

# Jules - Admiral Nurse ep transcript

**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 the space to talk to someone who understands.

No question is too big or small. In this episode two Admiral Nurses, Hilda and Vic, share their practical advice and insights on themes from Jules Story. If you want to listen to Jules's episode first, you'll find it right next to this one in your podcast feed coming up.

**Vic:** I think moving into a care home is definitely one of the most difficult decisions ever, isn't it?

Oh, it's a really difficult thing to do, but if you reframe it a little bit and think of it as a, as a, an act of protection or an act of love or you know, a way of, um, [00:01:00] exploring how to keep somebody safe and not just the person with the diagnosis, but everybody else around them as well. Actually, what. Kind of going these proactive steps to enable people to live as well as possible.

**Kola:** You'll hear Hilda and Vic explore things like how to manage if the person you are caring for becomes angry or aggressive, how to cope when multiple family members are living with dementia at the same time, and how to create joyful memories even as a person's dementia is progressing. If you 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.

**Vic:** And my name is Vic. I'm one of the Admiral Nurses at Dementia UK. So for this episode we're gonna be talking about Jules and her experience. And Jules's experience is one that is, [00:02:00] it actually sees her caring for more than one person caring for, for two people and actually this kind of care legacy in the decisions that she had to make because she cared for several people in her family, um, several different relatives.

And I think that's something quite unique around that.

**Hilda:** I think unfortunately because we're living longer, that will become more common for the next generation down. So it won't be as unusual to have it both parents with different forms of dementia.

**Vic:** Yeah, and I think if you are in that situation, where's the switch off?

Where do you, where do you get time to yourself? Because you've got two people who you are. Managing the care for you, making sure they've got the medication that they need, that their needs are met. And it's not going to be that they both need the same thing. They may have different needs and different wants and, and issues and, and different behaviors and even, you know, very different types of dementia.

So you've got the, the vascular dementia, which is obviously linked to stroke. And blood vessel [00:03:00] changes and cardiovascular health and, and the, the sort of symptoms that you might see with someone with vascular dementia would be different to the sort of symptoms that you would see and the, the, the behavior changes that you might see, the hallucinations, the sleep disturbances that you might see with Lewy bodies.

So dealing with two very different types of dementia as well.

**Hilda:** There's a saying that we often use that if you meet one person with dementia, you meet one person with dementia.

**Vic:** Yeah.

**Hilda:** In effect. All dementias, no matter whether you can have the same diagnosis, the presentation will be different according to the individual and the way their personality and the way they live.

But both of those forms of dementia can be complex, particularly un under one household. Trying to actually bounce the two things together. One area in particular was the, the mother's aggression.

**Vic:** Mm-hmm.

**Hilda:** And unfortunately, some, some people can show behavior like aggression or irritability that can be to do with which bit [00:04:00] of the brain is actually affected.

So it's more likely that someone with frontal damage is going to show a little bit more irritability, a little bit more aggression than as usual. Yeah. The analogy I normally use is, if you imagine when we grow up, we have like a gate, so we know socially what to say and what not to say. Mm-hmm. Somebody with a frontal condition, anyone that's got a any effect on the frontal lobes is more likely to have that gate slightly open or even fully open.

So those social controls and behavior don't actually happen in the same way.

**Vic:** Yeah. I'm really glad that we're, we're talking about aggression because, or, or behavior that comes across as aggressive because it's actually one of those really difficult things that people, um, don't always want to talk about.

And it might be things like shouting, it might be fire. It might be physical aggression, it could be resistance to care, not wanting to, to do something, or it could actually be [00:05:00] sudden mood shifts that somebody experiences or, you know, kind of coming across in a way that isn't, is, feels aggressive to the other person.

And, and for families, you often feel a sense of shame or stigma or. Um, kind of fear of judgment and, and also kind of confused about the behavior because this isn't how my loved one would normally behave. This is, this is a change. This is something that, that feels odd. And it can feel personal. Yeah, it can feel like.

The person doesn't like you or want you to interact with them. And, and I think that's, it's, it's actually, you know, one of those important things to say. It's not the person, it's not necessarily that's you. It's, it's actually the dementia. It's the condition. It's how their brain's responding to the, the kind of stimulation that's around it.

