

Jules - storyteller ep transcript

Kola: [00:00:00] Welcome to My Life with Dementia, a podcast from Dementia UK. I'm Kola Bokinni. After losing my dad to vascular dementia, I wanted to share stories of other families who are facing dementia and finding a way through it. So in this series, you'll hear how people are adjusting to life with dementia or the loss of a loved one.

And how Dementia UK's specialist Admiral Nurses, can be there for you in the toughest moments. If this is your first time listening, welcome, you can find the link to Dementia UK's Helpline in the show description and a wealth of information in every episode. If you're joining us again, welcome back.

Coming up in this episode,

Jules: I was happy to support my parents. Of course. It's something I genuinely wanted to do. But you can't help but feeling in angry that you've been dealt this life because you're trying to manage your household, you're trying to manage your [00:01:00] career, and at the same time, you're trying to manage somebody else's life.

Every aspect of their life you have to manage.

Kola: When Jules's uncle started showing symptoms of dementia, she had no idea that soon she'd be caring for multiple family members who all developed dementia around the same time, including becoming the main carer for both her mum and dad for six years. It was heartbreaking to see the ways dementia changed them, but Jules remained dedicated to keeping their parents safe and happy right up until they both died in 2025.

Now Jules is channeling at her energy into helping other families who are living with dementia.

Jules: My name's Jules Minter. I'm the daughter of June and Mick Minter, and I [00:02:00] live at the, uh, the beautiful coast in Lincolnshire. I have a very happy time there with my two rescue dogs and my five black rescue cats who are the apple of my eye.

I'm a communications consultant, so I get involved with internal, external corporate communications. Pretty much spent most of my life doing that. I grew

up in Stevenage, in Hertfordshire. And I was actually born in the house, um, that mum and dad owned for close to 58 years. We went from a wealthy background, you know, I grew up in a, in a council house, um, and it was such a beautiful, beautiful, beautiful home.

We used to walk along the river. We used to go out cycling every weekend. And because dad was in the RAF, we were dragged along to multiple aircraft museums, um, all over the country. My grandmother was a, a pianist for the silent movies, and my grandfather was quite well-known violinist. So from the age of [00:03:00] five, um, mum gave me the gift of music, and that continues throughout my whole life.

It is a very relaxing thing to do, actually playing piano, also a church organist. Um, I absolutely love it. Music's such an important part of my life and it was a very important part of mum's life as well. So mum was born in 1940 and she was an old fashioned telephone operator where they used to, you know, pull out the cables.

Um, dad was a telephone engineer and they met in Copper Mill telephone exchange. She was just the sort of person, if she had a pound in her purse, she would give it to someone on the street. Just very kind, um, very musical. And I can, I can honestly say that mum and dad gave me every single opportunity in life.

Kola: Dementia wasn't on Jules's radar at all. She didn't know much about it, but that began to change in 2018 when she noticed something wasn't right with her uncle.

Jules: My mum's [00:04:00] brother, Cyril, um, he didn't have any children and so I used to visit him, you know, four times a year. And he lived, um, lived at the Autumn Broads in Suffolk.

It was about 120 miles away. I remember I went round there and he was eating a can of baked beans that were cold. And it turned out his cooker hadn't worked for nearly, um, four weeks. He didn't know how to use the phone to call me, to ask me how to, to arrange for the cooker to be fixed. And then I remember he said, I've lost all my money.

And I said, what do you mean you've lost your money? And he said, I dunno how to access my money. It seemed to happen very quickly from the time we'd last seen him. I found there were plates of food, uh, with flies around them, and he was cooking for four people. He was cooking for his brothers and his sisters.

That was my first interaction with dementia. And even then, I wasn't quite sure, um, what it was. And that's when we started to read up on it and [00:05:00] research it. And then we realised that, um, when we finally, we did get him tested, he had sadly had vascular dementia.

Kola: Vascular dementia is the second most common type of dementia after Alzheimer's disease is caused by reduced blood flow to the brain.

And it can cause problems with concentration thinking and managing daisy activities.

