

Penny - 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 Penny's story to give some extra advice and insight from their perspectives. So if you haven't heard Penny'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 the Chief Admiral Nurse and the CEO of Dementia UK.

Vic: This episode is in part about something that many people might find incredibly hard to talk about, is actually moving a loved one into residential care. It's a decision that will be filled often with many emotions.

It might be filled with guilt, relief, grief, uncertainty, and often people feel like they're going through this alone as well. We've heard from Penny who shared lots of her experience, but I thought it would be really useful to, to pick some of that, um, through and have a, a, a bigger conversation about it. So what we're going to look at in this is a little bit about how do you know when it's the right time?

How do you choose a care home? How [00:02:00] do you deal with some of those emotions? What do you do if the home isn't right for, for you, and how to navigate through that? So in terms of when is the right time, this is such a big question. When does it feel like the right next step? For some people, that's when the person is no longer safe at home.

Maybe they've had frequent falls or maybe they've been leaving the house and going out or getting lost or forgetting to take their medication. Or it might be

actually that you are the carer and you are at the point where you are burnt out, where you're exhausted, you know, you're actually saying, I can no longer provide the quality of care, the type of care, or I just just can't give any more of myself.

It could actually be that someone's needs have become complex. They, they've become something that actually you're not capable of doing because you, you know, it might be that they need 24/7 supervision, or actually it's just difficult care that that person needs.

Hilda: Mm-hmm. Just, I want [00:03:00] to add to what you're saying, when is the right time, often from experience, people leave it until too late.

They leave it until there's a crisis and it is far harder to manage the process. When it's a crisis, you get very limited choice.

Vic: It's almost the wrong time, isn't it?

Hilda: It absolutely is because the heightened emotions and everything that's that's happening at the time. Trying to choose the right home is incredibly difficult at that situation.

Penny said, well, actually, I thought about it and Mum wasn't even recognising where she was anymore. So for her, that was kind of an indication that this could be the right time. So once you've got the right time, then it's about finding the home that's right for your loved one. And it varies. So some people would like these kind of plush hotel-like experience, whereas some people want more small and homely and you need to take that into [00:04:00] consideration.

Just because something looks shiny and bright and lovely doesn't mean to say that that care is going to be the best care. So it's finding what you think your loved one will actually prefer. Now why I say that it's more complex when you are leaving it to a crisis. When there's a crisis, often the decision is more or less taken out of your hand.

It's where there is a bed, so that bed might be miles away from you. It might be on the doorstep, but that home isn't actually suitable and won't actually cater for the needs. And sometimes you have to accept that the first place that the person goes to might not be the right place. And Penny found that she had to move placements a couple of times, and that's, that's a good thing to do, rather than persevering with something that doesn't actually work.

Vic: Moving someone into a home is difficult. It actually doesn't mean you failed the person. It's not, it's not [00:05:00] that at all. It means you're actually finding the right support for them to enable them at the stage they're at now or and the stage that you are perhaps at now as a family as well.

Hilda: When I was looking for those sort of setting for a loved one, basically when I go into somewhere, I'm walking into somewhere and I'm using all my senses.

What does the home smell like? Sounds a bit weird, but the smell is important.

Vic: Trust your instincts.

Hilda: Exactly. Yeah, it's trust your gut feeling. Look around. What are people doing? Are they engaged in things? Are they active? What are the staff doing? Is there a television on in the corner over there, a radio on in that corner, and something else going on in the other corner.

Too much noise. Those are the sorts of things I'd be looking for, and I would also recommend you don't just go once, you go a few times. So go at a busy time, and that might be in the morning, go at a more kind of [00:06:00] gentle time, ie, the evening, and go one day at the weekend just to get a feel for how that home functions.

I think that's really important. And also a home that actually understands dementia. Because I have had to move so many people in my career where the home is eager to fill a bed with a person, but actually do not have the facility to be able to deal with somebody that's got communication issues and dementia.

So then you end up having to move somebody because the homework wasn't done at the beginning, or it was a crisis admission at the beginning.

Vic: It's so important 'cause you have to think about actually what the person might need a little bit further down the line as well sometimes.

Hilda: Absolutely. The other thing I would suggest when you're looking and finding, you think you found the right home. Try some respite first.

So a week while you go for a holiday or just while you do things that you need to do. So the person is able to trial it to see, [00:07:00] actually, you know what? I would like to be here or I wouldn't like to be here. Sometimes it can be for a week or two weeks, and in some situations we say we'll do a review after a month.

It just depends on what the situation is and as far as it's possible, if you are doing it outside of a crisis, taking the person along to look at these settings as well, the care home setting, because that person will be able to make a judgment call as well as to whether that is okay for them or not okay for them.

