Chris - 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.

Both of Chris's parents had dementia. First his dad, and then later his mum too. It meant Chris and his wife spent most of their son's childhood juggling parenthood, full-time [00:01:00] work, and looking after his parents.

Caring for adult relatives and children at the same time actually has its own name. It's called sandwich caring. Over the years of his parents' dementia, Chris learned that sometimes carers themselves need help. And you don't have to wait until you reach a breaking point before asking for it.

Chris: My name's Chris Saunders. I'm 50, just turned 50. I work in emergency services in Sussex. I'm married with an 18-year-old son who's just started university. I'm an only child. My parents had me fairly late. They were fosterers, so they had me when they were I think sort of mid forties.

People say, did you miss not having a brother or sister? Well, [00:02:00] it's difficult to say when you haven't had a brother or sister. Our son is an only child as well. You know, siblings fight and argue when they're younger, and I think, I don't think I missed out on that part of it, but I think in later life and with what's happened, I would've benefited from having that sibling support, I think.

My dad was Ray, uh Raymond, born and bred in Tunbridge Wells. And my mum, Audrey, who was born in Ipswich. My mum worked for Dr. Barnardo's Children's Homes back in the day, and my dad, he'd done various jobs. He was a bit of a lad, I think, from what I can gather.

He was the type of person who would talk to anybody who was sat near him, be at a hospital waiting room or on a bus stop, or on a bus. He would start talking and be really embarrassing, you know, as a kid and would, you know, laugh at his own jokes, you know, in a good way. But it's just when you are that age and you're like thinking, dad, just, please don't. [00:03:00] Mum was quite different really. She was very prim and proper. They brought me up in the church as well, so there was very much that element to, to my life growing up. It was a good, happy childhood. They were, you know, very, very good parents.

Marianne: Chris' dad was in his seventies when he started showing early signs of dementia.

Chris: It was in 2012. I always remember it was the Olympic Games in London. He had various health conditions. He had diabetes and he would manage it himself, so he would inject himself with insulin. I remember Mum phoning me one evening and saying, I think there's something wrong with Dad. I can't wake him up for dinner.

And I, I sort of said, well, you can't rouse him? Is, is he definitely breathing? She was like, yeah, but I can't, I can't wake him up. And I said, he's probably in a diabetic coma. [00:04:00] I said, call an ambulance and I'll come over. They quickly worked out that he had given himself some insulin, but then he'd given himself some more insulin because he'd forgotten that he'd taken it.

Marianne: It started with these moments of forgetfulness, losing track of things that would've been routine before. But then came other changes, and now Chris knew something was really wrong.

Chris: Overnight, really, he just became a different person. Mum phoned me and said, Dad's acting really strange, I dunno what's going on.

I didn't know what to expect until I walked in and when I walked in I knew, yeah, something's not right. Yeah, something really isn't right. It was like a light switch. He'd gone and gone ‘flick’. You know, from someone who would never swear in front of me, he was effing and blinding. He was shouting. He was just very aggressive.

He would say things to me like real insults and be saying, you know, I'll always remember what you did. And I was like, what? What do you mean Dad? And he [00:05:00] said, I know what you've done. And said it with like real hatred. It just turned into someone different. If he could see himself saying that, he would be horrified.

Marianne: Raymond became paranoid, and he was having hallucinations.

Chris: He was obviously knowing who I was, but he was thinking that I'd been doing things behind his back. He would scour bank statements, not knowing what he's looking at. I think he thought I was stealing his money and, or doing something. He ended up in hospital and the doctors just didn't know how to deal with it.

A doctor came in and I, I was bringing mum in to see him, and we walked in the room and we saw him arguing at the doctor. It was just a mess really, because they obviously knew it was dementia, but they, they just didn't know how to talk to someone with, with dementia. Not that I did.

The worst thing was people say, oh, well, you know, that's, remember [00:06:00] that's not him. That's the disease speaking. And I said, I understand that, but it is him. When his body is there saying those things to you, to actually hear it come out of his mouth, it's very difficult to disassociate the two.

