

# Julie - 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 Julie's story, to give some extra advice and insight from their perspectives. So, if you haven't heard Julie's episode yet, go and give it a listen first.

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

**Vic:** Hi, 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:** So in this episode we're, we're actually gonna be exploring something that often gets brushed aside or people don't really talk about or understand. What's it like to live with dementia when you're living alone.

Living alone does not mean living without joy or purpose. In fact, many people live independently and they can do so safely and meaningfully. And actually it can be quite empowering to still be able to do that.

So I think what would be useful is to talk about some practical tips, and talk about actually how can you do that safely and well, what does that mean? Perhaps talk a little bit about purpose and routine and [00:02:00] actually what, what does that look like so that you can continue to live as good a life as possible.

It's about scaffolding. That's what I talk about often. It's like, yes, you can live alone with the right scaffolding, providing you've got support around when you need it. You know how to get support if you need it.

**Hilda:** When a person's living on their own, I think at times we need to remind ourselves that it's not all about having families and having the family connections. There's also friendship groups that are really important to people. We have a group that meets once a month on a Tuesday evening within Northamptonshire.

And in that group we have a kind of a peer group support for people that are living with young onset dementia and, that peer group, they are in contact with each other on a daily, sometimes, weekly basis. And they give that mutual support all of the time. They're not related, but they have something in common.

So [00:03:00] sometimes it's about having something in common with a person ie, friendship, long-term friendships. Or it might be that you've met people on this journey with dementia that are going to be friends going forward.

**Vic:** It's that wider sense of family and community. So, I guess if we start off by thinking about some of the day-to-day strategies that, that might be useful here. I'll throw to you in a second Hilda, but I was thinking about, for me it's about having a bit of a routine so that, you know, you, you, you've got some similarity, some structure to your day.

The other key tip that I use a lot is lots of labels and signs, if the person needs it. Not, you know, you don't have to automatically start doing this, but actually thinking, you know, maybe a label to say, 'this is the fridge'. Maybe on drawers to say 'knives and forks' or you know, whatever it is, goes where, and this is the airing cupboard, this is the front door.

So, some of those things around someone's house can just help them to know, how do I navigate my [00:04:00] home safely? Things like phone numbers by the phone can be helpful as well. So you've got those signs there to help. What other tips would you advise?

**Hilda:** I would say, as well as putting like notes, saying 'cutlery', put a picture, take a photo of the cutlery drawer and put your picture of the cutlery. Another thing that people have taught me in my career is, do you really need to have your wardrobe doors on? So it might be easier for some people if you haven't got a wardrobe door, so you can clearly see where your clothes are and what they look like.

Using technology to help you. So Alexa, and there are other devices too, you can actually use those to give you a reminder to communicate, to ask what time is it today? So all of those things can be quite useful. Another thing that I will say is try and declutter, because if you've got [00:05:00] too much stuff around,

it's difficult to find things if you put things down because there's too many distractions.

So try and declutter, if at all possible. Have a regular place where you put your car keys, for instance, a regular place where you put your handbag. The good thing about living on your own means that nobody else is gonna move your things.

So where you have is your place. You can leave it there, and the chances are it'll be there when you go back to it. It means that you are more able to do your own routine and that works for you. So that's a good point about having a routine Vic, because very frequently, it's when people change their routine when you start seeing this some problems.

So it's when people go on holiday, for instance. In a different environment, different routine. That can be a pleasure, but it can equally cause a little bit of anxiety as well with people. So those are the sorts of things I would definitely tip. And getting shopping delivered as well, really helps.

**Vic:** Making use of these services, absolutely.

One of the other things that [00:06:00] came out when Julie was talking was about that, that sense of purpose.

**Hilda:** Yes, definitely.

**Vic:** And I think if you're living on your, I mean, for all of us, we, we need a sense of purpose, but if you're living on your own, it's, it's more important perhaps than ever because you need that, something to get you up and give you that, that drive.