Jules: He seemed to go downhill really quickly, but then we didn't know how long he'd had it for, and perhaps because I didn't really know much about dementia. I just wasn't, you know, picking up the signs from it.

Kola: At the time, Jules was living in Bedfordshire and traveling down to ROS at least once a week to help look after him. Soon she and her family arranged carers to get involved too.

Jules: He had a fantastic social worker called Rachel, and she really did work very closely, um, with the family. I remember we had a meeting with her and by this stage he was wandering around the streets.

We tried [00:06:00] all the usual, you know, the GPS tracking devices on your wrist, but he would take the, the watch off, he would take the pendant off. We put alarms on the cameras in the flat, but it became really difficult with him being on his own to keep him safe. So that's when the journey started in terms of finding nursing homes or care homes.

I must have looked at about 20, both on the Autumn Broads, but also in Hertfordshire because it kind of made sense in a way to bring my uncle closer to where I was. I was living in Bedford, and also where my family were, which was in Herts. We finally made the decision to bring him back to Herts so my mum could visit him.

We found somewhere really nice that would take him and mum would go twice a week, um, to go and see him. In the end, he had a, a fall and within two weeks later, he died [00:07:00] partly of a fracture, but it was advanced dementia. By that stage I was with him, um, when he died. And it's tough. It's really, really hard.

My mum didn't want to be there at the end, so then I had to go home and tell mum that, um, her brother, her darling brother had died. And that's really tough to do that.

Kola: Cy died in August, 2022, but even before he passed. Jules realised this wasn't going to be the end of her journey with dementia

Jules: by now. We were pretty experts on, um, I, well, I don't think expert's the right word. I don't think you've ever become an expert in dementia, but we knew the signs, and I could see that mum was starting to exhibit some of the early signs that I'd seen in my uncle,

Kola: and it wasn't just June.

The same thing was happening to Mick.

Jules: Dad was also starting to [00:08:00] show some of those early signs as well. It was almost together. Dad was the first to be diagnosed. He went to the memory clinic and he was diagnosed with, um, vascular dementia. So his diagnosis was, was pretty quick. It was a while, actually before mum was properly diagnosed.

It must have taken, I think it was three years before she was formally diagnosed with Lewy body dementia.

Kola: Lewy body dementia shares symptoms with Parkinson's. Among other things, it can impact a person's thinking cause hallucinations, delusions, sleep disturbances, and memory loss.

Jules: We decided, um, with mum that we never talked to her about dementia.

We never mentioned it. We never used the D word. Never used it in front of her. She had seen her brother. Go through the worst with dementia, and she had too much and knowledge [00:09:00] of it, and I wanted to protect her from that. But I sometimes wonder whether in those early days, whether she realised that she, she had it.

There are times as a daughter, you're exhausted and you're thinking, why me? Why has this happened? Why, why am I going through this again? And I was happy to do it. I would not have changed it in a heartbeat. I was happy to support my parents. Of course, it's something I genuinely wanted to do, but you

can't help but feeling angry that you've been dealt this life because you're trying to manage, you know, your household.

You're trying to manage your career, and at the same time, you're trying to manage somebody's else's life, every aspect of their life, their lives you have to manage.

Kola: As June's dementia progressed. Jules and her sister Sue found a carer to start offering some outside help.

Jules: Becky became our lifeline. Um, she had lots of dementia experience. She [00:10:00] became like a sister to me. She became part of our family. But I was always told by Becky that with dementia, you have to be six months ahead and you have to make sure things are set up in the right way.

For example, quite early on actually, in dad's dementia, he put a plastic kettle on a gas hub. He was thinking back to the old days when you used to put a metal kettle on a gas hub. He basically gutted. He gutted the kitchen with the fire. Two fire engines came out and there was smoke damage throughout the whole house.

And when the fire brigade came, they said, this is the common cause of fires in the household. People dementia put in a plastic kettle on a gas hub. Now, if you'd have known that a year before when we replaced the gas cooker, you would've had, um, a halogen maybe. So Becky was always really good at saying, we've gotta be one step ahead.

