My life with Dementia – George 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.

George's mum, Linda, was diagnosed with Alzheimer's disease when she was just 57. George was 22 years old at the time. He's seen his dad become a full-time carer [00:01:00] and has supported his parents through some huge changes in how and even where they live. He's also grown closer to every member of his family in the process.

George: My name's George. I'm 28 years old. Currently I live in Leeds. My parents live in a little village called Coman Port. I spend a lot of time with my parents. Obviously, time together is very valuable at the moment. My sister is Mel. She's about six years older than I am. We've always had a very close relationship, and obviously I think what we've been going through the last few years has brought us even closer.

I grew up in a seaside town called Swanage, so I've got a lot of good memories of living there by the beach. It's kind of every kid's dream to grow up somewhere like that. My dad was originally from there. My mum was from [00:02:00] Yorkshire. She was really independent. She left Yorkshire when she left schools.

When she was about 18 or 19, she made the really brave decision to go down to Dorset. Just to find a job and kind of find the life for herself, which is really amazing. Looking back now, so my sister and I spent an early childhood there in Swanage. Moved up to Yorkshire when I was about four or five years old.

My parents met in a psychiatric ward. My mum was working there and my dad was a labourer. He was a plasterer and he was just doing, happened to be doing some work there. I think they met when my mum asked my dad to keep the noise down. Actually kind of sums up the whole relationship. Nothing's changed really.

My mum, Linda, I'd say the most outstanding quality I can say about my mum is really kindness. Growing up, I remember seeing that a lot in the way that she interacted with even just complete strangers. Even if it was just, you know, staff in a, in a restaurant or a shop or something, she'd come away as if she'd [00:03:00] just made a new best friend, really the way that she'd speak to them.

Just so much positivity and even just, you know, the way that she showed admiration for other people. It was really beautiful and that's, that's always remained that, that's never gone away. My mum had a very difficult life, and I think it's something that I didn't appreciate much when I was growing up, and I probably just didn't, you know, always listen when she was telling stories about her, her childhood and her family life, but she was one of, I think, eight children.

She had a difficult time at school, like her family didn't have a lot of money, so she would go to school with not the correct uniform. She didn't have everything that she needed. I think the fact that she did have such a difficult time when she was growing up is probably why she tried to make sure that my sister and I had such a good time when we were younger, you know, she just wanted us to have the best life that, that we possibly could.

Marianne: [00:04:00] Linda's best friend was her older sister, Sue.

George: Unfortunately, in. 2014, Sue was diagnosed with cancer. So there came a time when my mum knew that she wasn't going to have her for much longer. She decided to leave work and I think my dad said, you know, if you wanna take some time and, and spend some time with Sue, you know, that's fine.

We'll manage. Somehow. Looking back now, I think that was a really significant moment to lose her. I think it was around that time that she, she started to struggle. We started to worry a little bit about mum when we noticed her struggling more with everyday tasks. That would seem like something that someone shouldn't really be struggling with at that age.

And it wasn't just memory, which obviously we often attribute to dementia. It was other things as well. You can just pin it down to that person's behaviour. You [00:05:00] just kind of treat it as if, oh, well, they've always been like that even, even if they haven't. My mom's always struggled with vertigo and she's always had a little bit of difficulty with like her coordination and.

Those things because I've seen them as a child. I maybe didn't consider when they got worse that it might be down to to something else. She was starting to struggle with little tasks like writing and reading. But again, it still seemed like something that was just, oh, well she's been through a lot of stress recently.

I remember one day I think I'd come back from college because I was about. 17 or 18 at this time. And she was trying to do temporary work, like going to do a little bit of temporary admin. And I came home from college and my mum was there when she'd meant to be at work and she was really upset. She was in the kitchen and she told me that she'd been sent home from work.

She said that she'd gone to this place to do some admin or whatever, and she just couldn't get to grips with the software, with the computer, [00:06:00] even just the typing was really difficult all of a sudden. She was really upset because I think she didn't understand why this was happening. She was probably humiliated because she'd just been told, oh, you just should go home.

It, it must have been, you know, quite embarrassing, even though the truth was that something really serious was wrong. At that age, I, I didn't really know what even, how to react. Like I should have probably been more comforting than I was. I tried to, you know, make sure she was okay, but I think also because I didn't understand what was happening.

I just thought maybe she's just had a bad day. I think that was maybe the last time she went to work.

As a family, I think we started to suspect that something was wrong. But I think because of her age, you know, she'll have only been 55, 56 at this point. We thought it couldn't really be anything serious because she's so young, and I suppose we probably thought, well, 'she'll just be all right eventually' kind of thing.

