My life with Dementia – Admiral Nurses discuss Phil'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 Phil's story to give some extra advice and insight from their perspectives. So if you haven't heard Phil'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's Vic Lyons. I am Head of digitally delivered services and dementia at work, and also an Admiral Nurse.

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

Vic: So in this episode, we're going to be focusing on something that many people face, but actually few people talk about, which is dementia at work. We know through the story we've just listened to with Phil that actually this was something that he had different responses to as well with different bosses.

One in two of us will be living with dementia over the course of our lifetime, either with the diagnosis themself or as a carer for somebody. We also know that there's around about 71,000 people under the age of 65 who will have the diagnosis of dementia. And why was it a bit of a roundabout is because we also know that there's many more people who will be living

with changes that could be associated with dementia without a formal diagnosis.

So we know that. We also know that retirement age is going [00:02:00] up and up and up. Which means that many people will be working whilst living with dementia. So some of the stuff I think we'll we'll cover today is a little bit about how to talk to your boss about the diagnosis, what rights and supports you might be entitled to, what employers need to understand, how to involve the people in HR teams.

Maybe a little bit about some of the adaptations you might make, and then also thinking about what next, what after work, so planning for how to stop work, what happens beyond work. So there's some of the things that I, I think we'll probably cover in this. And also just to mention, our 'Dementia at Work' team have produced two guides that are there to help people.

So if you want to download those guides, they're available through the Dementia UK website and they're packed full of information designed to help workplaces be dementia [00:03:00] inclusive, and also to think about working families and what they need.

Hilda: I'd like to step back slightly and look at the diagnosis aspect, because part of getting the diagnosis and the delay in getting a diagnosis for young onset dementia means that those conversations start to happen a little bit later than they probably ought to.

So in total, it took Phil about two and a half years to actually get the accurate diagnosis, and he noticed a lot of things that was affecting his work. So for instance, his memory, what he calls a lag in his head, tremor, stress, tiredness, irritability to a certain extent. All of those things might be performance issues.

So it might be something that HR are called into, or a boss will have a conversation with an individual not realising that actually this is all down to a condition, not the person choosing

to be as they are. So by the time you get [00:04:00] to the point of diagnosis, having that conversation with a line manager, with a boss, it's probably a little bit later than it needs to be.

Vic: Yeah, good point.

Hilda: Yeah. So when you do have a conversation with the boss, you need to be able to inform them. As Phil is a nurse by background, and as nurses we have to disclose a dementia diagnosis and various other long-term condition diagnoses. So informing and saying, look, this is the diagnosis. This is what's happening to me.

And also probably educating them a bit as well, because from my experience employers might want to support you, but they haven't got a clue about dementia and they haven't got a clue how to support you. So it's easier to have a conversation like the second manager had of, well, actually I think you can't do the job anymore and it's better if you've got some dementia to kind of leave the workforce.

[00:05:00] That happens so frequently when I used to go out and assess people under the age of 65, it was much more common that people will have lost their job before I ever got to see them to do the diagnosis. Because people wrongly think it's a performance issue,

Vic: And I think people sometimes themselves make that assumption as well, don't, don't, they, they think, oh, I've got this diagnosis, I shouldn't be able to do this anymore. And I guess in short, you may not have to tell your boss, but if you don't, it could lead to other actions of the consequences.

And, and, and actually you're holding on to stress that you needn’t hold onto because you might be thinking, well, I don't want to tell people because I, I feel embarrassed or I feel guilty, or I, I maybe have a mortgage to pay and I don't want to admit this. But actually, if you have that conversation, it can

unlock some of your rights and those kind of reasonable adjustments that we talk about.

And these are protected things in the Equality Act, so, you know, you're entitled to them. It's, it would be wrong to be dismissed because of [00:06:00] this diagnosis. And yet we know that people sometimes allow the assumptions they have to stop them having those conversations.

Hilda: It's fear. It's it's fear. It's straightforward fear because people are frightened about telling people in case they have to lose their job.

And, and you quite rightly said, Vic, it's an expensive time of your life. You've probably still got a mortgage. You've probably got kids. Um. That's all kind of in the back of your head and you think, well, I better not tell the employer. But it's so important that you do, it's so important you can talk it through because employers can make adaptations.