It's almost interpreting and anticipating what they're gonna do next. [00:11:00] Dementia just chugs along and then suddenly there's a massive dip. And then we reached the point where we needed carers at night coming in, who would keep awake? That carer really was for mum. Most of the time,

Kola: June's dementia had always been more advanced in mix,

Jules: but as dad's dementia started to get worse, we were having to get carers in to help with dad's needs, and I felt my family home had turned into a care home, and I remember hating it.

I remember saying to the carer, what has happened to my family home? The home I was born in? For example, mum would look in the mirror. And not recognize herself, and she would be scared by that image. So every mirror in the

house was frosted over with spray and I hated it, but I had to keep reminding myself, this is what's needed to keep mum, dad safe in their own home.

And it didn't feel like my home anymore. 'cause there were strangers at the end of the day. The carers, however much you like them, [00:12:00] however much you know, we personally interviewed them. They're not my friends and they weren't my family. So I felt awkward about staying in my own home. I would rather stay with friends sometimes than stay there.

I remember the, the first time that I was standing in front of mum and she said, where's Jules? I said, mum, I'm here. It seemed like after that she didn't know who it was anymore. I just went upstairs and cried on my bed. 'cause I knew that day, you know, that day's gonna come, that when it does come, you can't deal with it.

You just really can't deal with it.

Kola: Some of the most difficult symptoms of June and mixed dementia came from the changes in their personalities and behaviors. Both of them could show anger that seemed really out of character. These kind of symptoms are often response to the strong feelings of confusion, overwhelm, and disorientation that [00:13:00] dementia can cause.

It's an aspect of dementia that can be difficult to talk about and incredibly isolating to go through alone.

Jules: I would do a three hour drive and I'd walk in the door to be told by my mum and dad how useless I was. You're useless daughter. You know, you're no better than a servant and you know, why are you here?

'cause you're no good. And that could go on for three or four hours of being absolutely battered. You do have to think though, that that's not, that's not my mum, dad saying that. They wouldn't say that.

Kola: June in particular, could be aggressive and even get physical with Jules. And Mick,

Jules: she would hit dad, she would bite me, she would pull my hair.

She could be really, really, she could be really strong. Even right to the end, the last week before mum died, she was, she was biting my face because she forgot how to kiss. That's really sad. So, yeah, I, I used to have bites all [00:14:00]

over me. I think one of the worst times that I had, I remember it was 2:00 AM and I was laying next to mum in bed and cuddling her and mum said she wanted to go to the toilet, so I took her to the toilet and she told me how much she wanted to kill me and I was scared because she seems to have such strength.

And I remember going into dad to say, dad, wake up. Dad, wake up, help me. And he said, I've gotta go to work tomorrow, Jules. By this stage, it was like 90, I've gotta go to work tomorrow, Jules. And I'm like, dad, no. Help me. And he wouldn't. So I went back into mum and she carried on for half an hour, and then she turned to me and smiled and said, I love you, Jules.

And that was it. The episode was over. People have said to me with time, you'll forget that and no, no you won't. I'll never forget that. And um. She won't [00:15:00] remember it after half an hour. She won't remember what she did, what she said, and she went back to bed and she slept. But did I sleep? No. I was absolutely traumatized by it.

This is the other side of dementia, the side that no one talks about, but talk about it. Let's get it out there. Let's, as carers, let's make sure that other people know you're not alone and we survive it. It's nothing to be ashamed of. So I've come across family members who won't take their mum or dad to a cafe because they're ashamed how they're gonna behave.

They might kick off, they could get really aggressive. People might stare at them, but people understand. I used to go to, um, you know, cafes and people used to look at me and nod and say, yeah, it's so, it's okay, love. It's right. I understand. I get it. I get it.

Kola: For Jules coping with all of this meant finding pockets of time to get some breathing space to do something that was just for her.[00:16:00]

Jules: I think music was my refuge and I think when my times have been really hard, and even now I still, I play my music, I play my piano. I go and play the pipe organ, I lock myself in a church and I go and play the pipe organ and that is my way of dealing with it. Some people may watch tv, some people may read.