Um, and it's not, it's not. Uncommon. It's more common I think, than people realize, and yet we kind of don't talk about it or, or if we do talk about it, we, we sometimes even say unhelpful things like, well, it's not really part of dementia to be aggressive. And, [00:06:00] but I would kind of counter that and say it's potentially part of every human's ability to be aggressive.

It's just that most of us know when to not use that response and how to prevent that from. Happening, but if you are not sure, or you're confused because of your dementia and your brain goes into fights or flight mode, your options are run out the door, run away from the stimulation that's causing this, or I'm gonna stay and I'm gonna try and fight against this and, and counter it.

So, you know, it's, that's, that's kind of why it happens. Yeah. Um, and it's, it's a normal thing that can happen to, to any human. And, and then I think. It comes around, how do we, how do we prevent that happening? If you can see somebody is starting to respond in a way that's becoming aggressive, what would we say carers should do?

What should that look like? Yeah,

**Hilda:** I mean, distraction tends to work more effectively, so people generally have a sign that they're becoming uncomfortable or [00:07:00] frustrated, probably getting a little bit more fidgety. Probably showing on their face that they're getting a little bit uptight. Mm-hmm. So intervening at that stage, not when the aggression occurs.

It's intervening at an early stage, so it might be distraction, like, I think I'm gonna make a cup of tea. Would you like a cup of tea? I tell you what, should we have a biscuit with that? Or it could be going out for a walk into the garden or going out to a cafe. Anything that's actually going to diffuse that situation.

Mm-hmm. So what happens if that diffusing doesn't work?

**Vic:** Yeah,

**Hilda:** if somebody gets really quite uptight and aggressive, obviously if they're in a safe position and they're, they're perfectly safe for themselves. Separate yourself from that situation. So go into another room, count to 10, count to a little bit more than that, then walk back into the room and say, oh, I was just going to put the kettle on.

Would you like a cup of tea? So again, using that technique of [00:08:00] separating out and then using some distraction as well.

**Vic:** And I think these are the skills that as Admiral Nurses, we help families with all the time, don't we? Absolutely. We kind of go, actually, what, what's triggering this? What's the root cause, if you like, of this?

Is it overstimulation? Is it pain? Is it first? Is it hunger? What's, what's going on? How do you step away when someone's behaving that way? Yeah. Is it okay to step away? Yeah. When someone's behave? All of these things that, that people don't know and they're, they're not sure. And also how to unpack it because if that's somebody who you love dearly and has all never.

Been somebody who's been cross or angry and all, you know, and actually this is such a sh change and such a shock. How do you cope with that? The, the emotional layers of that? And I think that's the sort of things that we help with. It's about assessing those pathways, kind of trying to work through what's the pattern, what's happening for that person.

And, and sometimes it is about coordinating services. Sometimes it's even about medication that can be used to help people, because it might be that the carer really needs a break, they need to step away more permanently. Mm-hmm. The situation is [00:09:00] maybe breaking down a bit and actually that that's the, the support that they need.

Um, so, you know, but we know that, um, for some people as well. If there there is aggression in the house, it's actually so important that you address the safety of that person. Absolutely. Um, you know, how, how, how safe are you? And it's not ever easy to have a conversation around that with somebody and, and to really consider.

Actually, what support do you need in the house to keep you both safe in this situation?

**Hilda:** And I think Jill's talking about care package that they had, and it worked for a certain amount of time, but it then became to such a situation that people felt that there were, there were some dangers there. Yeah.

Warning signs. That suggested that actually living at home wasn't gonna be possible for Jules's mum. So she then needed to go into longer term care. Mm-hmm. And that is a decision, it's a very hard decision to make, but for the safety of all parties, it's often one of those decisions that we need to [00:10:00] support people to be able to do.

**Vic:** I think moving into a care home is definitely one of the most difficult decisions ever, isn't it? It's a really difficult thing to do, but if you reframe it a little bit and think of it as a, as a, an act of protection or an act of love or you know, a way of, um, exploring how to keep somebody safe and not just the person with the diagnosis, but everybody else around them as well, actually.

You know, kind of going these proactive steps to enable people to live as well as possible. Uh,

**Hilda:** and it's, it's about selecting the right environment for the person as well. So for some people it might be they would want a big and bustling hotel-like Care home. For others, it might be a little bit more small and intimate.

