

Julie - storyteller 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. 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.

Julie was diagnosed with dementia when she was 54. She lives on her own and doesn't have family members caring for her. But she's found her own strategies for living independently [00:01:00] whilst building deep friendships and community through her work as a dementia activist.

Julie: My name's Julie Hayden. I live in Halifax in West Yorkshire. I'm 62 now. Born and brought up in Halifax. I was cheeky, quite bossy. I kept hold of that actually when I was an adult.

Marianne: At 18, Julie trained as a nurse and when she qualified, it was time to see something new. She took herself down south.

Julie: I decided I would head for London. Got my first job in Surrey at a new hospital down there, and then later on moved into London itself, working for St. Thomas'. I'd only intended going down for a couple of years. [00:02:00] I met my future husband and ended up spending most of my adult life down there and just came back to Halifax in 2015 just after my mum had died.

Marianne: After originally training as a nurse, Julie went on to work as an agency carer among other jobs over the years, and then in 2003, she decided to take her career in a new direction.

Julie: A lot of my friends were social workers, so I applied to go to university and was accepted to go to Brunel and qualified as a social worker and worked in older people services.

There was a connection with dementia because a lot of my clients were living with a form of dementia, so supporting them and their families. I'd only [00:03:00] been about three years, I think, as a social worker, and I started to feel the symptoms that something was going wrong. I couldn't concentrate. I

couldn't multitask in the way I did, and when I went out to assess people, I wasn't always picking up on what was there in front of me.

It was a paperless office. We relied on computers and sometimes I would go in, sit down in front of my desk, look at my computer and think, how the hell do I turn this on? And I'd just kind of look at it, and then I'd go away and get a cup of coffee and bring it back to my desk. And I'd have to look at it and study it for a while before deciding, I wonder what would happen if I pressed that button there, so then the screen would light up and then I'd, I'd remember that I had my password in my desk. I was too embarrassed to say to anybody, so I used [00:04:00] to hide it. I felt scared and I felt stupid.

When I was trying to explain symptoms that I was having, even though it was a caring profession, I got no understanding or support from my bosses, and was outrightly told, if you're having a problem, you are a problem. It's very difficult because although I went along to my GP, who on earth starts to think about possible dementia when you're still in your forties?

My GP tried and put it down to either, you're depressed, well yeah, I was depressed. Look at all the symptoms I was having that I wasn't having the symptoms because I was depressed. If you're a woman of a certain age, it's always put down to menopause. Which it might well be, but I just knew it wasn't. [00:05:00]

By then I was on my own. Maybe if I'd still had a partner, maybe they would've been looking on and saying, yeah, absolutely. You know, this is different about you. And maybe if I'd have been going along to a doctor with my partner or my husband and he or she'd have been hearing it from both our sides, they would've taken it more seriously.

I do hear from my friends who have partners, that doctors tend to listen to and to speak to that partner and kind of bypass them.

Marianne: Although Julie had worked with lots of people who had dementia, she'd never heard of young onset dementia. That's when symptoms start before the age of 65.

Julie: Given that there's a lot of dementia in my family, I sort of always thought that maybe it would come my way, but I, I always thought it [00:06:00] would be when I got into my seventies, eighties, something like that.

All told it took about five, five and a half years to get that diagnosis. The journey there was such that I was becoming less capable. I lost my job, and I

actually had to get to a point where I was having physical collapses on a regular basis. I had this kind of all systems breakdown, spent a month in a mental health unit, and while I was there, that was the first time anyone did a brain scan.

It was a CT scan. They did an MRI, but I wasn't diagnosed until I was 54. When the eventual diagnosis came through, I know that some people talk about going into great depression, and I was certainly [00:07:00] shocked by it, but in a way it was a kind of a relief because I could understand then what was happening.

I was told the diagnosis by a neurologist, but she just really said to me, yes, it's one of the dementias, not Alzheimer's because your memory would be worse, but it's definitely dementia. She scribbled out a prescription, pushed it across the desk, and that was it.

Marianne: In my mum's case, the diagnosis was finally confirmed to us by her GP.

He did ask us whether we had a power of attorney in place, but apart from that, we were given absolutely no advice. My sister and I had to do all the research ourselves, which is when we came across Dementia UK. Julie wasn't given any guidance about [00:08:00] where to find help or support either. She was lucky that as a social worker, she knew where to go.

Julie: I tried going to some of the local dementia cafes in the area, and they were very nice and they were very welcoming, friendly. But I was going and I was seeing people who were quite a bit older than I was, people who were usually more advanced. I wanted to speak with someone who is of a similar age to myself and find out how they were coping.

As I'd managed groups during social work training, I said, well, okay, I'll set up my own group. I got diagnosed in May 2017. By October, that same year, I had opened up the doors to my own young onset group.

Marianne: [00:09:00] Running the group was a way to build community and help others, but it served another function too.

Julie: One of the ways to stay well and active for as long as you can is finding occupational purpose. For so long, for years I just felt worthless and on the scrap heap of life when I was still only in my fifties.

To find that I could actually be useful again, was brilliant, especially with being on my own to have that focus around my day and my week. I didn't have the option of just turning my face to the wall and just thinking about me. I think

there are certain things which when they come along in life, they readjust your focus.

So many of us get fixed on material things. But the great thing about people who have come [00:10:00] through something like this is they start to realise what's really important in life.

