

Lizzie podcast episode transcript

Jim: [00:00:00] Welcome to My Life with Dementia, a podcast from Dementia UK. I'm Jim Broadbent. I'm an ambassador for the charity. In this series, you'll hear from people whose lives have been impacted by dementia. Lizzie's father, Rob, was diagnosed with young onset frontotemporal dementia in 2018. He was only 58 years old, and Lizzie was just 24.

Lizzie suddenly found herself navigating all the normal bits of young adulthood while also adapting to her new role as a part-time carer for her dad. Rob died in May 2024, less than two months before this recording.

Lizzie: I've got quite a small family. I have one brother called John, who's 32. I'm 31 years old, and then there's my mum [00:01:00] and dad. I used to be the terror to be fair. It would be me that would cause all of the, I would say, the drama. I don't know what really sparked it, but I would have this competitive kind of tomboyish manner.

But we're so different that as we've grown up it's like a lovely relationship with my brother. I hope I don't annoy him as much now, as I did when I was younger.

Jim: Lizzie and her brother John grew up with their parents in Shropshire, and Lizzie got lucky in the Dad department. She and Rob were always close.

Lizzie: He honestly was, was one of my best friends growing up and always was. And we would do things together all the time and have that shared humour. And I used to remember coming downstairs on Sunday, being super bored. We're like, dad, let's do something. He'd be like, okay, we'll get the bikes. We'd go out driving.

I think our relationship was, was, I want to say a perfect relationship for a dad and a daughter, because there was no friction apart from when he taught me how to drive. [00:02:00] He was like, A gentle giant, he was so kind, even when something annoying was happening. I remember this lady cut him off at the petrol station and we were like, he's mad, he's going to get out of the car and he's going to tell her, blah, blah, blah.

And he gets out of the car and he just politely says, "Well if you go round this way, I'll go this way and we'll both be fine." I was like, gosh, he's so kind all the time. I'm a bit more fiery, I guess, and so it's quite inspirational for me to have that as a dad figure. A very calm, pragmatic, sensible man.

Despite his sensible approach to life, he could also be very spontaneous and mischievous and be like, I've done something silly. I've signed us all up for a massive bike ride for charity. We're doing it and do things like that.

Jim: It wasn't just Rob, of course. It was Rob and Barbara, Lizzy's Mum.

Lizzie: She is the warmest, [00:03:00] bubbliest, stoic woman that you'd probably ever meet. Like, if you met her today, you wouldn't know what she's been through for the last however many years. So much love for my dad. They would have just celebrated their 41st, I think, wedding anniversary.

So it's a huge relationship and they were best friends and that love that she had for him was so evident throughout all of the way that she cared for him.

Jim: Lizzy was just out of university when Rob began to display early signs of dementia.

Lizzie: The symptoms that we were noticing were things like driving, you know, He was always the, the long haul driver in our family.

And suddenly he wasn't really able to get the bike or the clutch and he wasn't able to get off in first. He couldn't work it out. He's very mathematical. He could fix anything. He'd be my go to person for, I've just got something new. I don't know how to work it. Can we set it up? And there'll be no problem.

And we got him something for bike tracking and he just couldn't, we couldn't work it out. And he stared at it for a long time and didn't take it out of the box. And [00:04:00] I think that to me was this real, okay, something's not quite right. He was working at the time and put a lot of his symptoms that we now know with dementia down to either stress or just general life.

Jim: In 2017, Lizzie and her brother John and her parents went on a trip to Canada.

Lizzie: There was an instance where we were just driving to our Airbnb. He couldn't work out the directions and it paralyzed him. He froze in this car park. And that was a real panic for us because it was like, how do we, how do we move past this?

Because it's a mental block in his brain. And by the time we've deleted to get to the Airbnb, I just was bawling my eyes out crying. So was Dad. And we were both just had this lovely emotional hug, but it was like, we don't know what's going on. And I think that was the first time he showed me his fear with whatever was happening.