So I think there was a little bit of [00:07:00] denial, and then when other people interacted with her, like friends of mine, I think maybe they were more conscious that something was wrong because they had a little bit more objectivity, I suppose. I remember one time my friend texted me and said, you know, I've interacted with your mum a little bit and I've seen other people who act similarly and I think it might be a case of, you know, some form of dementia and maybe she should kind of go to get a memory test or something like that.

I find it quite frustrating actually. I, I think there was a lot of denial there, but I remember thinking, well, you know, I should know better than anyone. I found it upsetting for someone to tell me, you know, what was going on with my own mum when I thought, well, I'll, I'll know best. They don't understand.

I, I know my mum, I know the whole situation, so I know what's happening. Whereas, of course, that that wasn't the case. I. Over time, there were more things. She was not remembering names of people that she, she probably should have. My sister was getting engaged by that [00:08:00] point and uh, she still couldn't remember, you know, my sister's fiance's name, Paul.

It's like, okay, well maybe something is, is seriously wrong. It just so happened also that my auntie is kind of an expert in dementia. She's a university professor and she, um, does a lot of research into dementia care and that kind of thing. And I think she became a little bit more present and kind of advised my dad maybe that something was, was a little bit wrong.

So eventually she underwent a memory test. It was maybe the first kind of formal setting in which, you know, it was acknowledged that something might be wrong. So she was just asked a few simple questions, you know, what's the date? Who's the prime minister? What day of the week is it? And she couldn't answer any of them.

Marianne: Shortly after that appointment in February, 2019, Linda was [00:09:00] diagnosed with Alzheimer's disease. She was only 57. Which is categorised as young onset dementia. That's when symptoms develop before the age of 65.

George: I remember it was my sister who told me that she'd been diagnosed and I'd just come back from university, a little bit of traveling and you, we sat down and my sister said, just so you know, mom's gone through these memory tests since she's been diagnosed with dementia.

I spoke to my dad. Shortly after speaking to my sister, and it was that kind of thing of, we were talking about it without really talking about it. He said, you know, so Mel's spoken to you about what's happening with Mum? I said, yeah. And uh, he said, how do you feel about that? I thought, okay, you know, it is what it is kind of thing.

Yeah. The typical thing that a lot of like men say, don't they, so my dad said, I think the best thing you can do now is go and give your mum a hug. And actually, I remember, I, I, I didn't. [00:10:00] I just found it really hard to, I think at a time if I'd went and spoken to her and if we talked about what was happening, I think I felt like it would make it more real and I regret that.

Now, obviously, looking back now, I wish I'd gone straight in there giving her a hug and told her it was all going to be fine and we were going to figure it out. I remember the one thing that she did say about it was that she just asked us to not be put in a home, and she was kind of joking about it in a way.

It was, you know, it was almost like she was kind of being flippant in that that was her first response. But I think also deep down, she didn't want to go in a home. She wanted to stay at home for as long as she could. And of course, we, you know, immediately said that that was never going to happen. We, we'd be there for, of course, at that time we didn't know how, just how difficult things were going to get. We've always tried to respect that.

Marianne: One of the hardest things about a parent having dementia is that your role inevitably [00:11:00] changes. As the youngest of three, I was always the baby of the family. Even as an adult, I went from relying on my mum for emotional support and help with my own children to suddenly having those roles reversed. It felt strange and frightening even though I was in my fifties.

For George, this change was especially stark. He was still so young at the time.

George: I just finished university. I was still in my early twenties. Used to just thinking about myself and kind of taking your parents for granted, really. You know, I'll come back from university, they'll still be there moving back in with them.

They'll look after me until I kind of sort my life out, really. And then suddenly you're faced with this, which is, you know, you're not used to thinking about your parents in that way, that you could lose them. You kind of just expect them to always be there. I think there was something very isolating about the experience [00:12:00] because it wasn't anything that I'd seen other people go through my age.

It was a surprise for friends of mine to hear, even though friends of mine knew my mum and knew that she'd been acting a little bit differently, they still didn't expect something like this. And I didn't really tell many people to start with. Maybe it was partly because, you know, the more I kind of talked about it, the more like real it became, and also because my mum was still able to do lots of things.

I suppose it didn't feel necessary to go and tell everyone about it. So in very few cases I would be upfront about it and say, I've had this news, and it probably would've been really good for me to do that because it was quite a lonely experience, and especially in those early days. But I didn't, I just didn't seek it out.