But you do need that space, and you've got to find that, that time away from it all.

Kola: And Jules also made sure to create those moments of respite and lightness for her parents too.

Jules: Mum and dad loved to dance, so we would still take them to tea dances. I would take them to the movies. We would go drive around London.

We would walk along the the tow paths of the canals where they used to live. We would always put music on. We were always dancing in the lounge. Mum and dad used to go to dementia choir, which they absolutely loved, and I got to meet some really nice carers. And that would be my [00:17:00] couple of hours, um, respite and we could chat and sometimes we used to meet up and go out for dinner together.

The family members and the carers, we could all talk, we could all share information. And so I think that's really important that if you can find those type of groups where you can meet with other carers and you can chill, and you can relax and you, you know, you know, they're, they're safe, but you can get to have a little bit of downtime as well.

Kola: One of the best memories Jules has is from a special night out with Mick.

Jules: Dad had always wanted to go to a Coldplay concert, and so I think he was 89 when we took him and mum to go to their first Coldplay concert, and I remember dad looking around in absolute wonderment at all of the flashing lights and all the flashing wristbands.

I remember looking at his face and how happy he looked, so. Although you get that diagnosis of dementia, it's not, it's not [00:18:00] the end. You can still go on to lead a really joyful, a really happy life, and you can still do so much. It's not the end, honestly, it's not.

Kola: By late 2024 Jules and their long-term carer, Becky, were managing a team of 10 different carers.

Most days and nights. There were two carers staying in the house at any given time.

Jules: But the money, we just couldn't sustain it. The money was draining and I was trying to top up as much as I could. We did get some funding from social services, but it's really hard to know what you're entitled to. Now I get it.

Now I understand it. Now I know how to access it, but at the time, you know, you never stop learning in life, and I had to work out how this was all gonna work. Mum was being particularly bad with dad and I had to protect dad. Mum

would just walk up to dad. Dad could be watching a movie or [00:19:00] something and she'd just walk up to him and give him a really big hit.

She'd just hit him or she'd pick something up and throw at him.

Kola: Jules could see it was going to be better for her mum and dad if June moved into a care home.

Jules: We had no choice. We knew it was just probably gonna be for a short period. 'cause my mum, by this point, mum had really, really deteriorated.

Kola: This was one of the times when Jules really benefited from support from dementia.

UKs Admiral Nurses, they are specialist dementia nurses who offer free advice and support to people living with. And their family and carers.

Jules: When you phone the Admiral Nurses, you do get a world of experience and there's nothing they wouldn't have seen before. And it's just nice to know that you are talking to people who've seen it.

Kola: Anyone can call up the Dementia UK, help learn. To speak to an admiral nurse and Jules also had a local admiral nurse Lucy, who was able to help manage June's transition into residential care.

Jules: We did a lot of [00:20:00] research and we moved mum into a beautiful care home, a nursing home, and the staff there would genuinely caring.

I would come around the corner sometimes and they didn't even know I was there, and one of the carers, Vicki, would be cuddling up to my mum. On the sofa and that was genuine. And they would feed mum. They cared about her hair, they cared about her make, it was just, it was a really nice environment to be in.

It was, it felt like a happy environment. There was music there, you know, I was there every single day. I was there from morning until night. And I think the, the good sign of a care home is if you walk in at 11 or 12 at night to drop something off. For example, what is it like at night? And that, to me, I'd say to anyone looking at a care home, go in there unannounced in the night and see what it's really like.

Kola: June moved into that care home in December, 2024. By late [00:21:00] January, 2025, Jules knew her mum probably didn't have long left

Jules: by this stage. Mum. Mum had chosen, she didn't wanna go anymore. She clenched her teeth and she was refusing to eat because eating is the last bit of control that you have, and she was refusing to drink.

That was her choice, and we agreed we were never gonna force it. And the care home were really aligned with that as well. So she would be offered food. She didn't want it, that's fine. We're not forcing it. Two weeks before she died, I suddenly had this bright idea. I wanted to grant her her last big hurrah.

