

# Tommy and Andrew - 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 a space to talk to someone who understands.

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

**Vic:** When you are living with someone and loves someone with dementia, grief doesn't start with death. It doesn't start the moment that the person dies. You're kind of grieving those little losses over time. You are sometimes grieving [00:01:00] the impacts that this diagnosis is having on you as a family. Sometimes you're grieving the fact that the person isn't able to do things that they would normally do and enjoy things they would normally enjoy.

And it, it can actually, for many families, feel quite exhausting because it, it rolls, it's, you know, you're living with this sometimes for many years before the person actually does die.

**Kola:** You'll hear Hilda and Vic explore things like the benefits of music for people living with dementia, strategies to help men share more of their emotional lives with their friends, and how grief can begin to impact carers long before their loved one has died.

If you'd 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:** I'm Hilda Hayo and I'm the Chief Admiral Nurse and CEO of Dementia UK.

**Vic:** And I'm Vic Lyons. I'm an Admiral Nurse with Dementia UK. So today we're going to talk about [00:02:00] Tommy and Andrew and the episode that you just listened to, where they're talking about men and how men cope with

living with dementia. And one of the first things that I was thinking about is why do men find this difficult to talk about?

'cause we know they're experiencing the same experiences, the same emotions, but actually talking about it and having that conversation is something that. A lot of men struggle to do, and I think there's, there's possibly some reasons around this that what kind of were jumping out. In my head, I was thinking about how men are socialized, how men cope privately, not all men, obviously.

Mm-hmm. This is a slight, a generational thing. And a generalisation, but I think there's this, this. Tendency for men to feel like they've got to be strong, that they need to be the ones who are fixing problems and, and not burdening of people with their problems and their emotions. And, and I kind of mentioned generationally, 'cause I think for older men, um, I think this is even harder actually.

Mm. You know, they don't always have the language to express their emotions. I loved the fact that this was recorded in a [00:03:00] pub.

**Hilda:** Mm-hmm.

**Vic:** Because, you know, I've never been in a pub and heard men talking about their emotions, football darts, golf, all these things happen. But actually talking about the, their emotions and the impacts that things that are difficult and challenging can be quite scary.

**Hilda:** Absolutely. I mean, 30 to 40% of of people that are family carers are males.

**Vic:** Yeah,

**Hilda:** and don't tend to contact us in the same way as females. So over 70% of our calls near 80% of our calls are from females, from the Helpline. Um, males are much less likely to ask for help and for all the reasons that you gave Vic to be, to be honest, it's that I should be coping, I should do that, and very.

Frequently that means that they're not able to access the help and support that actually would help.

**Vic:** Yeah. I think even if you think about the word carer, you think about what does somebody caring for someone with dementia look like? What does the

media portray that [00:04:00] person as looking like? We do automatically start thinking about a woman, don't we?

Well, I, you know, we, we largely do we think about a woman, we think about a daughter, a, um, you know, a, a wife, caring. But actually if we, we consider the fact. That of course lots of women live with dementia and you know, they're going to have spouses and you know, live longer and later into life there's going to be lots of men who are carers.

And yet we kind of don't bring that into our minds when we think about a carer and what does a dementia carer look like? Or somebody who's caring for somebody. And I think if men. Are afraid to reach up 'cause maybe they don't feel seen in the media. They don't feel this is the role they should be in naturally they're missing out on so much.

Mm-hmm. Mm-hmm. Because they don't get, like you said, they don't get access to that support. They don't get the emotional relief, they don't get the practical advice. They don't get that feeling that I'm not in isolation with this. There's other people who are in the same boat who can help me. And, and that sort of silence that men hold with that reinforces that and it kind of feeds into it, you [00:05:00] know, makes it even more.

Scary to, to reach out. And I think that's, that's why it's, it's brilliant that this conversation's happened and that we're having this podcast today to kind of break that down for people and say, don't be afraid. Don't feel you have to carry this on your own. Um, you know, sharing isn't necessarily gonna solve the problem.

Um, but it will make the load lighter. It will mean that you've got people who understand and can walk that with you.

**Hilda:** And what I thought was interesting. Because when Tommy was talking about the effects that dementia has had on him as a person, and he was say, saying things like it affected his employment, it affected his relationship.

