Penny - 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.

When Penny's mum, Rosemary was diagnosed with mixed dementia, she said she wanted to live at home for as long as possible. So Penny did everything she could to make that happen. [00:01:00] Eventually, she would have to find residential care for her mum, but she had to find a place that was truly right for Rosemary.

Penny: My name's Penny Bell, and my mum has dementia. I live in Northamptonshire, in the countryside, in a little village, and I work as an audio producer, so I make podcasts a bit like this. My mum's name is Rosemary, and my dad's name was Philip. He died about 13 years ago now. My mum was originally from Scotland and my dad was from Hertfordshire, but through twists and turns, they ended up in Oxfordshire, so I grew up there and more or less lived in the same house for all my growing up. And my parents lived in that house then for 50 years.

My dad was the local dentist in the town. Everybody knew my dad, and we weren't allowed to walk around [00:02:00] the town eating sweets or anything like that. We had to be, we had to be really careful.

What I used to do was go to the sweet shop when I was catching the school bus home, which was in a different town where nobody knew me or who my dad was, and I could buy whatever I liked, eat it on the bus.

My mum was a music teacher originally in schools, and then she started to teach from home more. She did a lot of music events. She started the music festival in the town and um, she was always in choirs and accompanying people for things, so I felt like we had a really strong connection to everybody in the town that we grew up in.

She was an only child and so she was really encouraged with her piano playing and she ended up going to quite a good school in one part of Scotland with a fantastic music teacher who said, this is what you need to do. I think Mum was very keen to leave Scotland. She was quite [00:03:00] lively character, very chatty and bubbly, and I think she saw something exciting about going down south.

And so she wanted to go to London to study music. And amazingly, her parents agreed, and not only did they agree, but they moved themselves down south so that they were all together. They lived in Slough and my mum got into the Royal Academy of Music. She taught in schools around London for a little while, and then she met my dad and that's when they moved elsewhere.

She was really, really talented. I have a recording somewhere of her playing on reel to reel tape, actually, that just makes you realise, you know, she was really good. My dad also loved music and that's how they met. He played the double bass in a jazz band and then latterly, he loved singing and he sang in a barbershop choir as well.

They met at a Gilbert and Sullivan Society performance that they were part of. But [00:04:00] yes, growing up music was everywhere. I would be woken up on a Saturday morning because people had come for a piano lesson and they were playing scales really loudly underneath me, so I never got a lie in, which is really annoying when you're a teenager.

And I played the piano. I also played the oboe, and Mum taught me. I've got three daughters all quite close in age, and she taught them piano as well. She gave them lessons from, you know, as soon as they were old enough.

Rosemary: Come on, girls.

Marianne: In 2012, Penny's dad was very unwell and that's when she first noticed the early signs of her mum's dementia.

Penny: My dad had cancer for a couple of years and he got unfortunately worse and worse, and then it reached a peak and he went into a hospice and we knew he was going [00:05:00] to die. And all through that sort of final stage, just mum didn't seem to be coping with it in the way that I would expect.

It was kind of, it seemed more extreme in how she was managing it, but I, I just thought it's, this is, this is grief. This is an awful situation. Couldn't really put my finger on exactly what I mean, but it just didn't, something just didn't feel right. And then in my dad's final few days, he said something to me, I can't even remember the exact words, and I thought, oh, so he's noticed this as well. So that kind of made it seem a bit more, okay, maybe there is something.

And then dad died and you know, I sort of was helping mum through that kind of early stage. It was really awful. As time went on, I just started to notice more and more things and I thought maybe this is more than more than grief.

And then we had a Christmas where she came with us to [00:06:00] my in-laws. All the family that she's known forever since I've been married and all the other grandchildren in the other families. But she was calling people instead of their names. She was saying, oh, this gentleman said this, and this lady said that.

And then she asked my brother-in-law if he worked in the house. That coupled with everyone else noticing it as well. I just thought, no, I, something's not quite right. She had really good strategies in place. She was excellent at covering up. She'd say, oh yes, of course I know that, I just forgot for a minute there.

And that's where it feels a bit awkward 'cause you, you sort of want to acknowledge that they're coping 'cause they look like they are. But at the same time, you've just got an underlying worry.

Marianne: Little by little, Rosemary's symptoms were progressing.