I just thought that would make it more difficult. It took other people to ask and say, you know, 'Is your mum okay? She's been acting a little bit differently. What's happening?' Sometimes I felt like I'd be burdening [00:13:00] people if I talked about it and said, you know, that it was difficult and hard to process and that kind of thing.

Marianne: Soon after Linda's diagnosis, the family learned about Admiral Nurses, specialist dementia nurses supported by Dementia UK. They provide free advice and support to the whole family as well as the person with the diagnosis.

George: As a family, each of us kind of individually reached out to the Admiral Nurses for different reasons, and I think at different stages of this whole experience.

I remember my sister one day, this was very early on after my mum had been diagnosed and my sister said that she had reached out to them because she was kind of just struggling to understand what the diagnosis meant and what the future looked like and also. I think another thing that she wanted was to just have a conversation about dementia and how it might affect her, which is a very difficult thing to talk about with the family because I, I suppose she felt like a little bit selfish because she was, she was [00:14:00] wondering, you know, whether there was a risk of her having it.

And, you know, she'd had kids by then, she just had her first boy and you know, the whole thing was just quite scary. Suddenly you're asking questions about how did this happen and could it happen to me? That kind of thing. It's not the kind of conversation that you want to have with your immediate family, and certainly not with the person who's going through dementia.

because they're, they're going through their own thing, aren't they? So I think that she felt she wanted to speak to someone about that and ask those questions and not feel judged and just speak to an expert. Those early days after the diagnosis were very isolating. Especially, I think around that time it was during the lockdown, so I was living with my parents and this thing was in front of me all the time, but it just felt like there wasn't much I could do about it and I, I eventually reached out to the Admiral Nurses and I think my biggest kind of fear was about what the future held.

You don't want to speculate about someone's health and you don't want to. Make everyone upset about [00:15:00] thinking about life without that person or just, you know, life when they're struggling even more. But I suppose I had quite a lot of anxiety about how she might change and how the disease would kind of create more challenges in the future.

So I, I wanted to speak to someone without feeling judged, I suppose, and to just say anything and ask any question. So that was really helpful and a huge sense of relief in quite an isolating time.

Marianne: As the months passed, George and his family noticed Linda's symptoms getting worse.

George: Her memory obviously did suffer, but it was mainly a coordination. Her speech, she was so independent for so long, but now she was struggling to do things herself. She couldn't really cook. She was starting to struggle with like holding a glass when she was out in public.

There'd been a lot of situations where we'd be out and she'd drop a glass. My dad was kind of becoming closer to being her carer. [00:16:00] There was one day where I think I was at home, may have been during Covid, where she'd been out with the dog, and I remember shortly after maybe an hour or two later, there was a knock at the door and it was one of our neighbors and he was with my mum and he said, oh, you know, your mum got lost kind of thing.

She didn't know where she was, so I was just taking her home. So that was quite a big moment because nothing like that had happened before. It kind of signified that she was really starting to struggle. She was becoming very nervous that, you know, no one else was around. I remember a lot of the time, if my dad left the house to go to work or whatever, she'd call him, I think she maybe started to lose her sense of time passing.

So even if my dad had only been away for an hour or so. She would call a lot and say, when are you coming back? We realised we were at a point where she needed help.[00:17:00]

I felt a little bit, I. A little bit helpless really, because I wanted to be there for her, but I knew that there were certain things that she needed help with that I couldn't quite, you know, provide because it was getting to the point where she needed help with like eating, getting changed, things like that.

And, you know, I really wanted to be there for her, but I, I knew that she felt a certain amount of resistance about her children helping her with things like that. It was becoming clear that she would need round the clock care. So my dad took some grievance leave and uh, he eventually retired and he basically stepped into the role of full-time carer.

He said to me, he's worked all this time, worked for nearly 30 years as a fireman, worked in construction for years before then, and this was the hardest job he'd ever taken on. As far as my sister and I were concerned, we wanted what was best for mum, but we also would've completely understood if he didn't feel like he could take on this challenge.

But I don't think there was any kind [00:18:00] of doubt from him that he would be doing this. You know, he was committed to my mum and to making sure that she could stay at home and that she'd have someone looking after her. The next big shift was probably when my mum was ill with kind of like a flu virus at one point and she'd got up in the night and she was really unwell and she actually had a fall and she couldn't get back up because she was so sick.

So my dad unfortunately had to call an ambulance and take her to hospital and she remained in hospital for a few weeks and. We really wanted her to come home, but she obviously wasn't getting any better in terms of her mobility because she was in bed all the time. And even at one point my dad was told by someone at the hospital that they weren't sure it would be safe for her to come home.