Marianne: As his mum and dad needed more support, Chris's responsibilities were doubled. He was working for emergency services, often doing night shifts, caring for his son, and constantly going back and forth from his parents' house.

Chris: It was like fighting a war, really. You know, you'd put a fire out there and then something else would start, you know, or a dam we like, oh, there's a leak there.

Oh, oh, fix that one. And, and, and something else would happen. The weeks and months would go past because you're just trying to fix things and trying to deal with things. It was always a struggle to find, who do I speak to? Who? Who do I go to? I just remember it being constant phone calls, leaving messages for people [00:07:00] and hitting a brick wall, and hitting, and then you're just waiting for that one door to open to go, yes, can you help?

Our local authority had a dementia crisis team who were a mental health specialist who would go into a situation where there was a person in crisis. Dementia nurses, um, from the NHS would come in and they would make it clear that our job is to come in for maximum 48 hours to, you know, sort the situation out, do what we need to do.

They ended up being involved every day for six weeks. It became where we'd have to, mum would have to make sure the doors were locked when in the house because he would try and go out looking for his car and then wander, and we ended up with carers coming in three or four times a day. That got increased to six times a day.

But the problem is, is unless there was someone there all the time, it was impossible to manage because there was no one there overnight to help out and something could [00:08:00] happen in the hour or two hours between visits. So it was quite obvious that he needed better care.

I was constantly going there after work. I was going there in the evenings at night and trying to sort it out. It, it probably was a relatively short space of time, but it feels like a lot longer looking back. I spoke to my wife and I said he needs to go into residential care because mum can't look after him, but I need mum to be the one to make the decision.

She was very much, I need to look after him because he is my husband, you know, being loyal and until death us do part and all of those sort of things. Her response was, it's all right for you. It, it, it doesn't affect you, because you are not living with him. In her mind, she hadn't seen the wider ripples in the circles that came from that because, quite rightly, she was very much blinkered on what was going on at home, not realising that with any traumatic incident there are ripples.

There are people that are affected [00:09:00] further out and, I was keeping her going, but she didn't see that. And then obviously my wife was keeping me going and I was like, man, I'm not gonna say what I feel here.

The date he sort of escaped and disappeared, we had to call the police to try and find him. Turns out he just wandered off to try and get a paper, but he didn't know where he was going. Police found him, brought him back and, and that was the point my mum said to me, can you start organising whatever you have to do? So obviously I made the phone calls and within however long he was in residential care.

Marianne: Placing my own mum into a nursing home was a heartbreaking moment.

She'd always said that she didn't want to go care. It's something that my sister and I feel guilty about to this day, even though we really didn't have a choice. Towards the end, Mum needed 24 hour care.

Chris: How do you tell [00:10:00] your parent that I am putting you into care? You know, it's that everyone talk, even, you know, you hear it nowadays a lot. You know, I don't want to be putting my parent into care, and it's coming to that realisation that I'm going to have to do it. That time had to come because it was such a strain on us.

What we decided was for everyone's sake, it was just easier just to say, you, you're going into hospital for a bit. I think that's what we said. It was just a lie, 'cause it was the easiest thing on everyone. And, and he accepted it. This home had like a bus stop by the, by the door and it was like made like a bus stop, but it was inside.

And every time we visited, he would be sat by the bus stop and he'd got a bag as though he was expecting to come home. We'd come in and say, ‘hi dad’. And then we'd go back to his room, and it sort of reset everything. He still kept his sense of humour. I would go and see him and he'd say things like, I got, I got out, I got out overnight and we did the [00:11:00] bank job and, and the money stashed aside, I'll let you know where it is, you can go and get it.

And whether that hinted at his past, I have no idea, but. Funny times, but then suddenly really like upsetting times, he'd be saying, you know, look, look, look at the walls. Look at, can't, can't you see the blood pouring down the walls? And, and, and he'd see a cat giving birth on his bed and real vivid stuff.

He had previous heart problems and quite often with people with dementia, it's the underlying health condition that combines with it, that, that gets that person. So, he went downhill very quickly. It was about a year from being in residential care that he then got to the point where he was no longer able to eat food and then they withdrew medication.