He felt he'd let his his wife down. And I think that comes back to what you were saying earlier, Vic, about the way men perceive their role within that family unit. Mm-hmm. And what they're supposed to do and how they're supposed to be able to cope. And sometimes it's about. Keeping feelings inside, even with our loved ones, so we don't [00:06:00] have to talk about things that are uncomfortable and make us feel vulnerable.

**Vic:** I think that came out in Andrew and his dad as well. It did, didn't it? Yeah. Because you've got two men there who were both feeling this, all these feelings that we've just spoken about and, and, and actually we'll have different ways of coping, different styles, different positions in the families. So, you know, Andrew's dad, I.

Because he's Andrew's dad would've naturally wanted to protect Andrew as well, to shield him from some of what was going on to, to look after him. You know, they, they'd both be carrying different feelings around guilt and actually, how do I cope with this? And different ideas about, you know, actually accepting the diagnosis, accepting what was going on, and all of that brings so many different sorts of.

Tangible bits, if you like, that actually. How do you navigate through that in a way that you're, you're both on the same page. Mm-hmm. Um, and people tend to have these disagreements in, in families because, not because they don't love each other, but because they just see things slightly differently. You know, they sort [00:07:00] of are in a different page, in a different position.

And usually it's because they. They both absolutely love the, the people. They, they both want the best for the people and, and want to find solutions and fix things and feel a sense of responsibility, um, you know, around actually making the right decision. And sometimes, as we know in dementia, there isn't actually an obvious right decision.

There's variations of decisions that you can make at any time, and working through the right one can be challenging as well for people

**Hilda:** it can. It's about trying to find out where the other person is coming from, trying to listen to the person to acknowledge that their feelings and thoughts. And then to try and find some sort of middle ground.

'cause often there's a middle ground that you can both kind of agree on. Yeah, and I think this is where Admiral Nurses come in. So an Admiral Nurse can sit alongside that family, encourage them to talk about what it is that that's behind some of these feelings and some of these thoughts. And actually plan for the future.[00:08:00]

Because in effect, we are sitting there as a, as a facilitator.

**Vic:** And I think it's often about breaking down that fear as well, that, that families have. And, and, and, um, this, this certainly came up in Tommy's

experience as well, this sense of fear. This, um, you know, I've got this diagnosis, but I, I'm, I'm worried, I don't want to upset people.

I don't want to be a burden. And, and so I'm, I picked up that same sort of feeling of fear in both of them really. Um, you know, how, and talking about things can make them feel real. If you don't talk about it, it's on a shelf somewhere.

**Hilda:** Yeah.

**Vic:** And you don't have to acknowledge it quite as much. I think sometimes the, the fear of doing something is worse than the doing it.

As soon as you start doing it, you go, oh, why? What was wrong with that? Why was I so worried? That's the same message that I would say to men in general actually, is if you've got a friend, if you've got a, if you're living with this diagnosis, don't let fear hold you back from having that conversation.

'cause as soon as you start doing it, you'll probably feel this sense [00:09:00] of, ah, I'm glad I've started this conversation and I've acknowledged what's going on and the impacts that this is having.

**Hilda:** I think it was interesting that Tommy said that he goes out with his friends, but they never ask him about dementia.

Yeah. They never talk about dementia. And uh, sometimes I think that's about, they're probably not quite sure what to say and sometimes it's probably their fearing what that means. The diagnosis

**Vic:** worried about saying the wrong thing.

**Hilda:** Exactly. And then I think that, um. In some ways, Tommy probably ought to start the conversation first.

**Vic:** Yeah, yeah. I, I agree. Yeah. And just, just normalize it. Yeah, absolutely. You know, this is absolutely, this is something that we talk about other things, you know, if you, we, we talk about all sorts of other conditions and situations and, and normalizing it and bringing into the space mm-hmm. And, and being relaxed enough to do that.

But it's a big first thing to do, isn't it's, and I can see why. Tommy might not want that to define him and his personality. Of course, he, he wouldn't. Yeah.

But if people know, um, you know, and [00:10:00] he's got that insight and can have that conversation, it brings that clarity. He's still Tommy, he can still do the things that, that Tommy would want to do, but just needing a little bit more support and guidance around him

**Hilda:** and probably saying that to his friends.

**Vic:** Yeah.

**Hilda:** So saying, sometimes you might need to remind me that we've going to meet to the pub, so give me a call just beforehand. So try kind of picking up some different cues that could be helpful so his friends feel helpful as well.