Marianne: Research from 2023 found that possibly as many as one in three of all people with dementia live alone, and Julie is one of those people. Part of managing to stay independent means embracing tools that make the world more accessible.

Julie: I started to have the physical symptoms quite early. My balance started to go, so I needed to walk with a stick, and then after only a fairly short time I transferred to a walking frame because my balance got so bad I needed something to lean on quite heavily.

And that's quite a transition. And then coming to the decision that I can manage around my home with my walker, [00:11:00] but out on the street I need to use a wheelchair. I didn't want to go into granny image, but once I'd made that transition, it made my life so much easier and enabled me to have so much more independence.

It's easy to get frustrated even when you can still do something. It takes a lot more concentration, a lot more hard work to achieve what you once could very quickly and easily because you have to concentrate harder. You are constantly battling against that tiredness that is created.

Marianne: Julie also doesn't have a family member caring for her, which means she's navigating her dementia journey completely by herself.

Part of her support network includes members of a 'living alone with dementia' group that Julie co-hosts, [00:12:00]

Julie: Dementia Alliance International, who have that group. They started it up because so many people were talking about support they get from their partners and other family members, and referring to them as their backup brains, their 'bubs'.

And other people were saying, excuse me, that's great, I'm really happy you've got that. But for us it's different. We've got to find a way ourselves of getting through.

We can give each other tips if you're struggling with a particular aspect of living with dementia and you might find a different way around. And if someone could just turn around to a family and remember and say, oh god, you know, my head is really bad, or I can't concentrate just to say, could you give me some help with this?

Or could you actually do that for me? It's kind of like a, a gap certainly in service and in knowledge and provision that not [00:13:00] everybody has someone living with them or coming in to see them every day.

Marianne: All this means friendships have become especially important for Julie.

Julie: The best friends that I have are naturally the people who stuck by me all the way through my own diagnosis.

What you quite often find is that there are a lot of fairweather friends. You tell them that you've got dementia because that's sort of stigmatised. It tends to be a very predictable thing that, first of all, telling someone that you have dementia, they say, "Really, you've got dementia, you don't look like you've got dementia?"

And then the next thing they'd say, "Well, what is it that makes you think you've got dementia?" So I start to try and describe some of the things and they'd say, "Oh, well I do that kind of thing all the time." And then another [00:14:00] thing that comes up is, well, "If there's anything I can do." That was almost a guarantee that I would never hear from that person ever again.

I think people just get embarrassed or maybe they're a bit scared that perhaps you will start to ask things of them, and they don't want to get too embroiled in any support. But for most people, it's really hard to actually ask for help. I would rather be giving help rather than asking for it, and if I have needed to ask for help, it's taken an awful lot of courage and an awful lot of time for me to build up to that.

Marianne: Most of Julie's friends now are other people who are living with dementia themselves.

Julie: It's just that similar experiences so that you don't have to explain to someone why you're finding something difficult or [00:15:00] why today you are not able to operate on the same level you were yesterday.

It's just an acceptance and, and people automatically understand. A lot of doctors and other professionals will give you a diagnosis and then immediately say, "Okay, so now you've got dementia, you're gonna have to stop driving. Best stop working. You know, it's a lot of stress for you. When it comes to holidays, you know, don't be too ambitious. Holiday in this country, but I wouldn't go abroad just in case."

Marianne: Julie disagrees wholeheartedly with that approach.

Julie: Don't pull back from doing something until, you know, if it ever gets to where you can't do that anymore. Give yourself time to recover from it. And accept that but then move on to something else that you can still do and you'll build [00:16:00] your own network of friends and they will all help you through.

Marianne: Like Julie, my mum was a very sociable person and we encouraged her to carry on with her hobbies, like going to her weekly Scrabble group for as long as she felt able. It's about taking each stage of dementia as it comes. As Julie's felt her capacity for some activities changing over time, she started to introduce a little more support by having carers come to her home.

Julie: I would still wash and dress myself on most days, but a couple of mornings a week, I get a carer to come in and just help me reach all the bits that I find difficult to reach and give me that extra bit of help. That was difficult because it's exposing yourself and, sometimes quite literally, to other people, to complete [00:17:00] strangers.

Although the agencies will try to send you the same carers as much as they can, you really can't guarantee who's gonna be walking through your door. It could be a complete stranger who's walking in, doesn't know you, doesn't know your home. It's getting to know someone and trust them all over again. I can't really relax until they've been, and they've gone, and then I can breathe again.

No criticism of them. It's just that unease that someone else being in your home.

Marianne: The dementia groups that Julie's part of and her activism around dementia are all a source of rewarding work, as well as a focus for the energy she has to improve young onset dementia care in the UK.

Julie: What we are trying to do [00:18:00] as dementia activists is get dementia more widely appreciated and recognised as coming into the world with disability.

It's been accepted for years now by the World Health Organization as being a cognitive disability. As such, we are actually, theoretically anyway, included in all disability legislation in this country. So, we have rights.

Marianne: And Julie is continuing to fight for those rights. To see they're upheld. And that the voices of people living with dementia are heard.

A massive thanks to Julie for sharing her insights on living independently with young onset dementia. If you have a look in your podcast [00:19:00] 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 Julie'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.

You'll also find links to the website and other resources in the show notes for this episode. Thank you so much for [00:20:00] listening.