As a family, we traveled all over the world and mum and dad loved to fly. And I remember two years before mum died, she looked up into the sky and she said, I'd love to go on a plane. What's it gonna be like to go on a plane? And I thought, you've forgotten all of those trips you did to Australia and New Zealand.

And it made me feel really sad. So I knew what her loss hurrah should be, [00:22:00] and so I. Chartered a plane for 10 people and I appreciate not everyone's in a position to do this. I chartered a plane and the intention was going to be to take mum buzzing around the skies, um, over Norfolk and Suffolk. One last time I didn't realize how hard it would be to take mum out of a nursing home.

Social services, the crisis team, the care home manager, everyone said you're insane. You know, you won't even get your mum in a car other than getting her to Stanstead Airport. And I said, I'm doing it. I did the risk assessments for them. I liad with all the right departments, and we got all of the agreements we needed.

So we found a fantastic company that could take mum and I remember it was a really gray, miserable day and we arrived at Stan Airport and they laid on champagne 'cause we were also celebrating mum and dad's 60th wedding anniversary as well. They laid on cake. The staff were just, could not have [00:23:00] been better.

We had mum and dad, two carers. Um, we had friends on board. The pilots were in tears and we took to the skies. And when we got above the clouds, the blue skies, the sun came out. And I remember mum, for the first time in, gosh, maybe over a year, she smiled and I thought I was in tears. And I was like, yes, this is gonna go really, really well.

And mum drank for the first time in ages. She drank champagne. She um, she ate cake. Um, and I can honestly say when you see the pictures that you look out, and it was almost like she was looking out to heaven. It was almost like mum's dementia had left her in that one one hour in the air. I got my old mum back

Kola: a week after the flight. It seemed like Jules mum knew. Her time was almost over.

Jules: She spoke to [00:24:00] me and she said, Jules, I want you with me and I want to go home.

Kola: Jules rang her local admiral nurse Lucy, and explained what was happening.

Jules: She made it all happen for us. I had no idea how you bring someone home.

We had a hospital bed, Lucy, organized support. We had the assessment. And we took mum home.

Kola: They were able to use a service called Hospice at Home, which Jules heard about through her Admiral Nurse. It allows a person to receive end of life care in their own home, and it's something that's often offered by hospices themselves, by local charities, the NHS as well as private providers.

Jules: She loved Christmas, so it was February, and we blitzed the house for Christmas. Had to get the tree out, put the ball balls back on. Um, we had Christmas lights outside. The neighbors thought we were completely nuts doing Christmas in February. [00:25:00] I can honestly say bringing mum home, it was the best thing we ever did.

I've been told later on, it really does help with the grieving process 'cause we were in control of what mum was gonna eat, what she was gonna listen to, what she was gonna watch. And we had a party for a week. It was like a big party. We played Christmas songs, we had people over, we did dancing, we sang, I played music.

We had a projector that was projecting a movie on the screen, on the ceiling so that mum could lay in bed and look up at the movie.

Kola: June died on February 14th, 2025.

Jules: I just knew mum would choose Valentine's Day 'cause she was the ultimate. She loved Valentine's Day. She was the ultimate romantic, and I just knew it.

I just knew it. It got to about, about 10 o'clock and we put Cinderella on, which was her favorite movie, and I'm thinking it's 1107. So maybe I've got this day wrong. Maybe mum's, I've got it wrong here. We watched Cinderella [00:26:00] as the titles were coming up. I, um, leaned across. I kissed mum and she took her last breath.

It was, if you can describe it as a beautiful death, it was beautiful.

Kola: Jules's dad was asleep upstairs when June died.

Jules: It was really the next morning I, I worked out how am I gonna tell dad? Why should I have to tell my dad those wives died? So I, um, rehearsed it what I was gonna say. And, um, I walked into his bedroom and he said, Joel's mum's died, doesn't she?

And I was like, yeah. And he said, she came to tell me last night.

Kola: But although Mick understood what had happened in the moment, his dementia had reached a stage where he couldn't hold onto the information over the next six months. Jaws had to keep reminding him that June had died.