Penny: Suddenly she couldn't plan anything anymore. A plan would be a really big deal.[00:07:00]

And if I wanted to change a plan, you know, oh, we're coming a bit earlier, completely floored her. She couldn't deal with that at all. And often if we had a plan, she would ring me constantly in the days leading up to it to sort of clarify exactly what time we'd be coming and, and then I learned that it was better to just not tell her things until the last second.

So I suppose we were both sort of covering up for each other for a little while. I think she had an episode where she'd felt sort of a funny feeling in her head that she couldn't really explain, a sort of fizzing and popping. And she'd taken herself to the doctor. And so that kind of opened the door then for us to, to start talking about it a bit more.

Mum and I were always close and we always had quite an open, honest relationship. So it wasn't that I didn't feel I could talk to her, but I just, I felt like we were gonna burst a bubble [00:08:00] and um, life was gonna change. There was dementia on mum's side of the family, so I was aware of it and I couldn't really think what else it could be.

I was aware that, you know, perhaps we needed to rule some things out that it could be instead. And so the fact that she'd taken herself to the doctor then opened the door up for me to, to go in and have that discussion. But I, for a long time, I thought, well, well, I, if I think that that's what it is, can't we just manage it?

Why do we need to go and get a diagnosis? Why do we need to know for sure? That's what it is? But gradually, I began to realise there were maybe some new medications that you couldn't access unless you had a diagnosis, maybe certain help that you couldn't get unless you had a diagnosis. So it took about, 'cause I probably knew just after dad died, but it probably took another three years before we actually got a formal diagnosis.[00:09:00]

Marianne: Rosemary was diagnosed with mixed dementia in 2016. Mixed dementia is when a person has symptoms of more than one type of dementia.

Penny: It felt very gloomy to start with because there was nothing, nothing. I mean, if someone had just said, everybody's dementia is different, no one knows how it's going to progress for each person, but if someone had just said, you're still the same person this afternoon as you were this morning when you got the diagnosis, you can still do all the things you're doing, you know, enjoy life. No one said that to us. So immediately you go into this, oh my goodness, what's gonna happen? This is awful.

So if we’d just had that little glimmer of hope or positivity, I think it would've made a big difference, but we, but we didn't have that, we had to find that for ourselves. I mean, there was even a dementia club in the town we lived in. I mean, it's not a big town. We know lots of [00:10:00] people, but we didn't know that was there. Mum heard about it from someone else. She wasn't very good at remembering when she'd had conversations with people and she said, there's a place that's for people with dementia and it's where the library used to be.

And it just, it was a story that made no sense. So together we went into the town and walked to the place that she thought they were talking about, and then we've discovered that there was a club. So we were able to find out more about that and eventually that became a big part of our lives. But it shouldn't, shouldn't be like that, really, should it?

I'm lucky that mum is such a chatty, open, honest person. She never wanted there to be a stigma. Once she had the diagnosis, she was up for telling everyone straight away, everyone. She wanted to learn everything she possibly could about it. We had no information when she was diagnosed at all, she was able to get medication to help sort of slow things down a little bit, which was great.

But when I asked what do we do now? [00:11:00] Are there places we can go? Nobody seemed to really have any answers, so mum was really keen to find out. I think she took a book out from the library about Alzheimer's and I went to, um, something called the Alzheimer's Show and kind of found out stuff myself.

I googled things just to kind of just to arm us with some information and Mum was, was kind of up for that. At the very beginning, not long after she was diagnosed, we went to see a care home. I think it was because she used to go to that care home to accompany the choir. So it was one she knew and I said, well, why don't we just go and look?

Because my dad had not long died. She really got comfort from being at home with all their things around. We did talk about how she wanted to be at home for as long as possible. We both knew maybe eventually there'd be a point where that wasn't possible, but I just really worked hard [00:12:00] to make sure that that's what happened.

Marianne: Gradually, everyday things became harder for Rosemary and Penny had to work out exactly what care she needed.

Penny: It was very light touch in the start. Mum was really involved in music things. She was still teaching. She had a few children coming to the house. We made sure all of their, their parents knew and they were all happy to continue 'cause you know, this was the situation that had been going on for a little while we just didn't have a label.

So she was very hooked into that. She was in choirs. She accompanied a choir. The only thing that really changed was that she wasn't allowed to drive. But she could walk to lots of places. She knew lots of people, so people were giving her lifts, and if she got muddled up over music for going to the choir, they would sort of help sort her music out. Eventually they would keep the music and then just say, come along Rosemary, I've got the music, don't worry.

Marianne: As her [00:13:00] dementia became more advanced, there were times when Rosemary's health or safety was at risk. Like the day she got confused by her medication.

