Chloe and Amy - Admiral Nurse episode 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, are sharing their practical advice and insights on themes from Chloe and Amy's story. If you want to listen to Chloe and Amy's episode first, you'll find it right next to this one in your podcast feed. Coming up...

Hilda: very frequently, the families that I've supported.

The children don't want to speak to their peers about what's going on and actually start to withdraw themselves from their peers. Mm-hmm. Particularly sleepovers, play [00:01:00] dates, et cetera. Often a person that has this going on within their household, whether that's dementia or other long-term condition, they're reluctant to engage with that because they don't want people to come back to the house to see what's going on.

Kola: You'll hear Hilda and Vic explore things like how schools can support young carers. The importance of counseling to help manage the emotional strain of looking after someone with dementia, and how Admiral Nurses can help families prepare for the future with advanced care planning, including lasting power of attorney.

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: My name is Hilda Hayo and I'm the Chief Admiral Nurse and CEO of Dementia UK.

Vic: And my name is Vic Lyons. I'm one of the Admiral nurses at Dementia UK.

Hilda: We are now going to be talking about Chloe and Amy and their [00:02:00] experience of a mother who had young onset dementia. One thing in particular that Chloe and Amy were talking about is in the early stages with their mum, she started to get, um, fixation on certain things.

And one thing in particular that was mentioned was the jelly.

Vic: Yeah.

Hilda: It's not unusual for people with dementia, particularly if it's affecting certain parts of their brain to have a fixation on something. So it might be food, it might be. Routines. Doing things at a certain time or going to certain places saying certain things, changing appetite, changing what it is that they prefer to eat.

Those are the sorts of things that can happen in some forms of dementia.

Vic: Mm-hmm. Sometimes with food as well. It's the different textures. It's the tastes. Yeah. It's how they feel in your mouth and how easy they are to eat. So things like meat for example, often becomes something they don't want to eat. Or somebody wants more sweet things rather than savoury things.

'cause let's face it, sweet things are nicer to eat. So, you [00:03:00] know, there could be an element of that too.

Hilda: Absolutely.

Vic: What really struck me about this story was actually how young Chloe and Amy were, you know, you're juggling school and work and family life and actually what, what you expect mum to be able to do.

So it really highlighted for me what it is to be a young carer. Yeah. The, the impact that this might have on somebody, even if we, I know we'll get onto it later, but the rapid progression, the shock around someone's death, but, but you know, just actually getting that diagnosis, um, whilst. You, you are still young and, and we know there's hundreds of young carers who are out there now.

And, and again, they can often be hidden. Mm. Obviously people who are supporting parents, but also grandparents and, and all sorts of other illnesses as well. Yeah. Not, not just dementia, um, and young carer. Even do not always identify themselves as carers. Yeah. You know, actually going into a school environment and saying I'm a carer is something they really don't often want to do because it's kind of alien.

It's my [00:04:00] mum, of course I'm gonna help. Yeah. It's, you know, it's just, it's just part of life that they absorb. Because you're still very much in that formative stage, aren't you? Yeah. Of just working out who you are and what your life might be.

Hilda: You notice that a lot with, with families that I've got younger children.

Um, my specialism is working with people with young onset dementia, so I saw a lot of very young families and very frequently the children wouldn't talk about their feelings and what was happening for them mm-hmm. With their parents. Um, because they didn't want to burden them and didn't want to upset them so often they didn't have anywhere to actually go to.

Vic: Yeah. Nowhere to take it. Or even the language for it as well. If you, if I think about my teenage children, when they're upset, they don't always articulate what they're upset about, but I know they're upset because they, you know. Kicking the door or whatever, playing their music lounge. Yeah. There's other ways that you pick up, actually, this is causing some upset for this child.

It's not [00:05:00] usually they're gonna come and say, I'm actually really upset about X. Exactly. It's, it's the, the behaviour comes out in a different way.

Hilda: It does. It comes out in a different way. Or the person withdraws, so children withdraw and that's really important for. Speaking with the school, particularly if you've got a school aged child.

Mm-hmm. And I'm really pleased to see that that actually happened in this case. And when you speak to a school, a really good school, we'll be able to give you that extra wraparound support whilst you're at school. So you get the best. Time that you can at school, but also so you can be offered counseling and support, which was taken up and obviously made an awful lot of difference.

