all these beautiful memories and cherish Moments with her. Sort yourself the hell out. Like now what you need to do is think about what are you going to do for the rest of her life?

How do you help make her last [00:10:00] years her best years left and that was the moment, that was a realisation moment for me.

I'd heard about dementia, but I'd never thought, oh my God, it's going to affect someone in my family, or that had even affected like people that I knew.

Marianne: In some communities, there can be extra layers of stigma when it comes to conditions like dementia. Michaela has seen this in parts of the black community where she lives.

She thinks that's why she hadn't heard about other people living with dementia until she started sharing what was happening with her Nan.

Michaela: I had people who was like, oh, my mum's got it too. Or this person's going like, ‘I didn't know that.’ Or, ‘Why wouldn't you have said anything about it?’ There's a stigma attached to it because you see a change in your parent, grandparent or the person that you are looking after.

I feel like people feel embarrassment. They don't look the [00:11:00] same. They don't dress the same. They're not going to be able to behave properly, or they're going to act different. So if I keep them in, then I don't kind of have to worry about it. You still have to worry about it. Whether you keep somebody locked up in the house or you try to keep them out of public for as much as possible, you still have to worry about it.

And all you do is put more pressure on them and yourself, and you de-stimulate them even more. So it's, yes, this person has dementia and it is, yes, they are going to change, but you need to change as well. You need to allow them to be who they're becoming and you need to take them out in the world so people can see that this is normal.

This is a new normal way of life for people now. Like this is what dementia looks like. It's an illness. Like anything else, it's an illness like cancer. It's an illness like mental health. We can't lock people up or keep people away from other people because that really drives them into isolation [00:12:00] and they lose more years of their life from being stuck at home.

What I really like to do is try and get rid of that stigma. It's been so eye-opening into even how many of her friends had dementia that I didn't even know. And people living this journey in silence. Like, you are not on your own.

Marianne: Partly because of that silence around dementia. Michaela and her family had lots to learn about caring for Vanda.

Michaela: None of us was really aware of the stages of dementia. So for us, it was a learning path as it all took place. And for Nan, it was quite slow in the beginning, so everything was still quite normal.

We was just taking each day as it came, and then it became more of Nan waking up in the middle of the night thinking it was the [00:13:00] morning. Going on to cook a full on meal at like 10 o'clock at night or trying to walk to come and see me. And it naturally became, because Nanna had spent so much time with me, she was always trying to come to my house or come and see me or wanting to call me.

So it naturally fell to me to be her carer because we were just always together. For her, it was the known, I suppose. So I ended up being her full-time carer. I was fortunate enough in my role where I worked from home and my boss was really understanding so I could look after Nanna and do what I needed to do.

Your relationship changes from Nanna and granddaughter to mother and child. The dynamics of our relationship changed and it, I didn't love her any less for it, or I wasn't like, ‘Oh my God, now I've got two children.’ It just meant I have to look after her differently to how I would before. It's a whole lifestyle change [00:14:00] being a carer.

As it progressed and things got worse, Nanna ended up being with me like five days of the week. Her daughter would look after her on a Monday and a Friday, and then my uncle would do the night shifts, and then it ended up with me and my uncle would spit the night shifts. Because sometimes it'd just be easier for her to stay with me rather than going back and forth all the time.

And then my mum was obviously helping me at the time and doing the back and forth, and the picking her up and dropping her home and all of that stuff. They always say that with caring, it always tends to fall to one person. In the end with something like that, and it did for me with Nanna, and to be honest, I didn't mind it in the sense that whenever I've been ill or going through something, the first person who's always there is Nanna.

And when my daughter's been ill or going through something, the first person who's always been there is Nanna. So there was never a chance that I was ever going to not [00:15:00] be there for her. I'm going to make sure that you are able still to have fun. We're not going to lock you in the house because you have dementia.

Let's fight this for as long as possible.

Marianne: Although her commitment to Vanda never wavered, being a primary carer took a toll on Michaela's own health.

Michaela: I struggled with the sense of when you're a carer, you really want to try and do the best that you can, and what you forget is that you're human. You are not superwoman. You don't have a million lifelines and you can't do everything.

And so I found, I'm trying to be great at my job. I'm trying to be great at looking after Nan. I'm trying to be Mum. I'm trying to cook a thousand meals. I'm trying to do what Nan does, so everyone's life stays as normal as possible. Then there becomes a point where you break, and I found myself [00:16:00] going to bed at night just crying myself to sleep.