And I got that phone call on my mum's birthday to say, you know, it's best you come now if you want to say [00:12:00] goodbye, really. We arrived on a sunny Sunday in May, and we sat in his room as he was just sort of just breathing with his eyes staring and never, never forget that sight of his eyes just staring out the window and talking to him.

We arrived at 12 o'clock lunchtime and he drew his final breath at 12 o'clock midday the following day. We sat there for 24 hours. I do wonder whether he knew it was Mum's birthday, and he hung on until the next day.

And then immediately just felt relief. Just, uh, unbelievable relief, followed by unbelievable guilt for feeling relief. It was just up and down, up and down, you know, just thinking it's over. And, you know, just [00:13:00] I can, it literally physically felt my shoulders lift. Because it'd just been so weighed down by that, that stress.

So, Dad passed away in 2013 and then we thought, you know, we can take a breath now as a family and sort of just make up for lost time if you like.

And then it was 2015. My birthday, um, January the 10th, 2015. And as I say, Mum was very much an ardent churchgoer and had a phone call from one of her friends that she was close to who phoned me on a Sunday and said, is your mum all right? And I said, I think so. And she said, oh, she wasn't, she wasn't at church this morning.

And it was quite unusual that she wouldn't go unless obviously she was ill or whatever. The other thing was she hadn't sent me a birthday card, so there was a couple of things there. [00:14:00] And so I phoned her, and I remember her just saying, I, she said, well, I, I just feel odd. And that's her word was, I feel odd.

I don't think she knew what that meant really. I was like, right, I'm gonna get a GP appointment. She did some very basic tests. She then said, I'll do a referral to the mental health team or whoever it went to, and obviously then there's a wait.

I remember again exactly on my birthday, calendar year later, we had the appointment with the mental health team to see the, the specialist. He then repeated the test and then she scored even worse. He then said, you've got vascular dementia with Alzheimer's as well. The two mixed together.

I was just feeling, here we go again. You know, round two. I remember driving mum back and I [00:15:00] just said, how do you feel about what's been said there? And her words to me were, well, I'm just glad that I don't have dementia. When she'd just literally been told she had vascular dementia and Alzheimer's.

Marianne: Chris's mum, Audrey, lived alone now and not long after getting her diagnosis, she fell and broke her hip. The long stay hospital away from familiar surroundings and routine seemed to accelerate her symptoms. Chris and his wife were back in carer mode, this time for Audrey, and they had to juggle their caring responsibilities with parenting too.

Chris: I only learned the term sandwich caring some way through the journey. I was doing it, but I didn't know there was actually a term for it. You know you have a child or children and you are [00:16:00] looking after them as as best you can, but also looking after a parent. And we had the added pressure that I was an only child, so I couldn't hand over to a brother or a sister for me to sort of go, can I have a bit of time off? Can you look out for mum? I was the only one.

All the toing and froing and having a five-year-old that needed picking up from school. My wife worked, you know, we both worked, this was like having a second full-time job that we were both, both had really. You know, you want to give your child all of your attention when you are not at work, and it was impossible to do that because the phone would ring or the care line would go off.

As part of my job, I worked nights, so I would then be tired from nights. But then I'd also, on my days off or after a day shift, I would get a call from the care company that were monitoring the thing, saying ‘your mum's pressed her button’. So I'd then have to [00:17:00] drive over in the middle of the night.

So it'd be like I was on call and then I'd be tired the next day when I shouldn't have been, and that was a day when we were going out as a family and doing stuff. We'd have plans to go to the park or go to the seaside or whatever it might be, and then something would just come up. We ended up having to do her food shopping, pick up her medication for the carers. All that time was not being put into our son.

My father-in-law and mother-in-law were able to do some of that and we relied on friends and neighbours where we could.

You, you had to put the, the, the actual me not having the time with my son aside, it was more a case of we just need someone to have him so that he's not on his own. You know, you can't leave a 5-year-old on their own. And there were times where we were both needed. You are just trying to split [00:18:00] yourself that way and that way, and trying to make sure that, yeah, you keep things as normal as possible.