So knowing the person enables you to be able to select appropriately for the loved one and as well as that. When you go into the care homes. Have a look around. Mm-hmm. See what people are doing. Do they look interested? Do they look like, um, they're [00:11:00] engaging, they're speaking to each other? Or is there a television on, in one corner, in a radio on in another?

**Vic:** Yeah.

**Hilda:** Those are the sorts of things you're looking at. Sense of smell. Use your sense of smell. Mm-hmm. Visit at a time when it's a bit more bustly. So for instance, at lunchtime or a mealtime, go for a, uh, an in kind of an inspection visit. As an unannounced. Yeah. To see what's going on. Mm-hmm. I think Jules did comment about going at nighttime, having a look at nighttime.

**Vic:** Yeah.

**Hilda:** That might have been really quite useful for her. So

**Vic:** important isn't it, to see what's going on. Absolutely. And I think there's also about that flexibility. 'cause Jules had that did obviously go for that option, but she also had paid carers and she had hospice at home. So it's about knowing that just because you the solution works now.

Yeah.

**Vic:** It might not work. Next month for next year. And, and being flexible around those things and, and knowing what resources are around in your area and, and being willing to, to engage with them and, and actually I think the, both of the experiences that she had with the paid carers, that was good. That was a [00:12:00] positive experience.

I think the, the hospice at home. As well. But again, with the hospice at home, it's worth saying not everybody's gonna have that. Yeah. Um, available to them. And essentially what that is, it's when, um, care is provided in someone's own home to enable them to die at home. So it might not be available in your area.

Mm-hmm. It might not be what you as a family feel comfortable or want, or what the person themselves wants that might not have been part of the, their

wishes to actually die at home. They, they may potentially prefer to be in a hospital in a, in a natural hospice. So it's, it's. Kind of having those conversations, planning ahead and, and, and, and I think Jules did this really well, actually.

She did.

**Hilda:** Yeah. She really did. And, um, Jules spoke about the support that she actually had from the Admiral Nurse, um, during the, the kind of managing with her parents. But I think what we also need to point out is as Admiral Nurses, we continue with those families mm-hmm. Long after a person has actually passed away.

Um, [00:13:00] one person on my caseload, um, young Onset caseload, uh, I was supporting him after his wife died for two years. Mm-hmm. Before he felt that he was able to get his life back on track. So as Admiral Nurses, we are here for the family Right the way through. I loved the the example where she wanted her mum to have like a last flight on a plane.

**Vic:** Yeah,

**Hilda:** absolutely. And that must have been a logistical nightmare to organize and obviously it must have taken an awful lot of time and energy. And I am guessing that a lot of health and social care professionals were advising against.

**Vic:** You can imagine the risk assessments can't.

**Hilda:** I can absolutely imagine the risk assessments, but it happened and it was so positive.

So absolutely well done to Jules and a family.

**Vic:** Yeah.

**Hilda:** And then on top of that, setting up a charity called June's Wish so that other people can have the same sort of experiences or something that they really enjoy [00:14:00] doing at some stage during their, their process with dementia. Fan. Fantastic. Yeah, absolutely Fantastic idea.

**Vic:** It's a great idea, isn't it? Yeah. And do you know what I love about it as well is it's kind of that idea of joy and connection. Yeah. And doing something positive. Making a positive memory. You know, I think with dementia you can

very easily get into fear and loss of hope and all of these kinds of things, but actually this is going.

This is what we can still do. Yeah. This is something that's amazing that we can still do and make some memories. Admittedly, you know, you perhaps that mom's not gonna remember all the details of them. Maybe she is, but Jules will, she'll have pictures that she can look at, things that they can share together and, and having that, that experience together and, and it's just joyful, isn't it?

Absolutely. I love the idea completely.

**Kola:** If you'd like to speak to an Admiral Nurse like Hilda or. You can contact Dementia UK's Helpline. Just click on the link in the show description or visit [00:15:00] [dementia uk.org](https://dementia.uk.org). The helpline is open every day of the year except for the 25th of December. This has been our episode of My Life With Dementia, a podcast from Dementia UK.

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Thank you so much for listening.