Literally just crying, and I was crying because I felt like I wasn't good enough or I wasn't doing a good enough job. I felt like I was letting people down at certain points, and I felt like I possibly wasn't the best Mum that I could be to my daughter in the sense that she actually doesn't get any quality time with me because I'm worried about looking after Nan, and it's not that nobody else can look after Nans.

She's so used to having me there that I know that if I'm not there, that moment of confusion for her and just. Keeping her in a stable routine makes a difference. I would sit there and just cry.

It triggered my psoriasis in my scalp, so it meant that my hair was falling out. My skin was terrible, [00:17:00] and I got so overwhelmed and everything else going on. I wouldn't eat, I wasn't like really hungry. I've lost over a stone just from being ill and not being able to eat properly.

You get so consumed sometimes looking after everybody else, you forget to look after yourself. That is life as a carer. Those broken moments, I look at it now, and I'm like, how the hell did I do that? But you do it by sacrificing yourself.

Marianne: At the start of 2024, Michaela had an idea, something that would help with several things she'd been struggling with since Vanda's diagnosis. She wanted to tackle the stigma around dementia, find more support as a carer, and make sure Vanda's life stayed full of fun and community.

Michaela: It was my [00:18:00] 40th birthday coming up, and me and Tiana was going to go to Bali for, it was going to do two weeks in Bali.

So I said, okay, for my 40th, I am going to set up a dementia cafe. And the funds that I would've used to go to Bali is what I'm going to use to do the cafe.

Marianne: Dementia cafes are community-based meetups where people living with dementia and their carers can socialise, share advice, and do activities together.

Despite having myself and my sister, I know at times my Mum felt socially isolated. I really wish a dementia cafe had been available where she lived. She would've loved being with other people in that relaxing environment somewhere where she could take a knitting and have a cup of tea and a chat.

Michaela found an accessible church hall to host her cafe in.

Michaela: We opened the cafe for everybody over 70 and [00:19:00] those with dementia as well. There are a lot of people living with dementia who don't know that they have it and they're doing what I'd done with Nanna in the sense went, oh my God, she forgot where her keys were.

It's not dementia, it's, she's old. Like not worried about it, but that was what the cafe was for. So it was for those who were over 70 and those who had dementia, that's how Spring-Bleau dementia cafe was born. Spring from Nanna, her maiden name before she was married and Bleau from my daughter, coz her name's Tiana Bleau.

Two of my favourite people, and two people who had so much love for each other. What we really wanted the cafe to be was a place of love. Nanna was so welcome and so family-orientated. I wanted it to be somewhere where come and bring your grandchildren down. Come and bring like your family members down, or a friend.

I wanted to be a place where you felt at home and there was familiar faces and there was things that you liked doing and that was really important to me. And when I looked at cafes, none of them was open on the weekend and I was like, [00:20:00] this makes no sense. How was there not? Like the weekend's the only time where you get with your family.

And I was like, no, Nan will kill me if I do it on a Sunday, it's church day, so let's do it 11 till one 30 every other Saturday.

We will have things that appeal to everybody. So we aren't just singing and dancing, come and have some tea. We are like, do whatever you want to do. So we will have a knitting section where people can come and do knitting. And what's really nice is that the kids, so my daughter comes down, my nieces and nephews will come down and come and help at the cafe and they will paint nails, put face masks on.

The kids will go around with the tea, biscuits and sandwiches. We have dominoes for those who like dominoes. And we'll play people's favourite songs. The guys love word searches there. And every week I take them in, they take them home and every week I'm like, no, you can just leave them there. And they're like, she won't mind if I take this.

I'm like, I like just [00:21:00] let them take it. Let them take it at this point. So we buy research books continuously. We play bingo now all the time. They love a game of bingo, and a lot of our carers will sit there and talk to each other and it's a place for them to get together and just vent and breathe. And it's, it's, it's so lovely.

It's so lovely. It became way bigger than what I thought it was going to be, and it made such a difference and touched so many people. When we're at the cafe, we talk about the worst situations and the best situations. And with dementia, although it's difficult, there's some beautiful Moments. Even in Nanna's journey when we thought that there wasn't any more of her left, at some point she always made you realise, I'm still there, guys.

Like, don't lose me. Don't lose me yet. I'm still here. I remember I said to you earlier about a village. This is a village of family [00:22:00] and friends. Some of the people who run the cafe are my godparents, my Mum's best friends. My best friends. I keep saying to everyone, the cafe isn't just me. It's not Michaela Williams behind Spring Blue.