It was really, really tough. The parent has become the child, and the child is still a child. So, you know, they both need attention and yeah, it's really, really difficult to sort of juggle that. I think just people need to, to know that, however easy it is to say, don't feel guilty. You just have to not feel guilty.

You know, you don't love that child any less. It's just there's often no other solution to the problem. He was my dad and she was my mum. And you're like, it it, they've looked after me, so we'll do what we can until the point of which I can't physically cope with it anymore. And we got to that point.

Marianne: I was lucky enough to have a sister to share things with.

She lived near mum and became her carer, and I would support her on a regular basis. And that was tough [00:19:00] enough, but when you can't share that burden, it can become totally overwhelming.

Chris: Up until dad got ill, I hadn't had any like proper stress in my life, so that was all new stress to me. I just felt myself building up and just getting snappy with my wife and obviously young child as well, who's messing around and doing child things. Seeing that happening and then thinking, this isn't me.

With dad and with mum, it became every time the landline rang, I immediately went into a sort of heightened state of alert and into this stress state, like straight away, because from where the phone was, I could see their number on there. I'd be like, you know, immediately you feel your heart beating out of your chest because you think what is, what is happening, what's gone wrong?

And then you [00:20:00] answer the phone and actually it's nothing. And then you've got that adrenaline running and obviously that's not good for you. And then it would happen again, and it again, and, and it just would, it would just stack up on top of each other. And then if it was actually something, then you've got the stress of dealing with that.

As well as being at work as well, and, and then being tired from not sleeping. It became a perfect storm building up to the point where I just was like, I can't, I can't deal with this. I had a breakdown with dad, and I had a breakdown with mum where I just got to that point where I couldn't work. My mental load was just like, nope, can't do this.

Can't do this. Something's gotta give. And I was signed off work, more than once for it, but that sort of takes one thing away, which is work, but it doesn't take away the actual stress. You still got to deal with it. [00:21:00] It just sort of manifests itself in, in physical ways, you know, that high alert, all the things that go with stress, not wanting to eat just, just horrendous really.

But it, yeah, it happened, it happened a few times where you just got pushed to the limit and, and nowhere to turn really. I think I let it get to the point it went too far before I sort of realised I went beyond the point I should have gone to, if you like. You are just on this sort of runaway train.

That's what it feels like. A runaway train that's just going, going and going and, and you are on it, but you can't put the brakes on. Certainly like with mum, everyone would say, well, you know, look after yourself, you know, you can't pour from an empty cup. And you know, everyone had that advice to you and you're like, that's great, but you know, I've got no one to, no one else to fill up the cup, 'cause we are, we are, we're struggling to deal with this. Ended up on antidepressants more than once because there's one of the, you know, at the time only thing that would really help.

Marianne: One of the other things that helped Chris was [00:22:00] connecting with an Admiral Nurse. 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.

Chris: I mean, all throughout Dad's relatively short journey, I didn't have a clue that they existed, and it was through the GP, this lovely GP that mum had. She mentioned about Admiral Nurses and I was like, well, what's that?

And she said, well, someone who's a qualified nurse who can come into the situation and maybe open doors, offer advice. I was like, well, yes, please, yes, please. You know, this is what I've been searching for. We got a phone call from our Admiral Nurse. And it was like, weight had come off my shoulders because she was brilliant.

Um, absolutely amazing. She came and visited us at home, you know, gathered all the information, [00:23:00] said, what is it you need? What is it that you're, you're struggling with? She said, well, alright, I, I can send an email to that person. You know the people that you can't even speak to on the phone that you know, exist in an organisation, but you can't get, can't get their email, you can't get their phone number, but you need to get clarification, you know, to do with funding or to do with whatever it might be.

She had the keys to the doors. She would be able to go, that's right. I'll send an email to whoever it was. And, and it just seemed like magic. And she was lovely. She understood. I mean, I dunno where I'd be without her even just talking to how, you know, she'd be like, how are you? How are you doing? Is there anything you need?

Marianne: Audrey had been diagnosed with vascular dementia and Alzheimer's in January 2016. For the next few years, she lived at home with carers coming and going multiple times a day, and Chris himself was stretched physically and [00:24:00] mentally between work, home life and his mum's care.

