

My life with Dementia – Admiral Nurses discuss George’s episode transcript

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

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

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 a Chief Admiral Nurse and the CEO of Dementia UK. George was speaking about his experience of his mother being diagnosed with young onset dementia. George's experience is by no means unique. Often you find that, at the stage, a person gets a diagnosis of young onset dementia, their children are at of an age where they're learning to be independent. So they may be leaving the home to go to university. They may be kind of embarking on their first job. They may be still in the sixth form or even still at school.

And the support that people need is not necessarily forthcoming. And from my experience of working with families that are kind of very young when a [00:02:00] dementia occurs, sometimes they like to keep it to themselves. They won't necessarily tell the school, they won't necessarily tell their kind of peer group.

They won't necessarily want people coming back to their house because there's an embarrassment factor. So I think that in George's situation, the guilt you feel, because you want to have your own life, you want to go away from home, you want to study, you want relationships, and then realising, actually that means everything falls to Dad while I'm away.

And then you start to feel guilty about that. What I would say is. Would your mum want you to feel guilty about that? Would your parent really want you to feel guilty about that? And the answer would always be no. No, they don't. They want you to enjoy your life. They want you to set off and become independent and do the things that they did when they were a similar age.

But do speak to people because so many families I've worked with have kept it to themselves.

Vic: I think that's [00:03:00] really important. So I was, I was looking at some stats around this and we'd know that it's about 25% of young carers will be caring for somebody with either a mental health issue or dementia. And some of them might be very young.

And I think you're absolutely right when you talk about that they, you know, they may still be in school, they might be navigating friendships, identity, who they are as a person, and also seeing the impact that this is having on the parents.

And that can feel really hard. And, and I think one of the things that's also interesting is that these people, that the voice is hidden. Because they don't talk, they don't share it, or the schools don't necessarily pick up that this is what's going on for the person.

Hilda: Within Dementia UK we recognise that people that they're living with young onset dementia and their families often need that specialist support because of the way young onset dementia affects them as a family.

So on our website, there are a lot of materials that are very specific to young [00:04:00] onset dementia. We also have the Young Dementia Network that we host as a a charity, and you will. Be able to get loads of material off there as well, and you can join that group as a member. And therefore you can be more involved as little or as much as you like within that Young Dementia Network.

We've got two Consultant Admiral Nurses that are actually working and specialising in young onset dementia. And another Consultant Admiral Nurse that actually specialises in children and young adults. And again, these are the people that can help with the real complex issues that people are facing within those families when you're living with young onset dementia.

What I've found from experience of working in the sector is that sometimes, younger people don't want to sit down and they want, don't want to talk to you face to face, but obviously at times there's other ways of doing that. Texting, for instance. Joining different forums might be useful as well.

And [00:05:00] I know that there's one that's kind of international now called Lorenzo's House. And that was set up by somebody that, um, had young onset experience and living in Chicago actually. And that has been such a great force for good that people can engage with other people that are living that experience and they are of a younger age.

And you can do that online. You don't have to go across to Chicago.

Vic: And it's so important though, isn't it? Of course. It those digital services that somebody can use in a way that you know, who, if you're 16 and you're, you are maybe not going to phone a helpline or want to go speak to your GP about the fact that you know whoever has got dementia.

But actually if you can text somebody, if you can use web chat, if you can use those kind of experiences to connect with somebody, it's maybe just going to be a bit easier for that person.

The other thing that George talked about was the setting up lasting power of attorney, and I think this is a really important thing.

The number of families we speak to as an Admiral Nurse who haven't done it, or they know they should, or they're not [00:06:00] sure, or they don't even necessarily understand what it means. So I think it's important to say there's, there's two types of lasting power of attorney that somebody needs to set up.

And essentially what it is in, in both of these cases is a legal document that allows somebody to say, if I can't make these decisions. This is the person I trust all people because you, you can appoint different people to make these decisions on your behalf. If someone's got diagnosis of dementia, actually ideally before, but we all should do it.

It's sensible adulting, but yeah, lots and lots of people listening, I'm sure haven't got powers of attorney. Maybe even people in this room don't, don't do it quite when we should. Uh, well it took me ages, but there's two types. So there's health and welfare, which is basically saying, this is the person I trust to make decisions about my health and, you know, my, my wellbeing and my welfare.

The other type is about property and finances, and you'll meet lots of people who've done it for property and finances. [00:07:00] But maybe not health and welfare. It's important to do both because if you're living with a diagnosis of dementia, you are going to need both of these documents essentially. And when someone has got this diagnosis, they'll also reach a point where potentially they haven't got the capacity to make that decision.

So it's really important to get these set up as soon as possible so that you can make sure the person with the diagnosis has got the, their wishes are respected, you know the right people are providing that support for them. When you do that, it actually takes away some of the stress that you might feel later on because you've done it.