I think he felt like he'd failed in that way. I remember those days going to see her at the hospital coming home and seeing my dad at home in this empty house [00:19:00] without her there, and I think he just felt really helpless, really dejected. I think that was one of those really pivotal moments where we realised just how much more difficult things had become.

Marianne: This was one of those times when the family turned to dementia. UK's Admiral Nurse Helpline, George's dad rang up while Linda was in hospital.

George: He spoke to the Admiral Nurses about how to get her home, what he maybe had to say, and you know, what his rights were really. And they gave him some really good advice on the right conversations to have and how to get mum home, which eventually he did.

And I think he just needed that support at that time. He needed that affirmation that he could look after her, that he could be confident in his role as a carer, but also I think he just, we all needed to start thinking about what the future looked like. She would need some carers. We tried to introduce the concept of carers a few times up to then, but my mum was still very resistant.

She didn't want any people coming into her home and helping her. [00:20:00] But now it was getting to a point where my dad just did need this extra support. He couldn't, he couldn't do it on his own. And so eventually my mum came home. She now needed a wheelchair. She was in a hospital bed in the living room. My parents had already been exploring the possibility of leaving their home and moving into a bungalow to make things a bit easier, but that became a need.

Now, that was another big piece of news was that my parents were leaving their house and having to move elsewhere, especially for my friends. because we had a lot of good memories in that house of my friends coming over and, and you know, spending time there. And of course for my sister and I, it was our childhood home.

So they moved nearby to a village and kind of transitioned into this life that they're in now. They have the bungalow, which is. It's far easier now that mom's in a wheelchair, they have ramps, that kind of thing. Mum has her own hospital bed that she's helped in and out of at the start and end of every day.

They have carers come at the start and end of every day to [00:21:00] help her. They're very routine based, my parents, and obviously that's quite a big thing with people who live with dementia is the importance of routine and certainly that's the case with my mum and dad. My mom's the one who lives with dementia, but I think equally it's good for my dad as well to have that routine.

Like he knows the kind of things that mum needs throughout the day and it's, it usually is at the same time, and then around that he kind of knows when he has his own time to exercise and do whatever, but you know, everything is built around mom's needs. She's not in a position where he can leave her on her own.

He can only do so when the carers are there or when myself or my sister or someone else are there to be with her. He even has one of those kind of baby monitors. So if he's in the garage and goes on the exercise bike, he'll, he'll know if she wakes up and needs him or anything like that. Which again, that's one of those things that I remember going to my parents and seeing that there.

And it's another thing that you look at it and think, oh wow, that's quite a big change to have that there. I suppose it inspired kind of a [00:22:00] change of behavior for my dad who. Is very kind of focused on the here and now. He had to start thinking about what care would look like for my mum going into years in the future, being more forward thinking really.

There was also other things that we needed to think about around that time, which kind of played into the moving house. So lasting power of attorney. There was quite a few things like that that, you know, my sister and I were involved with that we needed to think about. Again, it's those things that you're quite surreal to be going through those decisions with your parents at that time.

Because you know, it's not a very nice subject. You're kind of talking about legal documents to do with making decisions about your parents if they're not around or can't make decisions for themselves. We kind of did that for my dad as well.

You know, we got all the paperwork sorted in case for some reason our dad wasn't here anymore in case anything happened to him.

Those are those big kind of moments where, you know, especially for me being at the [00:23:00] age that I am, it's quite surreal to be thinking about those things. If the whole experience is taught as anything, it's that life throws these things at you sometimes and yeah, you've kind of got to be prepared for it in a way.

Well, you, well, you've just got to confront it. So we transitioned into this period of time that we're now where. My parents have a good routine. They're quite busy actually. My parents, they do, they do a lot, which I think is really good because it would be quite easy for them to just stay at home, maybe go out a couple of times with a dog and not do much else.

But certainly my dad is very proactive. He's gone out and looked for things for him and mum to do and to be involved with, um, rather than just kind of focusing on what he has to do and then not worry about anything else. He really goes out of his way to make sure mum is still participating in the world.

They'll go to singing groups. There's a working farm where they'll go and spend time and my mum can go and see the [00:24:00] animals and my dad does little jobs here and there. And there's other people that my mum can be around, people who have dementia and some people who are just helpers there. So there's kind of lots of things that we try and do to make sure that they're still active in their community.

