# My life with Dementia – Phil storyteller 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. Last year I lost my mum, Maria to dementia. I've written a lot about the condition over the last few years. Because I felt that it was something often hidden behind closed doors and not really spoken about.

In this series though, you'll hear directly from people whose lives have been impacted by dementia.

Phil retired in 2023, about five years after he started showing symptoms of dementia with Lewy bodies. He had an incredibly rewarding working life as an NHS nurse, [00:01:00] hospital manager, and then university lecturer. When he found out he had dementia, he saw the best and worst sides of how employers can respond to this diagnosis.

**Phil:** I'm Philip, but everyone calls me Phil. Only ever call me Philip when you're telling me off. I come from Ashford in Kent. I'm originally from Warwickshire. I think of myself as a 28-year-old. Unfortunately, I'm not, and I'm 62 and I've been a nurse for 40 years before I retired, year before last. I have, or I am living with Lewy body dementia.

I think the people who've known me the longest would describe me as quirky. They would describe me as slightly anxious, [00:02:00] someone who likes to talk to people. I love hearing people's stories. I am married to Debbie. We trained together, and this was in 1981 when we first met. She went past my desk. I thought she looks nice.

From that point on, we kind of hit it off. We, we seemed to laugh a lot, and that was it. We, we stuck together through thick and thin ever since. She's a very bubbly person. And I think that's one of the things that attracted me to her. She's got a lovely sense of humour and when she laughs, she will make everybody else laugh because unfortunately she has the most disgusting habit. If she's taken unawares, she will snort. So that normally gives everybody another 10 minutes of enjoyment.

She is now becoming my [00:03:00] memory. Which is important. My experience of having dementia is that the memories of long ago tend to remain. It's the memories of today, yesterday, the day before, that tend to go.

So actually when I'm thinking of the people that I've met since I've had my diagnosis, who I now call my close friends, they are still holding memories for me that are just as important as the memories that were 20, 30 years ago.

**Marianne:** When the teenage Phil finished school, he didn't know what he wanted to do yet.

But he soon realised he needed a career that would let him be around people. So, in 1980, Phil applied for nurse training.

**Phil:** Three years of sheer [00:04:00] joy. Debbie had qualified ahead of me. We got married just before I qualified. We had a house we could just about pay for, and I started in elderly female nursing. It was great.

Taught me so much about humanity. Talking to people and pushing against the system a little bit, because in those days it was very institutionalised. It didn't matter what the patients wanted. This is, you know, it was 10 o'clock, this is what happens. I did three months and then I went into intensive care and I was terrified the whole time that I was gonna miss something.

But eventually I discovered that I was quite good at it.

**Marianne:** Phil did more training and rose up the ranks until he was one of the most senior nurses on the unit. In 1992, looking for a new challenge, he moved into a hospital [00:05:00] administrator role and eventually, several promotions down the road, found himself the hospital manager.

He was responsible for running two hospital sites. It was a chance to push even harder for a new era of patient-centred care.

**Phil:** And we were able to make so many changes that I hope altered how we cared for people. To turn it back into humanity again rather than just, you know, that patient is the patient with. It was John whose wife is coming to see him, and he's really, really worried.

I stayed in that role gradually working my way up and through the hierarchy and the bureaucracy of the NHS. I then found myself again in a strange situation by someone [00:06:00] tapping me on the shoulder during a meeting, and it was the acting dean of the university saying, you don't fancy coming for a couple of years and just helping us with our programme of education.

**Marianne:** And that led to the next chapter for Phil as a teacher. He became a senior lecturer at a university training the next generation of nurses.

**Phil:** And I loved it. Utterly, utterly loved it. Teaching, educating, nursing is about caring. Nursing is about the other person, not about you. And I think actually that philosophy has helped me develop a sense of wellbeing and also looking out for other people.

Dementia doesn't seem to be a disease that impacts instantaneously. [00:07:00] One of the most difficult questions to answer is, when did it all start? When did you first notice it? It's not like a major trauma where you know you've had your leg cut off and it's the here and the now.

Dementia is a progressive disease that is often slow, has many, many characteristics and can hide itself behind other situations and other symptoms. I would have been in my early fifties, so at the time I was in a senior post at the university managing academics. So it was stressful. I felt I was getting older. I think I was realising that my body wasn't as responsive as [00:08:00] it used to be, and there were occasions when I would forget things.

I was finding a lag in my head. Lists became more prominent. They were things that I lived by. I found myself behaving slightly differently. My mannerisms might change. My facial expressions weren't necessarily the ones that people would have expected.

**Marianne:** My mum's symptoms developed gradually like this too. It started with constantly forgetting where she'd put things and it moved on to things that couldn't be put down to absent mindedness.

