Chris - 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 Chris's story to give some extra advice and insight from their perspectives.

So if you haven't heard Chris's episode yet, go and give it a listen first.

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

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 the Chief Admiral Nurse and the CEO of Dementia UK.

Vic: So we've just listened to Chris talking about his story and one of the things that came out in that was about stress and actually what's a normal amount of stress and the emotional rollercoaster that you can go through when you're a carer.

And I always talk about it as a rollercoaster because if you think about a rollercoaster, you don't know what's coming next. You don't know what angle, what turn's gonna happen. Caring for someone with dementia can be such an emotional rollercoaster, such a journey.

Hilda: When you start feeling the effects, the physical effects of stress, the physical effects of caring, when you don't have those resources to cope.

Not surprisingly, some people say, look, [00:02:00] I just can't do this anymore. Or how, how can I be a carer and hold down a job and have a family? There isn't enough of me to go round. And I think you commonly hear that when people are phoning our Helpline or phoning our clinics.

Vic: So we know that a certain degree of stress is, is normal.

Um, especially in potentially in the early days when you are, you're trying to navigate new routines, appointments, all of the things that you've got to do, or then when things become more complex, these are points where you're going to feel this, this kind of pinch of stress. But actually, what do we mean when we talk about chronic stress?

When it becomes intense, when it becomes unmanageable, when actually it becomes something that really you don't want to push aside but get some help with. Some of the, the things that you might be feeling is if you're feeling constantly exhausted, um, not just a bit tired, but actually exhausted, even when you wake up feeling, you know, I've had a good night's sleep, but actually I'm waking up feeling tired.

Or it might be that you're having [00:03:00] difficulty with your sleeping and that can either be you're sleeping too much or not sleeping enough. Or, you know, not sleeping a good quality of sleep. For some people it's that feeling of hopelessness or detachment, or it might be things like losing interest in things you enjoy.

The stress levels have gone to such a degree that I'm starting to check out a little bit, and I'm not quite connecting with the situation in the way -

Hilda: It's going through the motions. Isn't it? Just going through the motions.

Vic: Yeah, going through the motions, but not, a bit detached or watching yourself going through a situation rather than feeling I'm in this situation and I'm dealing with it.

For some people you start to see physical manifestations. So people talk about headaches or stomach pains or, or even panic attacks, anxiety attacks, that feeling of trembling or, or tremors. And then the other thing that you see quite a bit is that kind of tearfulness, irritability, um, you know, that kind of just feeling overwhelmed by, by life.

And, and I think these are the kind of things that, you know, if you're, if any of those, [00:04:00] you've gone, oh yes, I feel a bit like that. It's actually potentially this is the time to talk to somebody.

Hilda: Sometimes it's, it's not you as a person that recognises some of those symptoms, it's other people recognise, oh, you, you're not speaking very much, or you look really tired.

Vic: That’s a really good point. Because you might be the, the partner of somebody who's the main carer and you are, you are watching them and thinking, actually they're saying they're fine, they're coping. Okay. But this is what, what I'm seeing. If you are listening to this and you think, yes, I get that.

So actually thinking, what can you do? You know, obviously speak to an Admiral Nurse, that's that's one useful thing that you could do. You could speak to a GP, a counsellor, or, or even a friend or a colleague, you know, reaching out and having those conversations, because we know that people often feel that actually I should be able to do that, or I should be able to cope with this.

But what carers often tell us is, I wish I'd spoken to somebody sooner. Yeah. And Chris talked about that as well. It's that I, I should have asked for help sooner. Yeah. Um, I shouldn't have carried this myself. [00:05:00]

Hilda: Sometimes in the journey of living with dementia, people need a break. Respite care is there for both parties in truth. So respite care can be something like somebody coming in and sitting with the person that has the diagnosis while you go out to have a hairdo or go out to the dentist or go out and just have some time, some free time.

Or you can have respite care that's within a care facility, for instance. So for instance, if you wanted to go on holiday for a week or a weekend or a couple of weeks, the person that's living with a diagnosis would go into a facility and be looked after for that period of time while you have that break.

An alternative to that would be somebody [00:06:00] that's called a live-in carer. So they will come into the household, they will stay overnight. Will make sure that everything is going really well and safely at home so that you can go and have a break on a holiday or do whatever you need to do as well. People like to have some sort of clear start and end time to most of the stressful journeys that they go through in life.