Penny: So she'd get the medication in a blister pack and that was fine.

But then one week she rang me and said, oh, they've changed the blister packs. I can't, I can't open it. I don’t know how to get in there. And eventually I went over and all that had happened was that she turned the blister pack the wrong way round and she didn't know how to turn it back and see that it was the same as before.

That's when I thought, oh, perhaps we need some help 'cause I couldn't be there every morning. I was an hour and a half away and I had three children. I was trying to, you know, run their little lives as well. I eventually managed to find someone who could go in in the mornings and make sure she'd taken her tablets at least. Over the next sort of few months, I realised she wasn't really eating properly because she was forgetting to cook or not buying enough food.[00:14:00]

So then I felt like perhaps somebody needed to just make sure she had her meal, so then it, it became two visits from someone else that wasn't me. And then I would go over as much as I could in between. It just gradually ratcheted up. She went to this dementia club that we discovered, um, and she'd go once a week, then twice a week.

Then eventually she was going most days. So then that covered the middle bit of the day, and, and so it went on until we were having four care visits a day and someone to make sure that she got into bed. With dementia, you sort of, it's like a rollercoaster. So one minute you think, oh, that's it. I've got everything covered.

The strategies are all there, but every now and then, something would go terribly wrong and I'd be back to square one and then I'd have to think again. Okay, how are we gonna get round this one? It was stressful and emotional. It was hard to leave. My kids had to be more independent [00:15:00] earlier on in some ways and figure stuff out for themselves, do their own washing, actually got to that point where they were, I mean, they were becoming teenagers, so probably they needed to learn all these things, but it felt like there, there wasn't a choice.

They needed to sort of do that kind of stuff. So I felt a bit conflicted. They always need you for, you know, as they get older, they might not physically need you so much, but emotionally things happen at school and they wanna be able to talk about it. And I felt very split because I also wanted to make sure mum was okay and I was desperately sad that my dad wasn't there.

I remember one time the fuse went in the house and for various reasons there was no one there that could help mum by going into the house and just flicking the switch. And, um, I couldn't explain it to her. She couldn't grasp what I was saying at all. It just made no sense to her. Um, it involved her going into the garage and finding the key to the, there were too many steps.

So I just, I ended up just driving over, [00:16:00] um, just to flick the switch. It was just really hard to try and make sure everybody had what they needed, constantly feel divided and that you're not doing well in either camp.

Marianne: I remember my mum got her medication totally confused until we changed her pharmacist to one that could give us labelled pouches with the days and time on, and we bought her a dementia clock so she knew what day it was. Even then, my sister would pop around every day to make sure she'd taken her tablets.

Eventually, my sister became mum's official carer.

Penny: I didn't realise I was a carer actually, until quite late on when someone said, well, as a carer you can blah, blah, blah, and I was thinking, oh, I'm, I'm not a carer. I'm a daughter. I'm a mother. But you don't realise that's what you are. I think. I wasn't worried about me.

I wanted [00:17:00] to make sure everyone else had what they needed, but I think over time you don't realise it does take a toll. 'cause it's just, it's just there all the time, every day and, and ratcheting up. She would've been on about five visits a day and then things started to go wrong in between.

That was one occasion where she was found lost outside in the street and a stranger found her and she was very disorientated. This person that found her called the police, and eventually they found my number and the police said to me, well, she can't be at home now. This is too much. She needs to go into full-time care.

This is not enough. And I just thought, no, it's not the end. No I'm sure I can sort this out. I'm sure I can figure it out.

I couldn't bear that she wasn't gonna be at home with her things and [00:18:00] the reminders of my dad around her. She still got comfort from being there. So I thought there must be a way forward. So I then decided we would try having someone in the house all the time, 24 hour care. Surely that was gonna work.

And I was part of that, so there'd be a day where I would go over and you've got kind of a rotation of carers. Eventually it just, it just became too much. Mum began to not recognise that she was at home, having different carers wasn't helping. I was going over more and more and more. And then I think maybe 'cause mum was stressed out, perhaps by having so many different people in the house, her behaviour became more difficult to manage.

She wasn't able to go to her club anymore, which was kind of one of the big chunks of her care. And then that's when I realised, no, we can't this, this, I think not knowing her home. Then I thought, well, it doesn't matter now really where she is. So that's when I realised that [00:19:00] she'd have to go into care.