It's the village that keeps it going for the community.

Marianne: The Spring Bleau Dementia Cafe became a huge part of Michaela's life, and Vanda's. It helped keep her active even as her dementia continued to progress. Then just before Christmas 2024, Vanda got sick with a virus and she ended up in hospital just like with her stroke back in 2022.

Michaela did everything she could to get Vanda home as soon as possible. She was discharged on Christmas Eve.

Michaela: They gave us all antibiotics. For her, that was fine. She was eating, drinking, swallowing. [00:23:00] She went home to go and see her daughter for the day, and then she was going to come back and stay at mine.

And when we next saw her, she'd just stopped eating. She'd stop swallowing and wouldn't put anything in her mouth. At this point I'm making ice lollies 'cause it's the only thing that she is swallowing. She's taking bits of food, but not a lot of food. It's not going down. The doctor came round on the Friday and she said, I'm going to have an honest conversation with you.

And it was at that point that she said, Nanna has not got tonsillitis. And she said it was the last stage of dementia where they stop. Swallow in and eating.

I was like, how did that happen? Like it literally happened so quickly and she said, unless she eats and drinks [00:24:00] over the weekend, we're gonna have to go to palliative care. And I'm like, what do you mean going to palliative care? Like she's dying like. She was just fine. Like she was eating, drinking. We just had Christmas together.

Like how are you telling me that she's potentially going to like, I just don't understand. But you can see in Nanna's eyes, she's tired. She is so tired. And so over the weekend we tried every two hours of giving her soup. It's all through the night of giving her food and drink to try and get her to eat as she just wasn't doing it.

The only thing that she could do was suck an ice cube and put that in her mouth and ice isolates, and that was the only thing that she wanted to eat, and she didn't take any solids after that whole weekend. On the Monday, the doctor [00:25:00] came back and then they talked about getting a hospital bed in front.

And so we changed the front room around to make it a hospital bed. And then she was like, I start telling people to come and visit and start saying the goodbyes to her.

She could just look at you and that's all she could do, and you could hold her hand. Tiana would come and lie down next to her, but the bed and just hold her hand. My cousin came out, he lost his Mum to cancer, so I was like, what happens now? What's it going to be like? And so was like, oh, well, sometimes there's like a gasp or they open their eyes and as we was talking about, Nanna woke up, like she opened her eyes and Sue was like, I'm going to call everybody because it's, it's going to be now.

Does me, Tiana granddad in the very, we told her We love her. We think [00:26:00] she's amazing. I thank you for everything that you've done for us. And then she just went to sleep. She literally just went to sleep and it was so peaceful and so calm, and then that was it. And she was gone. She was surrounded by family and surrounded by love, and that's what we wanted for her.

Marianne: Vanda died at home in January, 2025.

Michaela: Now it's about being more present and looking after granddad and Tiana and making sure that they're okay and honour her in Nan's name, and just making sure that we just don't forget who she is. She lives through all of us. Like I cook now, granddad calls me Little Vanda and Tiana's baby.

Vanda. Now, her memory just lives on in so many people and you hear so many people [00:27:00] talk about her and have all these amazing, wonderful stories. They keep me going. It is really weird because there's kind of a piece in it as well, and it's just my selfish emotions as a human right, like missing her. We are still going to do the cafe and the plan is to be bigger and better this year than we were at last.

The plan is to go out to every doctor surgery, every care home, every church in our local area with flyers saying that the Dementia Cafe is there and we are here to help. If you can't get there, we will get you there. If you need any other help, please let us know. If you need someone to talk to, we can put you in the right direction.

We have that love in the cafe, we have that love through our own family. And when they talk about the story of Nanna, they'll talk about so much love and how much of a difference that she made in people's lives.[00:28:00]

Marianne: Thank you, Michaela, for telling us about. And for sharing the story of the Spring Bleau Dementia Cafe in Luton. If you have a look in your podcast feed, you'll find another episode right next to this one with Hilda and Vic. Two of Dementia UK's Admiral Nurses, they dive deeper into some themes from Michaela's story, offering advice from their perspectives as specialist Dementia Nurses.

This 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 [00:29:00] in this episode by visiting the Dementia UK website, it's dementiauk.org

You'll also find links to the website and other resources in the show notes for this episode. Thank you so much for listening.