Vic: One of the things Penny mentioned, what was actually really good in her mum's current care home was the dementia communication tools that they used. But what do we actually mean by this? So essentially it means speaking slowly, speaking clearly, using simple language, connecting with the person rather than talking over them or about them.

Using things like eye contact and a calm tone, maybe touching somebody so that they know that you're, you're talking to them and you're [00:08:00] communicating with them. We all use loads of gestures. If you could see me sitting here now, you would completely know that. So using things like, you know, the, the sign for a cup of tea or cold, putting a jumper on, or going outside or going to the toilet. These are all things that you can use gestures to help that communication with somebody.

Hilda: I think sometimes using picture boards as well is useful, particularly when, say for instance, a person selecting what they want to eat, so showing them, well, this is ham and egg and chips, and this one's a cottage pie.

So people are able to point, because sometimes the verbal ability is going to be affected with dementia but always think the understanding, the comprehension, might not be affected.

Vic: When you've chosen the home and you've got the [00:09:00] idea about the home, you then end up with another big set of emotions, actually, which Penny spoke about, which is that emotion of clearing up the house. Moving, moving things out, moving that person into the home and that whole transition. And, and that's a really hard thing to do, especially if someone's lived in a house for 40 years.

It, it can be practically a hard thing to do as well as an emotionally hard thing. You get to the point where almost every object you pick up holds a memory and you think, oh, we can't bear to throw this in the skip or to throw it away. Taking your time to do those things. Do them in a calm way.

And you can even sometimes start doing some of this before you need to as well. You know, doing the bit of that decluttering, deciding what are the special trinkets, what are the bits that actually we really need to keep? Because when

your loved one goes into a care home, they can take some of those things with them to put in their room.

I think it's also important to just think a little bit about the financial side of this as well, because of course this can [00:10:00] play a huge part of making decisions and the whole role in choosing a care home. So if you are, um, using local authority payments for this, so if local authority are paying for your care for your loved one, you might also feel that you don't have as much choice or your options are limited.

You do still have choice. You don't have to accept just a bed. Although of course if you're at that point of crisis, sometimes we know that families do have to do that and you can have less say. So actually visiting homes, doing it before you need to, doing it in advance, working out which are the ones that the local authority will pay for.

Even sometimes useful if someone's just above a threshold 'cause you might think, well, you know, potentially money is going to run out and, and you really don't want someone to potentially have to move home. So it's actually thinking about what's a good home for, for my person now, but which actually might work for somebody for the next couple of months.

There probably isn't always gonna be a perfect answer, it's just about actually what feels like the best choice. What feels [00:11:00] right for us as a family now. That probably leads a little bit into some of that feeling of guilt as well, doesn't it? And, and that kind of sense of broken promises and, you know, how many times have we worked with somebody and they've said, you know, I promised I'd never put mum in a care home.

Or, and here I am now, or, you know, I should be doing more as a carer rather than needing these, these emotions are really common, aren't they Hilda?

Hilda: Oh absolutely. The feelings of guilt will be there. Pervading everything that you do as a carer. That's one of those things that unfortunately does travel along with a long-term condition such as dementia.

Actually trying to deal with that, think about, well, what would mum actually really want? If she was in this position and she was caring for somebody, what would she really want? Would she understand that, okay, you might have promised that because it was a different circumstance, but now you're in a position where you can't live up to that promise.

[00:12:00] So I think it's about coming to terms with, with some of that, talking it through, talk it through with an Admiral Nurse on the the Helpline. We're open seven days a week with the exception of the 25th of December. Book an appointment with the clinic, because they're common feelings, the guilt feelings that we all feel as carers. No matter how good you are as a carer, like I say, they're all pervading. They will affect all of us in that situation.

Vic: One of the things that Penny spoke as well about was the, the podcast that she did with her mum, and essentially that's that life story work. And as Admiral Nurses, we talk all the time about the benefits of life story work, but what Penny did really beautifully was actually capturing mum's voice and, you know, so not only her story and her sense of humour, but her, her voice as well, which Penny could listen back to.

I would urge everybody listening to this to really think about life story work. It might be making a scrapbook, doing a memory book. Recording somebody.
[00:13:00] Voices is powerful, isn't it? It's something that that's beautiful to listen back on.

Hilda: Sometimes people make it into like a collage for like photo board, what they put on the wall.

And that helps as well with the staff because when the staff oh, oh is that you, when you are a little girl or a little boy and it, it actually makes that person a real, live person that that's got a life.

Vic: The more you can give them to help them build a picture of the person, the more they're gonna be able to communicate with them and build those connections and, and do things that are meaningful for that person.

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 [00:14:00] 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.