And often with dementia, you don't get that in the same way and you get this feeling of guilt that you're actually feeling that you want it to end, because wanting it to end usually means that the person is going to, to pass away, or it means that somebody's going to go into long-term care, then that makes you feel guilty.

So it's a, it's definitely a roller coaster from a physical perspective, from a psychological perspective and also from a guilt perspective. Yeah, it's, it really is quite challenging to be able to manage that. As well as trying to have a life.

Vic: And I think there's two, there's two things for me there.

So [00:07:00] there's one about the, this kind of sandwich carer role. And for anybody who, who maybe is listening, if you're not sure, sandwich caring is when you're supporting an older parent who is living with a condition, and in this case obviously dementia and also younger children, but sometimes it's actually used when you are working as well as providing care. We, we use that terminology.

And it's got this name because it's, it's real, it's valid, it's recognized. This is a really stressful time because you're trying to give a lot of yourself and, and when you were talking about that kind of cycle of guilt that people go through and, and Chris spoke about this as well, you know, there's stress, relief, stress, relief. That can be exhausting and it's really common to feel those ways.

That guilt at thinking, you know, of course nobody wants their loved one to to die. Nobody wants that to happen. But almost this sense of, you can see that when that happened, it would end. It would end this kind of pattern that you've got into, this cycle that you, you're into, and [00:08:00] that that guilt response and feeling is one that we, we know really well.

We hear from lots of people who tell us, I feel guilty for feeling this way. I feel guilty that I've not got enough time to give that I, I feel this sense of wanting to get off and finish this journey.

The two assessments that I always recommend that families have is, one is a carer's assessment. Which is an assessment of the carer's needs and actually gives them some guidance and some help around things that might be there to help them.

And the other is a needs assessment, which is looking at the person living with dementia and working out what their needs are so that they can kind of try to get a care package in place to meet those needs. To arrange either of these assessments, you need to go via social services, so you can go directly to Social Services or you can contact your GP and ask them to put you through to Social Services to have those assessments.[00:09:00]

Hilda: One of the other points that Chris brought up is about the difference in the presentations of dementia between his mum and his dad, and certainly it depends on the different variety of dementia and which bits of the brain is actually affected. So that can make a big difference as to how that person copes with life, how they behave, how they show distress and whether or not they've got memory issues or changes in personality or behaviour.

And I think with both of the parents, they had very different presentations because they had very different forms of dementia. And just because you can deal with one particular set of behaviours and one type of dementia, doesn't mean to say you're going to be able to with other types of dementia as well.

And I know from, from personal experience of of having both of my in-laws with dementia. The behaviours and the way they were as people were completely different. So for, for one person, there was a [00:10:00] definite change in personality, but for the other person, not at all.

Vic: Yeah. It's interesting. And that will change over the course of someone's dementia, won't it?

Hilda: Exactly. Yeah.

Vic: I think the other piece that jumps out for me was that, that Chris talks about when mum left her appointment and actually didn't recognise, didn't know she'd got this diagnosis. That in itself is heartbreaking, but not that uncommon in a way. Because we know as Admiral Nurses that when somebody has got that diagnosis of dementia, the person themselves isn't actually always completely aware of that. They're not always able to retain that.

Hilda: Yeah, definitely. It's not unusual for people to misperceive what's actually said to them in the appointments.

Vic: But you know, if you're a family member and you're in that appointment and you've got that, that chance to ask those questions. If you don't understand something when you're talking with a GP or any professional, just say things like, can you explain that in simpler terms?

What does this mean day to day? What might this mean longer term? But take all of that with a, a pinch of [00:11:00] salt perhaps, because with dementia, you, we don't always know. We, we, we can't predict this is what's going to happen in the future. It can be difficult. Um, you know, and, and I think that's, that's the thing.

We know it can be difficult. We know it can be hard to live with a diagnosis of dementia. We know that people are going to have this for many, many years in, in many cases. And over the course of that journey, there's going to be lots of twists and turns. And bits you don't understand.

So keep going back and saying, explain that to me in simple terms. What do I need to know now? What does this mean to me today? And focus on that rather than the kind of what ifs and maybes for the future.

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 [00:12:00] 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 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.