Julie actually spoke about how she couldn't find a support group. She couldn't find a service for her. So she started her own, didn't she? She set up her own group, which is amazing. But I know that not everybody's going to be listening to this and be able to go and set up a group. So I was thinking about what purpose might look like.

And essentially it'll be different for everybody. We will all have different things that will give us purpose. It might be something like volunteering. It might be going and working in your local charity shop, or doing some gardening in the community space or whatever it is. Doing something to volunteer.

For others it might be creative hobbies. So, you know, knitting, crocheting, or painting or whatever it is, something that [00:07:00] takes that creative lead. For others, it might be something like gardening or plants or pets or something that involves caring and nurturing something.

Because it's about adding those moments of joy to your day as well as the, the kind of stuff you have to do to live. It's actually what are the bits that are going to add that purpose to my life.

**Hilda:** Sometimes people say, but there aren't any groups about photography or painting or doing things for people with dementia.

And I say, well. Why are you going to a group where people with dementia? Interest can be apart from dementia. Because you are a person apart from that dementia. You can choose what you do. So, enroll at local college, find like-minded people. Go to your local gym, go for a swim. Whatever it is that you feel comfortable doing. [00:08:00]

**Vic:** One of the, the things as well that Julie talked about was getting carers in. If you are struggling to do something and you want to do something, like you said about doing the online shopping, these services are available. The local authorities can come and do a, an assessment, a needs assessment, looking through what's your needs, what, what things might help you to stay independently.

And actually then you can start to think, okay, I need to start getting some carers in to help meet these needs. There's agencies like Care Home UK that you can use to choose the care needs that are out there, if you have to pay for them yourselves. If you're eligible for funding, you might not have that choice to, to start paying for some of those, but actually looking through what services are out there that can help me stay independent, stay at home.

What services might, might I be, and that might be somebody helping you to get in the bath or to have a shower or to do some personal care, or it could be somebody doing the housework, or the [00:09:00] hoovering or whatever it is. Or even something to go out with to a local club. You know, it's actually going, what services are around that I can potentially make use of to, to help me live independently?

**Hilda:** I think it's about looking at your needs and how you best can have those fulfilled.

**Vic:** Yeah. Let's talk about something that's often overlooked. Occupational therapy. So many people don't know what occupational therapists do, or that they're, they're available and I, so I do think of them as a bit of a hidden gem.

You can be referred to an OT by your GP or via a memory clinic or an adult social care team if, if you've got one. Essentially what they will do is their whole role is about enabling someone to live independently and, and they'll go in and they'll look at the kind of everyday tasks that we do and think, where are the safety points?

Where are the risks? How can I help make that somebody safer? So it might be things like equipment, rails, memory aids, easy to use kitchen tools that just helps [00:10:00] somebody to, to keep them independent. Or it could be bigger things. It could be adjustments to someone's home to reduce some stresses that have been identified.

**Hilda:** Absolutely. And the adaptations that they can kind of provide or encourage you to have fitted will make so much difference to your everyday life and will aid with your enjoyment of everyday life as well.

**Vic:** You can be referred to an OT by your GP or via memory clinic or an adult social care team if, if you've got one, in most cases it's free, it's support that's available through the NHS.

So do reach out and speak to your GP if you think an occupational therapist assessment would be helpful.

Living with dementia, living alone, it's, it's not gonna be easy. But that doesn't mean it can't be done, and it doesn't mean that lots and lots of people aren't doing it. We know lots of people are living alone and, and we know that actually their days can be filled with comfort, joy, happiness, and, and quite a good sense of control.

So I always sort of say to people, you know, you, you might be living alone, [00:11:00] but you're not alone.

**Hilda:** Correct. Yeah.

**Vic:** You, you can, there's support out there. There's people who can help you and, and do connect with them because I think if you are living on your own and you're alone and you are lonely, that's a very different thing.

It's actually, how do I, how do I connect? What do I need to do to, to sort of keep those connections in place?

**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 has been an episode of My Life With Dementia, a podcast from Dementia UK. Please do subscribe in your [00:12:00] 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 [dementiauk.org](http://dementiauk.org).

Thank you so much for listening.