Yeah. Um, within this family,

Vic: there's so much school can do, isn't there? Yeah, there's loads. Absolutely. And especially again nowadays, you know, schools have got pastoral care. Yeah. They've got flexibility. They've got children in schools with all sorts of different needs. Within that school system and you know, they want to, to make that school experience the best that they can for the [00:06:00] children who are, who are in their care.

So they, they've got better understanding in, in how to support these young people. So actually having that conversation and saying, this is what we're living with as a family and bringing it into that environment so the school understand rather than thinking. Well, this child's late again, or they haven't got dinner money or they're, they're distracted or they're not doing very well, their grades are slipping.

If they understand, they can make the adjustments and, you know, and actually support that child. It might not be that the, the young person goes and has a conversation with their peers mm-hmm. About what's going on. Mm-hmm. Because they might want school to be normal. Yes. Children don't like to stand out at school, do they?

They like to be, I'm one of them, the, the crowd. But actually if the school know they can provide that flexibility and that support in a gentle, soft way to support that young person, um, throughout their school career.

Hilda: You have a good point about the peers. Very frequently, the families that I've supported.

The children don't want to speak to their peers about [00:07:00] what's going on and actually start to withdraw themselves from their peers. Mm-hmm. Particularly sleepovers. Mm-hmm. Play dates, et cetera. Often a person that has this going on within their, their household, whether that's dementia or other long-term condition.

They're reluctant to engage with that because they don't want people to come back to the house to see what's going on, so they get further social isolation, which is really upsetting.

Vic: And of course, if they're caring for somebody, they might not be able to do these things anyway, because if you're absolutely, at whatever age you are, if you've got to get back home because you've got to make a meal or give somebody medication, or you don't, somebody can't be left alone because paid carers have gone or whatever.

Whatever that situation is. You, you are going to miss out on some of the things that, you know, uh, a young person without caring responsibilities would just take for granted. Yeah. So it's that difficult balancing act, isn't it? It's very difficult. Chloe and Amy spoke about that, you know, trying to work, trying to study, trying to care around the clock and, and provide that support whilst still working out.[00:08:00]

Who they are as people Yes. And what they want to be. And you know, the things that are important for them. And, and they spoke quite a lot about teamwork. Yeah. And that kind of sustained them because they'd got each other.

Hilda: Absolutely. And what was interesting, I thought Chloe and Amy both said the same thing, that they felt like they were giving something back to, to mum because she'd always given to them.

So I thought that was a really nice way of looking at things. But it comes back to what you said before, they didn't say. Because we were carers. It's because she's

Vic: mum.

Hilda: I'm doing that because it's my mum. Yeah,

Vic: yeah. It's, it's, it's so true, isn't it? And then you start, stop thinking about the whole emotional side of this and actually what, what does that look like when you're this young and you're carrying this much emotion, you know, this, this sense of role reversal.

And then you get this sense of why me, why mum wires that can creep in. And that's. Quite normal because it is unusual. Um, it's rare to have a diagnosis at, [00:09:00] at the age that Sarah was. So I think it's, you can't look to your peers and think, oh, well they're going through it as well. 'cause the chances are.

They

Hilda: probably not.

Vic: They're not,

Hilda: yeah. No, absolutely. And I think the conversations that they had around, for instance, um, do not resuscitate and a, a kind of lasting power of attorney, um, and actually looking at advance plans, what, what is it that's going to be best for mum? That's a very difficult conversation to have when you are a child or a young adult.

It's a difficult conversation to have when you're seventies, eighties, nineties. Mm-hmm. Let alone at that age group. And that responsibility must have been really difficult for them to be able to cope with at the time.

Vic: It would've been interesting,

Hilda: but they did it fantastically from what we heard. When you get to the situation, when you're starting to talk about advanced planning, what,

what should we do when Those are the sorts of things that's really important to talk through with an Admiral Nurse.

You can either do that on the Helpline, you can do that in a [00:10:00] clinic, or you can, uh, kind of get the skills of one of our specialist young onset nurses. We've developed some special services and support for people that are living with these conditions. So we've got a Consultant Nurse for Young Onset Dementia.

Mm-hmm. Um, but we've also got a Consultant Nurse that deals with all of the complexities that can happen with children and young adults as well, uh, because we don't know how many people are supporting their parents living with dementia.

Vic: Yeah.

Hilda: We simply don't know those figures. There are a lot. I know.