I didn't actually [00:05:00] think for a second it was dementia. So it was kind of like, I don't know what to say in this conversation. So I'm going to make light And kind of say, well, dad, you know, you've done this, you know, mum's going to kill you kind of thing and trying to make a joke out of it. And he laughed along and he was like, oh yeah, it didn't get better.

So dad put it down to stress originally and didn't really want to go down the diagnosis route. Which I know is super common, especially with people who are in their 50s, 40s, you know, would never think it's dementia. People, A, don't want to accept and go through that process, but also there could be so many other things that could be.

Yeah. I'd graduated from uni the year before, moved out completely from home. I'd just moved out to London. I was living with my best friends, and we were having a great time. I was still able to go out, have dinners, enjoy life, think about work, be stressed about work, and all the normal things that you'd be doing in your early 20s.[00:06:00]

Jim: Things back home at her parents were slowly getting harder.

Lizzie: He would stare at people, he would stop in his tracks, he wouldn't be able to find his way home. I was 24 when he was officially diagnosed,

Jim: Rob was under 65, which means this was young onset dementia. It's estimated there are over 70,000 people living with young onset dementia in the UK. Rob was diagnosed with frontotemporal dementia, which is a rare form of dementia that can affect a person's personality, their behaviour, and also their speech and language.

Lizzie was at work when she got the news.

Lizzie: I remember it really well. Like, it's one of those memories that has, like, stuck in my brain. I work in the fashion industry. I was a product developer at the time and we were in a fitting. Um, we had a model there, dress on designers there. In the middle of fitting this prototype, you [00:07:00] know, must go out.

And I get a message from my mum saying, we've had the appointment. It's frontotemporal dementia. There's no cure. We're going to wait for

whatever the next steps are sort of thing. And I remember thinking, I remember thinking immediately relief. I remember thinking, good, we've got an answer for what's been going on because it's now been going on for a couple of years.

Yeah. I said to one of my best friends who I was working with, I don't know how I'm meant to feel right now. It took a long time after that message to sink in, of like, the repercussions of that diagnosis. There was that half relief and half, oh God, what's next? But not floods of tears and emotion. Like, I, it kind of got blocked in my head.

I didn't have that knowledge that I have now of dementia being the umbrella. and all of the other conditions coming under it. Which probably also meant that's why I reacted the way I did when I found out, because I didn't have that understanding. Maybe it's a blessing at the [00:08:00] time, um, but through the years now and from understanding his condition more and more, you can have it in your fifties.

It's not something that just happens to grandparents. It's what a lot of people my age would feel.

The major things that were different were things like going out with your friends and trying to have good times. But constantly being tethered in your mind back to what's reality at home and seeing things play out in real life that could then trigger an emotion or a feeling that could then make me cry, get angry.

All these emotions could suddenly come out and my friends would be like, well, where's You know, you're in your twenties, you're out in London, people are drunk, someone might be acting like an idiot. But that behaviour that this person's showing is actually what my dad can show because of his dementia. So everyone's here laughing and having a great time at this person.

So all I'm thinking of, Oh, well, my dad did that the other day and it was awful. And it was like mortifying for him and for everyone else involved. [00:09:00] So my whole rest of the evening's ruined. Everyone else's evening is kind of dampened. It was always, I couldn't ever just let go of that, that memory. I couldn't let go of what was going on in reality and just have a good time.

Jim: For many young people in Lizzie's position, all this can mean is a big shift in the parent-child relationship, young adults, and sometimes even children. Become part-time carers for their parent.

Lizzie: If I think of uni times, you'd go home and be like, Oh, my mum's going to make me the dinners, you know, everything's going to be done for me.

And it's kind of like a little holiday in a hotel when you go home to see your parents. And my dad used to honestly spoil me like a princess and he would bring me like a fried breakfast every Saturday and Sunday to my room. When I would go home, it was put on your carer's hat, and it was how can I support Mum, how can I do anything in this house to make it easier for my mum, and then how can I care for dad to give Mum respite.

So as lovely as it is going home, it [00:10:00] was put on your carer's hat to help in any way you can. There was big chunks of time where I wasn't able to go home, and so you would then see the difference in behaviour quite drastically from having those gaps apart. To see dad's abilities, you know, lessen every single time I was going home was really like a really emotional thing for me as I left.