Jules: He basically didn't want [00:27:00] to live without mum and he, he would say quite amusing things. So he'd say, can I use my bus pass to get to heaven to go and see mum? Which I thought was quite sweet actually, that we were caring for him. And you know, he was doubly incontinent and I, you know, it was one thing cleaning mum up or showering mum, but then you're having to do it for your dad.

And the first few times it's really hard. He was RAF, he was a proud man and there was his daughter, you know, cleaning dad up. And so you've got to kind of put yourself into a different space really. And you do it. And I was proud to do it. So the days were going by, he was given up. We lost dad in August.

So that was almost six months to the day when, um, mum had died. [00:28:00] He had a stroke, ended up in hospital. They wanted to, um, start giving dad more meds and force feed and I said no, because we had the power of attorney for health and finance, and I would urge anyone to get that, get this consent form so that you know what that person's wishes are.

And we had that all in place. I knew that dad didn't want, he didn't want a feeding tube. So I said to the doctor, that's not their wishes. That's not dad's wishes. And so the doctor said to me, you're right. Take your dad home to die. So we took dad home and this time it wasn't Christmas, it was Arias themed.

It was, again, we created a, a nice atmosphere of dad. You know, my dogs were coming over. They used to sit on the foot of his bed and protect him. And it was really nice that the same people that looked after mum were also, um, they were looking after dad and he was deteriorating really fast within a couple of weeks.

Yeah. [00:29:00] Dad had made that decision to join Mum.

Kola: Mick died on August 29th, 2025.

Jules: My whole life for seven years has been dedicated any free time. Was dedicated to mum, dad, and my uncle, and you've suddenly got all this free time. I throw myself into work and I keep busy and I know there's gonna be a point. I know I'm motoring along and there's gonna be a point where I'm gonna take a massive dive over that cliff.

I have got fantastic people around me. I've got really good friends. I've got one friend, Lynn, who basically every single day checks in with me and she will send me a goodnight picture every single night. And I've got friends around me who've gone through something similar with, um, with dementia. I've kept in touch and they've become friends.

Becky's become my friend, Vicki, where in the nursing home where mum was, she's become my friend. I've kept friends with some of the other carers who were [00:30:00] either the dementia choir or in the nursing home, and there is a really good support network out there. You can't just put the duvet over your head and just stay in bed.

You've got to, you've got to find a way to get out there. You, you have to carry on with life. That's what. That's what parents, that's what my parents would've wanted for me,

Kola: as well as work and friendships. Jules is also thrown herself into a new project that she hopes will help a lot more people. She started a charity in Hertfordshire and Bedfordshire with plans to expand around the whole uk.

Jules: The impact on mum with the flight was so incredible, and I want to make dreams. I want to make wishes come true for other people. So I put my focus

and my energy into setting up June's wish people who towards the end of their dementia journey, [00:31:00] we will be granting them their, their final wish, whatever that may be.

And it could be anything from. Fish and chips at the seaside. I wanna fill the ocean or the sand on my feet one last time. Two, I wanna go up in a Cessna plane, or it could be something very simple. For example, there's a couple who want to experience a romantic meal in a care home one last time so we could organize a chef.

And so there's loads of ideas I intend to dedicate my life to helping people with dementia. And I think I found my calling in life. I found something that really means something.

Kola: A big thanks to Jules for telling us about June and Mick and what it's like to live with dementia as a family carer. If you are in a similar situation to Jules, you may find our next episode, especially useful Dementia UK Admiral Nurses, Hilda and Vic. Dive deeper into some of the themes [00:32:00] that came out in the episode.

Offering advice from their perspectives. Our specialist Dementia nurses, Hilda and Vic's episode will be out two days after this one. So look out for it in your podcast feed. This has been our episode of My Life With Dementia, a podcast from Dementia uk. Please subscribe in your podcast app to get new episodes as soon as they come out.

And if you've enjoyed this episode, why not share it with someone you think might find it useful? You can take a look at the show notes for a link to our support services, which include online resources, ways to contact Dementia UK helpline, and information about Admiral Nurse Clinics. Thank you so much for listening.