Like when I found her trying to boil instead of fry an onion. She looked at me and said, I've forgotten how to cook. Another time she chose a book from [00:09:00] my shelf that she'd only just read. And she was short-tempered when I pointed it out. She was in denial for a long time.

**Phil:** I would lie about being told things.

Oh, I, I wasn't told that. I, I didn't know anything at all about that. Oh, I haven't read that. I haven't seen that.

I started bumping into things. There was a slight tremor in my hands. I used to mend clocks, so you need fine movement. It's only now that I can honestly say that I didn't stop doing the clocks because I didn't have time. It's because I couldn't hold the tools and I just didn't want to accept that there was something wrong.

I put it all down to stress. That tremor is anxiety. People made [00:10:00] comment that my interaction at meetings could become a little bit assertive. They didn't use the word aggressive. They used the word assertive. People would ask, are you all right? Yes, I'm fine. I think Debbie would say that I would use up all of my battery, my physical battery, my mental battery at work, and come home, lay on the bed with my clothes still on and go out for five to six hours. Because I'd used everything up. And this so I said is, is my early fifties.

At no point in this time would I've even considered dementia. There were changes for a good couple of years. My wife, my son, started to notice more and more. I have to say, if it hadn't been [00:11:00] for my wife saying, we want you to go and see somebody, I probably wouldn't have gone.

**Marianne:** So Phil went to his GP and he was referred to a memory clinic.

**Phil:** I went through the various tests and things and they said, you are presenting as a red flag, so we are going to put you forward for more tests. Subsequent visits were far more in depth, much longer, two to three hours with psychologists. The conclusion at the end of this assessment process was that I had mild cognitive impairment, but I also want to refer you to a neurologist because there is a physical symptom that we can't investigate. And that was my tremor.

**Marianne:** So there were more tests and investigations to [00:12:00] come, but for now, Phil had some kind of answer, a diagnosis of mild cognitive impairment.

**Phil:** I told my line manager who said, I'm sure it's gonna be fine. Yes, I, I think I'm gonna be fine as well. I don't think there's anything but it's, it's worth investigating and let's, let's do it.

Whilst I was going through that investigation phase, I stood down from management roles, so I no longer had to manage staff, which improved the situation. I wanna stress at this point that I was working for a British university who had an occupational health service that was separate to the university, and that's really important.

Because it meant that if I went to see them or if my line manager asked me to be seen by them, they would give independent advice, not the advice that the [00:13:00] employer would want to hear. And I think that that is the most important thing. So I think I felt quite protected in terms of employment.

So I continued on, but of course we are now getting to the point where I'm going for more investigations and memory was starting to deteriorate again, and this was despite pulling back on various things. So I did start to get a little bit anxious that perhaps things weren't as okay as I had perhaps first thought they were. I had a whole series of scans, PET scans, all of those types of things. And then I had my lumbar puncture.

I was seen by a specialist, who is an absolute shining example, both in terms of expertise and humanity. Spent two [00:14:00] hours, not 20 minutes, two hours with him, Debbie and I, he did all the physical investigations, and he said at the end of it, what do you want when you walk out of this door? And I said, I just want to know what I've got. He said, you just want the dots joining up. He said, I am convinced as I can be that you have Lewy body dementia.

**Marianne:** Lewy body dementia shares symptoms with Parkinson's. Among other effects, it can impact a person's thinking, cause hallucinations, sleep disturbances, and memory loss too.

**Phil:** For me, it, the whole experience going from the start of the assessment process to getting the final diagnosis was about two and a half years. [00:15:00] Was there a sense of relief? Yes. People say, were you devastated? I said, no, I wasn't devastated because at long last I had a name for this thing. Debbie and I went home that night after getting the diagnosis, and we talked about what we were going to do.

As a registered nurse, I have a legal obligation to disclose any illness that could impact on patients or anybody that I provide care to, whether that care is just verbal or physical care. So the first day back, I told my line manager. This person was again brilliant, said, okay, what can we do? What can I do? There was no preconceived ideas.

We can talk, I'm sure, [00:16:00] a long time about people's responses to, to telling other people that they've got dementia, but her one was, okay, look, I get the impression that you want to keep working. Is that the case? I said, yes. She said, right. So what can we do to help you? So my line manager, my head of school, and potentially the dean - absolutely fine.

Outside of that group, they didn't have any idea at all, and I think that's where I've become so, so aware since leaving work of my own volition when I chose to, of the people who have lost their jobs because they've been either pressurised or told to leave on the day after they've given notice of their diagnosis.