And of course between then it's just my sister and I making sure that we see them regularly and take them out for meals and that kind of thing. She really responds to music. So my parents listen to the radio a lot.

Music is something that really can bring her to life. It's really like magical when you see it affect my mom. Especially some of the favourite bands that like she grew up listening to in like the eighties, like boxing, music and Brian Ferry. She, it's like a spark when she hears that stuff on the radio.

And it sometimes it can be a really useful remedy when there are difficult moments. Like when she has to have help with getting changed or just some moments that aren't very pleasant for her. Music can be quite a good, you know, comfort [00:25:00] in those times.

Marianne: George and his family also did something else really proactive.

They started a regular meetup for the community in their parents' new village.

George: My dad said that he'd been thinking about maybe setting up some kind of support group for carers and the people that they provide care for. Just in the local village because he thought maybe that there'd be a few people who were in a similar position.

So it achieved a number of things. It meant that they would meet other people in the village that they could talk to and, and, you know, connect with and build up a bit of a community. But I think it also meant that my dad could give back a little bit because we'd all been going through this for years now.

And over that time you accumulate quite a lot of knowledge about how it all works and what support is out there, and things that you kind of wish you knew at the start of the journey that you now were suddenly an expert in just because you'd lived with it for so long. So we came up with this idea to create a support group every month where we'd, we'd meet [00:26:00] locally and we'd just invite people along who were providing care for someone, and people that they were caring for could come along as well.

It didn't even have to be necessarily dementia-related, you know? So we had people who were living with Parkinson's, for example, and it could also be people who weren't carers anymore, but had been at some point, I suppose. We were also conscious of the fact that one day. My dad will be on his own and he'll have been a carer for so long and will kind of have lost his main purpose in life.

You know, we try not to think about that too much, but that will come a time and we wondered what it must be like to lose that after so long. We thought it could be good for people in that situation. So what that kind of became was a support group for people every month, and it could be a relaxed space for people to just chat about what their situation was, if there was anything in particular that they were struggling with.

Also, we've had people from charities offering services that people might not be aware of because you're not necessarily directed to those things immediately. So it's been good to direct people towards [00:27:00] guidance and support, but I think for some people it's just been the fact that there is that space and that they can come to a place to share what's been happening over the last month and what they've struggled with and be very honest about it.

Marianne: George also found another way to channel his energy for supporting his parents through fundraising. He's a passionate runner, but not just 10kms or even marathons. We're talking ultra endurance distances. He'll run the length of multiple marathons in one go.

George: For a long time I've wanted to do something to give back to my parents, especially seeing the way that my dad has really stepped up in his role as full-time carer and just how committed he's been to my mum and to making sure that she does stay at home as she's wished.

You know, he's been an absolutely such an inspiration and I try and be around as much as I can, [00:28:00] but you know, there's certain things that I don't feel able to do, and. It can be quite hard to find a way to be supportive for, for both of them. So I kind of wanted to find my own way of paying tribute to them, and I suppose just showing how much I care really.

I spoke to my dad about this and we decided that it would be good if I were able to raise some money for Dementia UK whilst taking on some kind of ultra endurance challenge. So I came up with the idea of running along the Leeds Liverpool Canal where I'd done a lot of training. I suppose I couldn't help notice those signs saying, oh, it's this many miles to Liverpool.

And I thought, has someone ever just run the whole thing? Like, could someone do that?

Marianne: So in late 2024, George made his first attempt at running the entire Leeds to Liverpool Canal path. He raised over £3000 for dementia UK That day. Conditions were freezing and [00:29:00] icy, and George had to retire from the challenge at mile 99, but his plan for 2025 is to get back on the canal path, aiming to complete the full 127 miles.

George: When you have something like this in your life, you can feel a little bit helpless. And obviously my dad's amazing and he's a huge inspiration, and when I see him so dedicated to this role with all his challenges, it just makes me feel like I can do anything that I set my mind to. If you're running like a hundred miles, you can't think about mile 100 when you're at mile 32.

You have to think about the mile that you're running without sounding too trite. I think that's kind of true of life. You can't think too much about what's. Coming ahead or what's happened behind you. You have to kind of do your best in that moment. And that's crucial to my relationship with my parents.

And I think it's crucial to the kind of care that we give mom. We just have to do what's best for her in that moment and be the [00:30:00] best versions of ourselves we can be and cherish the time that we have and just be grateful that we still have time with her.

Marianne: Thank you so much to George for telling us about his mum and sharing his family's journey with dementia. 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 George'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. [00:31:00] 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 dementia UK.org.

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