Yeah. You know, there's no confusion, there's no stress. You can put it away once you've done it and go, right, fine, sorted. It might feel awkward having conversations about money and finance and health and what we don't like doing it, do we? But actually sitting down having who's healthy? He's healthy to do so.

Hilda: This is why I started having a lasting power of attorney drawn up at least five years ago. But you were able to have that conversation with your, your kids

to say, look, if [00:08:00] something happens to me or your dad, this is what we need you to do. So it was a healthy conversation.

I think as well as doing that, an advanced care plan is also useful. The advanced care plan is where you say what you want to happen as you approach the, the kind of the stage where you probably can't make those decisions. So for instance, with an advanced care plan, you could say, if I've got a really bad chest infection.

I don't want the antibiotics. I don't want you to prolong life unnecessarily. So those are the sorts of discussions you can have as well with your family members, because the advanced care plan as well as the lasting power of attorney, it kind of covers two different angles as well, and it just makes it clear.

What you would like to happen when you get to the end of setting out those wishes in advance.

Vic: Absolutely. So families don't have to guess even Oh, and think, well I don't think mum would've liked this.

Hilda: You can lean on what Mum said and you get so many [00:09:00] arguments within families.

Oh, Mum wouldn't have wanted that. But actually we did have that discussion and yes, she did say that. Yeah, she did. So I think it, those sort of things are really important.

Vic: And I think if you're listening to this and you're thinking, okay, I should have this conversation, but I'm not quite sure how to do that.

This stuff, that's bread and butter for us Admiral Nurses to know about. And I say give time, don't do it while you're trying to do personal care or while you're trying to rush somebody to a day centre, or in the evening when they're very tired and they want to go to bed. Think about I, I want to have this conversation.

Let other family members know in advance. Yes. And say, look, you know, we're going to have this conversation about finance, property, wellbeing, end of life, or whatever it is you're going to have. Say, we we're going to have this together and I think it would be useful for you to be involved, um, you know, and speak to each other.

Share some of your thoughts beforehand so that you're not sat there with one family member saying, mom, you'd never want to go into a home. And the other person's saying, oh, but I think it'd be good. Yeah. So, so you kind of have that conversation before [00:10:00] so you're on the same page. Yeah. But then allow time, um, try to make sure that, you know, you pick your moment.

So if you know the person with dementia you're going to have this conversation with is having a bad day mm-hmm. Or they're a bit distressed about something, obviously not a good time to start having conversations Yeah. About, about these types of things. So it's about picking your time, doing your research, having the forms available, or if you need to, um, because the forms you, you can either fill them out yourself or you can get someone to fill them out for you.

You can go and get legal advice. And that's a bit of a personal choice as well. I mean, you know, they, there is a cost of doing the forms, but if you actually think that's better because we've got an external person and we can sit and go through them with them, you know, it, it's useful to do that for some people.

[00:11:00] The other thing that I was thinking, listening to, to this story is, and I was going to try and borrow some words from George, because I really liked these words. He talked about how life froze things at you. Yes. And you, you, you can't think miles ahead. What he talked about was think about where you are now. And I know he was talking about running a bit here. Yeah. So he sort of said, but what mile are you at now? Yeah. Where am I at now? And actually, what's going on now for me? And, and don't think. Too far ahead. Yeah. The apart from when it comes to lasting power of attorney, then think ahead, then put it in the box and and do with it.

And then when you're in the day to day, it's going, what mile am I at now? What's going on for me now? What do I need to deal with right now to get me to the next minute or to the next mile, or whatever it might be. And I, I also really liked the idea about being a bit proactive. Yeah. And looking around for things.

Finding things to keep you busy. Yes. Getting involved in the community because you know, they're the things that will actually really help you with this diagnosis.

Hilda: And I, I [00:12:00] particularly liked with George's dad, the monthly support group that he set up. I think that's so needed because there are very little services and support that are specifically for people that are living with young onset dementia.

And often when I've been working in that field, people are saying, yeah, I went to that particular group, but everybody was about 20 or 30 years older than me, so I didn't go back. So going somewhere. Where you've got something in common where there's a peer group that that will actually understand what you are going through and you can support each other.

We run a group on, on Tuesday nights in Northamptonshire. On the Tuesday nights, we, we meet up, we go to a pub, we have a, a meal, and we are there for a couple of hours and we've got a good, strong group of people that are living with young onset dementia. And you've never heard anybody laughing so much in your life?

I wonder, we don't get thrown out of the pub to be frank with you, but there's support that they give each other and the [00:13:00] advice and the, oh yeah, that happened to me and this is what I did. Mm-hmm. It is invaluable. Absolutely superb. So hats off to George's dad for setting up that group. They are so desperately needed and hats off to George as well with his endurance events.

Oh my goodness. I can't even imagine running for 20 minutes, let alone some of the endurance events that George is doing.

Vic: Absolutely. That strength and that power to do those things is, is fantastic. Super.

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.

[00:14:00] 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 in this episode. By visiting the Dementia UK website, it's dementiauk.org.

Thank you so much for listening.