Vic: And I think for us it's probably, 'cause obviously as nurses we have regular touch points and supervision with our bosses and line managers.

But I know in some organisations you just don't, that's, that would consider a massive luxury. You, you wouldn't have that. So even finding that time to have that conversation can be quite tricky. And you know, actually what point do you do that? Think about actually booking that time, booking that appointment, considering what you need to take with [00:07:00] you, because you said it earlier on Hilda, about educating them.

That boss may never have supported the person living with dementia who wants to carry on working before. They, they may have no idea about what the law says about that. Or any idea about actually how practical that is in the workplace.

So actually, if you go into that meeting in a planned way, with the information about your rights and what support you might

need so that you don't fall into this assumption that you've got this diagnosis, now you need to stop work. You can go in and say, I've got this diagnosis, but this is how it affects me. This is the reasonable adjustments I might need.

Some of the adaptations that I've known people living with dementia talk about are things like maybe a buddy, somebody to work with you to support you. It might be having written instead of verbal instructions so that you can revisit them. It might be checklists or visual clues or reminders and tech and [00:08:00] things that you can use to help you structure your day.

For some people it might be a quieter workspace to work in. So there's less distractions about, and certainly in the episode we listened to from Phil, he talked about a sudden move and you know, and that restructure, which he wasn't consulted in. So actually making sure that if your your employer knows that you've got this diagnosis, they can think ahead and think, okay, this might potentially cause an issue.

Hilda: Absolutely. And I think that sometimes employers are making the suggestion that the person leaves work because they're frightened of the safety aspects as well, which are often a fallacy. Getting HR departments involved is really quite useful from experience and, but on top of that occupational health.

Some firms, some bigger firms have got occupational health departments, some haven't. But you can get an independent occupational health assessment and that will [00:09:00] often kind of enforce with the line manager that actually this person can still do X, Y, and Z.

Vic: It's valuable. It's so valuable, isn't it? And I think getting the involvement of your people team, if you are lucky enough to have one.

And then I think it's about for the employer to focus on what the person can do. Focus on the skills that they can do and yes, be mindful of the things they can't but, but focus on the

bits they they can do and then check in on a regular basis. So doing your occupational health assessment or involving your people team and then ticking the box to say you've done that and not revisiting it for a year or however long isn't enough.

You need to check in, you know, sort of every, every couple of months really.

One of the things that we need to talk a little bit about as well is about that how do you [00:10:00] decide when's the time to stop work? What does that look like? What does approaching retirement or ending work look like? Because nobody wants to work forever. As much as you may like your job, you'll get, you'll get to a period where, where it's time to to end that role.

So what advice might we share there?

Hilda: I think for most people, retirement means that you're going to kind of leave one part of your life that's often been a very important part of a person's life to start another chapter of your life. So having interests, having things that you enjoy doing, as well as working, before you suddenly retire.

I'll give you a scenario here. My husband who hasn't got dementia, but he is approaching his retirement age, he has no interests whatsoever. But he said, as soon as I retire, I will develop interests. It doesn't happen from my experience of working with people many, many a year. [00:11:00] So for me, retirement means that you've got things that will replace the fact that you're doing a nine to five Monday through Friday.

So it's about Phil doing the things that he enjoys, finding things that will still give him that sense of fulfilment, because obviously Phil coming from a healthcare background as well, and he likes working with people, he needs to find things that fulfil that part of his life. So it might be working with, with other people on a voluntary basis, or it might be that he joins a particular group.

It might be that he actually gives his advice and support to newly qualified nurses or student nurses. So there's lots of things that you can still do and contribute to. And at the end of the day say, yeah, I did that and that worked really well. Kind of replacing something with something else that he can still feel value for.

Vic: Retirement is that door, isn't it? To kind of [00:12:00] rest and reflection and, and a new purpose, which like you, you said earlier, it's how do we find that purpose? The kind of key thing for me is to say, when work stops, it doesn't mean your life stops.

Work stops life doesn't.

Hilda: Exactly.

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.

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 [00:13:00] 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.