It's very much down to you to find somewhere, which certainly at the time that I was looking, and also if you need somewhere quickly, you don't always have a lot of choice. We were lucky that we could look for ourselves, but at the same time, you don’t know what you're looking for.

Marianne: Penny had to learn what was important in a home for someone with dementia.

And what was important in a home for Rosemary specifically.

Penny: I went to look at so many homes. I was also in a dilemma about, you know, mum loved the town she'd been in for so long. Should she stay there where her friends were, or should I move her nearer to me, Honestly, I was driving all over the place, looking at homes here and homes there, and in the end we reached a point where she needed somewhere right away.

And so I picked somewhere and it was near to me and she went sort of for respite for two weeks to [00:20:00] see how it went. And I thought, well, if this works, let's, let's do this. But there was something about that home that wasn't right for mum, and I felt really bad about that, but, um, it wasn't right.

Marianne: Penny moved her mum back home again, reinstating all the carers and support.

While she looked for a different place,

Penny: I found somewhere else and she went there and I thought, this is it now. This is it. But unfortunately, the communication with someone with dementia, it just wasn't there in the way that I would've liked, and I could see that it was affecting mum in how she was behaving.

At that stage thank goodness I'd found Dementia UK's Admiral Nurses.

Marianne: Admiral Nurses are 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.

Penny: They had a Helpline, and I relied on [00:21:00] that so much because there was nobody in the community telling me what to do or helping me.

It was really me. So I'm so glad that I called that Helpline because they were able to say to me. No, it's not the right place. It's not the right place. And that gave me the confidence to say, okay, it's all right. I can look for somewhere else. And then I found where she is now, which turned out to be the most brilliant place.

I worried a lot about disrupting mum again and moving her, but actually it was the best thing I did. I am so glad I had those early conversations with Mum because at least I had a sense of what she wanted. But you do feel like you are taking on responsibility to make decisions on someone else's behalf, which you are doing.

There's a constant worry and a feeling of guilt. Is this the right decision? And there's no one else to really discuss it with 'cause ultimately [00:22:00] you've got to decide. I had power of attorney and you know, it was my responsibility to make the right decision. If you were looking in on someone else having to make that choice, you'd be like, of course that's the right thing to do.

When you're making it for someone that you care so much about, you are choosing things for their life that they would normally have done themselves. It's, oh, it's so difficult. And I still feel guilty now because I worry do I visit her enough? Has she got all the things that she need? Would she want that?

Would she not want that? Have I stayed long enough? Have I overstayed? Is it too long? Should I go more frequently but for less time? I feel guilty all the time. The only thing that's, that's good now is seeing her so content and settled in her environment and that she doesn't know who I am specifically, but she knows that I'm someone that she [00:23:00] likes.

I take comfort from that.

It took me about a year to get used to her being someone else's responsibility. I didn't have to make sure she'd had her tablets, didn't have to make sure she had her clothes there. And that was really weird that year. And I went a lot. I went a lot. I was just like, is she definitely all right? Is it okay?

But she settled so quickly and easily. She had freedom to be herself. And after that year, I began to sort of bed into, okay, this is our new normal. I think it's, it's shifted my thinking on residential care. I mean my, I, I know I'm lucky that we could choose where mum went, but my visits now are, as much as I feel guilty and I worry about her, when I go, what we have is the quality [00:24:00] time together for however long that is, you know, however long I go that time where I can just sit and hold her hand or we can look at some photos or I can play the piano to her.

I'm not having to think about sort of her physical care in terms of what medication she's taking and has she had a wash today? It does mean that you are free to see her as her.

Rosemary: Oh dear, I'm ruining your programme.

Marianne: That’s Penny's mum, Rosemary, back in 2016.

Penny: We started recording together from the day that mum was diagnosed. And some of that was because I think we just didn't really know where we were going with it. And it felt like we were having a good conversation and being quite open and honest about dementia.

And I thought, well, that's a good thing we should, you know, we [00:25:00] don't want there to be a stigma about talking about dementia. As time went on and I, I realised there wasn't really any support or help for us. I started to find out things by going to the Alzheimer's show and looking stuff up and then going to talk to people.

And I thought, well, goodness, if you know, we can't be the only ones in this situation. There must be other people and 'cause it's something I can do. I thought, well, let's make a podcast.

Marianne: The podcast Penny made with Rosemary is called Discovering Dementia.

Penny: So then we started to take a microphone with us wherever we went.

Mum was so up for it. It was a lovely little project that we could do together. Maybe it was a little bit cathartic as well, we were able to talk about things.