Chris: Various things happened around the home, and it was clear that she wasn't gonna cope much longer.

I was getting to the point where I can't carry on like this. We can't carry on looking after her, getting her shopping, getting her medication. And then in 2018, we had carers come in, they come in the morning for a breakfast visit and she was slurring her speech. They phoned me and said, we're calling an ambulance.

I came over, she collapsed on the floor, had a massive stroke. Spent about three weeks in hospital. My wife and I were worried that they were gonna discharge her back home, and we'd already got to that breaking point and we were like, I'm gonna say I can't cope. She needs to go into residential care.

We had this 'best interest' meeting. They talked about the options like live-in [00:25:00] carers or residential care and everybody put their piece across. And so it was decided that she would need to go into residential care. I then had discharge nurse come in one side sitting next to me and the social worker at the other side, and they plonked a booklet of all the care homes in West Sussex on my lap, and the discharge nurse said, there are a lot of sick people in this hospital that could do with your mum's bed.

And I was like, well, I do understand that. And he said, uh, yeah, we need her out of hospital by Friday. And this was on the Wednesday and I was due back to work on the Thursday. And he said, this is a booklet of all the sort of approved care homes. You can have a look through. And if you could find somewhere that's got a vacancy, let our social worker know.

I got home and just stared at it. One of them was a care home that Mum and I had looked at for when we were looking to put Dad into residential care and they had a vacancy. I then reported back to the social worker. [00:26:00] They did their thing and she got discharged and went there. The fees were four and a half thousand pounds a month, and obviously I didn't have that money.

Marianne: The family found out that they weren't eligible for financial help from the local authority, which meant Chris would have to sell his mum's home to cover the costs.

Chris: They give you 12 weeks free. They give you that time to sell the property. Which is no time at all when, when their property was still full of furniture and not in a state to be sold.

So my wife and I literally spent two weeks clearing the property, getting it ready for sale, and we got it on the market in two weeks and got a cash buyer within 24 hours. Fortunately, it was in a sort after village, but the money didn't arrive from the sale until after the 12 weeks. I had phone calls from the care home saying, you know, [00:27:00] sending me invoices for like 12,000 pounds and all sorts of things.

And I, and that was stressful because I, I didn't have the money and they were chasing me for the money. Eventually it arrived and then I had to pay out huge amounts of money initially and then just continually pay that out. And, and the money ran out last year. 380,000 pounds just gone.

So that was 2018. She, she moved in there. Because of the stroke and the dementia. She was, um, very quickly bedridden. She then stopped communicating. I would go in and visit where I could, but I did. I did find it very difficult to go in. Then covid hit and during covid I was told that she was refusing food.

She caught covid twice and she was put on end of life care in 2020. And she was losing weight, and they were saying that, you know, like with my dad, it could be any time [00:28:00] now. And she managed to last until February of last year.

And then you go through the relief and guilt and all of that again.

Now I've come out the other side where you know, both parents are no longer with us. That chapter has closed and that gives a lot of time for reflection. I do feel that, you know, yes, they're your parents, but not everyone is capable of caring. Not as in they don't care but doing the physical things because there's a lot of expectation on children, relatives, to step into that role because the resources aren't there within the local authorities to do that.

People shouldn't feel guilty to say, I can't do it. You know, I, I physically can't do it. I will do what I can, but I can't do all [00:29:00] of it. Looking back on me back then, that's what I should have said. We took on all of it because we didn't know where else to turn. You have to look after yourself. At the end of the day, you have to look after yourself because then you become the problem.

If you've got young children or a partner. Then it takes its toll on that, and then that causes other problems. So yeah, not everyone can physically care. Don't be hard on yourself. If you can't cope, it's okay to ask for help. It just absolutely is, because you have to think of the bigger picture of the other people that are being affected.

The ripples in the pond, when the stone gets thrown in. The further family, the further friends that it affects. If you can't deal with it, then ask for help. That's what I'd say.[00:30:00]

Marianne: A huge thank you to Chris for sharing his story and for being so open about the challenges of being a sandwich carer. 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 Chris'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 [00:31:00] 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 listening.