'cause I know the county that I was working in, we had a lot of under 16 year olds, um, that we were supporting, but they need support in a different way. Mm-hmm. The conventional services won't necessarily be able to do that in the same way as you can if you are actually specialising in it.

Vic: There was something for me as well in terms of the support, is the support that they provided each other.

Hilda: I think you made a good point earlier where you've got, uh, another [00:11:00] brother, sister that can be of a support that is fantastic, but so frequently I've come across situations where there's. Only one child and that one child carries the whole burden. Yeah. Um, and I think that that can be incredibly difficult.

Yeah. And you do need specialist support for that.

Vic: That's where the health, more nurses and other services, whatever they may be in the area, come in so that you've got somebody who you can talk to and you can get that support so you're, you're not on your own. The other thing that came through in this story was about the, the sudden death that Sarah had, um, and obviously, which wasn't actually caused by her dementia.

It was something else that, that caused this. It was a brain hemorrhage, wasn't it? And, and that for families often feels. That sense of shock. Mm-hmm. That almost this sense of, um, disorientation because you've kind of got this idea about where things are going and then something suddenly sort of curveballs you.

Yeah. And you, you didn't see it coming. And, and this feeling of, um, [00:12:00] almost. Um, kind of collapse 'cause you've been on autopilot for so long. You've been so busy. You've been in this caring role, giving as much as you've been giving. Mm-hmm. And you suddenly, without this caring role and this sort of, um, loss of purpose Yeah.

This sudden readjustment and having to get back to, you know, Amy actually described it, didn't She is going from full-time caring to nothing overnight. Yeah. And, and that's something carers tell us all the time. It's been so consuming. That, you know, the person suddenly died. And, and how do you pick up your life again at that point?

Yeah,

Hilda: I think that, um, one of the issues that came out of there as well is, and, and often I've seen this in, in my practice, is when you've got somebody that's going into respite and something awful happens, like the person dies or they ha break a leg or something happens that's awful and you feel such guilt.

You think, oh, probably I shouldn't have done that. Yeah, I shouldn't have let them go there. I was enjoying myself and look what happened whilst I was enjoying myself. So [00:13:00] very often you need some counseling to enable you to get through that because those guilt feelings can be really quite strong.

Vic: I think you've hit it on the head there with that counselling because you know when you lose somebody suddenly through anything, you may need counselling, but especially if you have.

Being a carer, because you've got that sudden loss. You've got that sudden loss of this is who I am, this is my, my role, this is my identity. And you've carried so much.

Hilda: Yeah.

Vic: That, you know, I've worked with many carers who describe something that's almost sort of akin to kind of PTSD at the end of their caring, because you've held so much and you've had to keep going and, and almost like the adrenaline of it all keeps you going and, and you, you can't get off because it's, you can't just stop.

It is quite common that the impact of what you've been doing really hits you once the person, yeah. Is no longer with you. And they, they've, they've died. And then I think there's something about those kind of missed milestones as well.

Hilda: Yeah.

Vic: You know, and they, these girls are gonna feel that going forward, aren't they?

Yeah. You know, the 21st [00:14:00] birthday, the weddings, the first children, all of the things that you would

Hilda: Yeah.

Vic: Ordinarily look to your mum to, to experience with you or to give you guidance and support and, and, you know, wanting mum to be present.

Hilda: But what came across really clearly was that Chloe and Amy have got a really strong relationship and, and I would think that they would, those two together will be quite a force Yeah.

Going forward. And they will support each other. And I think, um, the difference in age group. I think made a difference as well because in effect, um, the a person that that's got kind of losing a mother figure quite early on mm-hmm. One of the other siblings will adopt that mother figure role. And so it's not always the oldest child.

Vic: Mm-hmm.

Hilda: Interestingly, it can be the all, so yeah, I think that. Yeah, they'll be, they'll be good, strong support for each other in the future.

Vic: They will. And these early experiences that they've had, um, are gonna shape their identities forever, aren't they? Mm-hmm. They're gonna always carry [00:15:00] this with them. And that connection, I would imagine.

Yeah. You know, that sense of, we've lived through this together, we've done this together, we've learned and. The, the resilience that you see in young carers is, is amazing, truthfully. Yeah. You know, they, they're resilient, they're resourceful, they're often quietly brilliant.

Kola: If you'd like to speak to an Admiral Nurse like Hilda or Vic yourself, you can contact Dementia UK's Helpline. Just click on the link in the show description or visit dementiauk.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.