When talking to HR, it was only the, one of the most [00:17:00] senior members of the HR that actually understood anything. My first encounter with HR on giving them the diagnosis was that, oh, so you'll be retiring then. Those were the exact words, because the assumption is that the person with dementia, and I'm sorry about this stereotype, is someone sitting there dribbling, et cetera. There's no understanding of the shades.

People with dementia are on a journey. For some people, that journey starts with no physical or or minimal cognitive alteration. Towards the end of the journey, it is a complete breakdown. But between that beginning and ending, there's so much of life

Trying to explain to people that you have invested [00:18:00] in me a vast amount of money to do a job that I know can still be done. Why would you want to get someone in who's a newbie who has no knowledge of systems or processes or whatever? Since my diagnosis, I've had conversations with hundreds of people who have got a diagnosis and those people who are caring for people who are living with dementia.

And I think the one thing that comes across is that they all say people view dementia in their own unique way. And often people will see it as, oh yes, my grandmother had that, so therefore, you must exhibit exactly the same as my grandmother. It's almost as though the stereotype for people with dementia is stuck in one place.

**Marianne:** So the university's HR team [00:19:00] saw Phil's diagnosis as a reason to retire on the spot. But they couldn't push him out because of that independent occupational health team. It was their job, not HRs, to assess his capacity to keep working. With the help of his supportive line manager, he made a plan to carry on.

**Phil:** We agreed together that this would be the course of action. I would amend my workload. There would be a need for me to advise my governing body, which I did straight away. And the final thing was that we, with me in control, would determine who would actually need to know. I made some conscious decisions in agreement with my line manager.

One, I would cease all direct clinical patient care. That when I was in clinical [00:20:00] practice supervising students, that there would be somebody else supervising me. There would be monthly meetings with myself and my line manager, and through monthly meetings with my line manager, occupational health, and myself.

I then had a meeting with occupational health. He knew what Lewy body dementia was. He said, the balls in your court. If you want to keep working, then my role is to monitor you so that you can keep working safely up to a point where you feel that you can't, or I feel that it might be detrimental. And I said, yeah, absolutely fine, I do not want to cause harm to anybody, so please, let's, let's definitely, let's do that. And we had a very harmonious couple of years.

What I would want to say to anybody is [00:21:00] if you know that you're heading in this direction, with a possible outcome, have a look around you and think about how your employer has looked after people in the past. Those people that may have been pregnant, those people who've had mental health issues, those people who've had cancer.

What has your organisation done? Does your organisation have an occupational health department that is independent? And if it is, refer yourself. They can give you confidential advice.

**Marianne:** Phil was lucky to have a great line manager and occupational health consultant, which gave him that two years of continued well supported work as he lived with his new diagnosis of dementia with Lewy bodies, but unfortunately, it didn't last.

**Phil:** There was a [00:22:00] change in the head of school. There was a change in my line manager to a line manager who wasn't a nurse and didn't have any understanding of dementia or Lewy body dementia. And the culture of the organisation ceased to be as open as it was. The degree of resistance that was starting to be put up started to worry me a little bit.

Then came an instruction from my line manager that I was to move offices. I said, I don't want to move offices because I'm comfortable in my office. It's got two large windows giving almost 50 percent's worth of light on two sides. They said, no, no, um, we are concerned because you might fall down the stairs.

I'd had no falls. Yes, there were stairs to the office and this [00:23:00] was a building that didn't have a lift. I said, but I, I've never had any problems. And I was put in a basement room with limited natural light, and I was with nobody else. So I went from companionship to isolation, light to dark. And I felt vulnerable.

I didn't feel as though I was being listened to. I was getting a growing sense that things were not favourable, and I thought, is it better to go out under my steam? So I talked to Deb about it and we said, yes, I think now is the time. So I wrote the letter and said I am now considering ill health retirement.

**Marianne:** What [00:24:00] happened to Phil shows that in a workplace, every link in the chain of support needs to be strong. Phil had always intended to work until he was 65. And he retired at 60 despite having plenty left to give. But he tries to see the positives in what happened.

**Phil:** The bottom line is that I got two and a half years worth of employment, two and a half years of feeling, I'm still Phil. I'm not dementia. I know, and we are being realistic here, that as time progresses, my abilities will deteriorate. That's what the disease will do. But I am going to keep resisting it, taking part in research, raising awareness, doing whatever it takes.[00:25:00]

**Marianne:** Enormous thanks to Phil for sharing his experiences of navigating a dementia diagnosis at work. If you have a look in your podcast feed, you'll find another episode right next to this one with Hilda and Vic, two of Dementia UK's Admiral Nurses. They dive deeper into some themes from Phil's story offering advice from their perspectives as specialist dementia nurses.

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.[00:26:00]

You'll also find links to the website and other resources in the show notes for this episode. Thank you so much for listening.