**Vic:** I think that's it, isn't

**Hilda:** it? Yeah.

**Vic:** Yeah.

**Hilda:** I think Tommy hit the nail on the head when he said, still having a sense of humor.

Music really helped him to, to live with dementia as well as is possible. And very often people, a lot of people will say that they enjoy music, they enjoy listening to music. It helps them to feel calmer and much more relaxed. So finding different ways. That help you to manage whatever it is that's going on in your life at that particular point in time.

'cause there will be [00:11:00] highs and there will be lows, particularly if you're diagnosed. And the same with the carer, family. Carer.

**Vic:** Yeah. And I think music came through really clearly in this, didn't it? And, and, and we know this all the time. We talk about the power of music and the impact that music can have, but it certainly provides people with those connections, those kind of windows into normality and enjoying.

Something wonderful together. And you know, and I've certainly worked with many people who even in advanced stages of dementia can remember their favorite songs. They can sing along and enjoy them. So even if someone's dementia is more advanced mm-hmm. Still using music is going to be really powerful and, and provide that emotional connection, that joy, that.

And for many of us, it triggers a happy part of our brain as well, and makes us smile and dance and move our bodies. So, so lots of other positive benefits, definitely. Um, but for some people it might be other things. It might be cycling, walking, interacting with animals, or going to the theater or, you know, all sorts of [00:12:00] different things that are going to bring those moments of joy and, and enable you to, to still be you.

Andrew talks about anticipatory grief or rolling grief. Mm. And this is something that lots of people will identify with, and they perhaps only when we tell them what it is and that this is a real thing. Yeah. Because when you are living with someone and loves someone with dementia, grief doesn't start with death.

It doesn't start at the moment that the person dies. Actually what happens is as the person changes and that things change for them, and you're kind of grieving those. Little losses over time. You are sometimes grieving the impacts that this diagnosis is having on you as a family. Sometimes you're grieving the fact that the person isn't able to do things that they would normally do and enjoy things they would normally enjoy.

So it's a kind of changes in personality, changes in the person, changes in how you see yourself and and how that person interacts with you and, and it is ongoing. It can actually, for [00:13:00] many families, feel quite exhausting because it, it rolls, it's, you know, you're living with this sometimes for many years before the person actually does die.

**Hilda:** And I think so often people don't realise this is part and parcel of a long-term condition, whether that's dementia or another condition, and think that this is, this is abnormal. This, this person's still with me, so why do I feel like this? Yeah, and like you say, it's rolling, it changes. Over time. It, it doesn't always stay as, oh gosh, this person is going to be dying soon and therefore I'm going to feel this way.

It doesn't, sometimes you'll feel angry.

**Vic:** Mm-hmm.

**Hilda:** Sometimes you'll say, what? Why has this happened to me? And, and I think that's very, very difficult for people to come to terms with. 'cause you'd expect that after the person has actually died, you don't expect it to happen to you whilst the person is still living

**Vic:** and while you're still caring for

**Hilda:** them as well.

Exactly. Exactly That. Yeah. We are here as Admiral Nurses for people, whether that's on our Helpline, [00:14:00] whether that's our clinics, whether it's dropping us an email.

**Vic:** Mm-hmm.

**Hilda:** So please contact us because particularly men, they don't tend to ask for help, and it's not a weakness. It's not something that you should avoid doing.

Sometimes it just someone to talk to. We're confidential listeners in effect. So sometimes it's just offloading or someone to talk to. Very often when I, I speak to some male carers, they offload and at the end of it they say, thank you for your help. And I didn't say a single solitary word. So sometimes just getting that offloading can be really helpful.

**Vic:** Starting to have those conversations and, and opening that door is, is, is only gonna be better because as I said earlier, it might not make it all go away. It, with dementia, it can't. Mm-hmm. But actually it can, it can help, it can start you on that journey to coping better with that diagnosis. Absolutely.

**Kola:** If you'd like to speak to an Admiral Nurse like Hilda or [00:15:00] Vic yourself, you can contact Dementia UK's Helpline. Just click on the link in the show description. Or visit [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 an episode of My Life With Dementia, a podcast from Dementia UK.

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Thank you so much for listening.