You, you haven't told me that bit about not being able to finish sentences before.

Rosemary: Well, that's only very recent. That is within the last fortnight, I would say, or months maybe.

And so I'm, I'm much quieter now, which is a great relief to most people. [00:26:00] So, she's quiet now. This is great.

Penny: I think a bit like when you're a teenager and you're in the car with your parent and neither of you are looking at each other and you can have quite an open conversation.

Perhaps recording a podcast was the, the way that we were able to kind of talk freely or at least bring up the subject of a conversation around whatever it might be. And it was also a moment just to be still, and it's nice now to look back and hear mum being mum. Really what I've done is record the whole process of dementia.

And there came a little bit of time where things were really hard, and although I was recording stuff, uh, and mum was agreeing to be recorded, I just wasn't in the right place to be able to turn it into something. It just, it was all too raw and I still have a lot of that stuff and I'm, I'm sure at some point I will [00:27:00] do something with it 'cause I know that that's what mum would want because she was so on board with, let's break the stigma, let's talk about it.

I suppose it's not surprising that I find the kind of last bits so difficult, but she's still mum. That's the thing I see now. She's still mum in there. Even though she doesn't have the words, her words are not words.

She still has the same turn of phrase in the way of raising her eyebrows and you know that's that she's still there. I was talking to someone about dementia the other day who works in the field, and they were saying often with carers, you know, ratchets up and things get harder, and then you reach a crisis point and then things are resolved and it's maybe not for another two years that any of it hits you.

And I just started crying because that's exactly what happened to me. I've had a very sort of difficult time processing everything over the last year. [00:28:00] When mum went into care, I had to then sell my parents' house, which they'd lived in for 50 years that I, a house that I felt safe in. That meant a lot to me, that I can still picture every room in my mind now, and I had to kind of dismantle it basically and move all the things on, except that I couldn't.

So I got so far with that, and then I just bundled everything up and put it into storage. I just couldn't, I couldn't deal with it at the time. But what it's meant is that for the last two years, I've been sort of unpicking it all and going through everything and making sure that I do justice to every single thing that was there.

And I think that that process, because it's all tied up with, I think my dad dying, I didn't really have a chance to grieve because I was straight into looking after mum. I think eventually it catches up with you and that's really what happened.

But also there've been some joyful moments, like [00:29:00] I've found all the silly film that you know, they took, and so I've been able to look at that and sort of be reminded of happy childhood and that kind of thing.

So hopefully the end result will be lots of positive memories. I spent 10 years looking after mum, and it was the forefront of my mind every day for that time, along with my family and juggling that. But what I've done now and with some help is I've gone back to playing the piano, which I'd sort of stopped and I've joined a choir, and those things really make me feel connected to my parents in a way that I didn't realise would happen.

And I've started to sort of see friends more and you know, just get back into life, I suppose. I've got such a supportive family. I'm really, really lucky that they are all there and encouraging and I get a lot of joy from watching them live their lives too. [00:30:00]

Marianne: So the new normal for Penny now is just that. Living her life, spending time with her husband and daughters, and seeing her mum as much as she can too.

Penny: She's about 40 minutes drive away from me now. She has lots of things going on in the home that she can be part of or not. Every day, every minute is different. I'll go over on afternoons and we get a cup of tea together and just sit, or I've been before and she's been in a cross mood, so I've just followed her around being cross and she'd be like, get away, don't come.

You know, so you've gotta be prepared for the ups and downs. Um, and it's not personal, it's just where she is on that day with her dementia. But then other times I've gone and, you know, she's held my hand and stroked it and looked lovingly into my eyes and called me darling, which is always nice 'cause I know she knows I'm [00:31:00] someone.

And I've played the piano or we've joined in whatever's going on in the home. We might start off in her room together having tea, but two minutes in she gets up and leaves. So I go and follow. It's just whatever. They've got a beautiful garden and we, we go out and walk around the garden if she's in a walking mood.

And quite often my kids will come as well when they're home, you know, so we'll go together. So I'm sort of in a pattern of going to see her as much as I can and just take whatever there is that day and, and, but she's still there. And that's what I love is I can still see mum there and we can still laugh about things and that's always amazing.

So there are joyful moments.[00:32:00]

Marianne: A huge thank you to Penny for sharing her and her mum Rosemary's journey with dementia so far. 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 Penny'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 [00:33:00] find links to the website and other resources in the show notes for this episode. Thank you so much for listening.