I would keep it together at home and then I would drive down the motorway in floods of tears processing what changes happened since the last time I'd visited. I think there's more support going for children, which is absolutely fair enough, and also for, for older adults, but for kids of parents with dementia who are still quite young people who are in their 18 to 35 forties, like in that age bracket of young adult, I feel like there is a lack of support there, especially when they won't live at home. They'll probably live somewhere else. They might not even live in the same [00:11:00] country. So it is all of these different things that they have to contend with.

Jim: One of the other challenges Lizzie now faced was managing the separation between her personal and professional life.

How much are the two supposed, or allowed, to blend?

Lizzie: You're meant to keep everything professional and you want to impress and you want to kind of get your foot into whatever career path you want to do because you're fresh out of uni and you're full of these like energies. I remember being in a fitting for children's wear actually and having my home phone number pop up on my phone.

And it's my dad, and he's pretty much non verbal at this point. So I'm thinking something's wrong, I'm panicking, he's just giggling on the phone. I'm in an absolute state, but also being asked to fit something, and I'm being tugged in this direction because I can't just stop a fitting to say, I need to deal with whatever this is.

It kind of felt that I was just being pulled in these two mental directions, and that was an [00:12:00] impossible thing to kind of balance for a long time. As the months and years went on, I was really unable to separate that side of my life from work. And fortunately, I work at such a great company for how they supported me during that time.

I remember my, one of my bosses was like, How are you doing? And I cried my eyes out to him, and I had to sit in his office, and he was, it sounds so small to say from a, from a boss, but when you think about how corporates run, you, you might not always expect that, especially when you're in your twenties.

Jim: Now some of Rob's symptoms that Liz has mentioned, loss of speech, giggling, staring, frontotemporal dementia. And it's often the behavioural changes, especially in someone as young as Rob, that can be misconstrued by strangers.

Lizzie: When Dad was out walking, he's six foot something, he's a big guy, he's not talking anymore, so imagine you're walking past him and he stops in his tracks and he just stares at [00:13:00] you.

Women, and I understand this, women would be like, what's going on? That's quite threatening. Men would find it aggressive. And we had a lot of instances where men were aggressive to dad and he couldn't respond to them verbally. He might giggle or he would just would continue staring. We had instances where he would come home quite upset from a walk.

We were in a car park and a young, a young guy, I think roughly about 14 maybe, started on my dad because he was staring at him in front of all of us. And it was like, well, if we, we need to protect you and if we even were with you, and this is still happening, something needs to drastically change.

Jim: So Lizzie came up with a simple idea to make her dad a t shirt.

It said, 'Sorry for staring, it's just my dementia.'

Lizzie: Thankfully, he wore it, and luckily, as soon as he did, the public's perception of him changed. They offered help, and they were so much kinder, um, just because they then instantly knew what was going on. [00:14:00] It's a very simple strategy. Not everyone would wear a t shirt that said that, for sure.

But it definitely worked in our case and we were able to continue dog walks and along with handing out cards at restaurants that said, Hi, I'm

Rob and I've got dementia. We were doing all the things to try and raise this awareness, but we really needed something so visual because of his particular symptoms, it had to cut through the noise instantly.

Jim: Inspired by how effective Rob's t shirt had been, Lizzie started a social enterprise called, This Is Dementia. She made t-shirts with dementia themed designs and sold them to raise money for Dementia UK. It was about raising awareness, but for Lizzie, it was also about finding something she could do.

Lizzie: Probably a lot of my coping mechanisms went into this business to help me deal with what was going on. I funnelled it into my work. This is dementia and the social Instagram page that we have built that [00:15:00] community for people to also reach out because I personally really struggled in my twenties trying to find support groups for dementia.

I remember calling up the GP or calling up all of these local, um, dementia action groups in London saying, can I come along? I feel I need support. And I was turned away from them all because I didn't have dementia and I wasn't bringing my dad. So I was kind of like, had the door shut on me from all these angles.

I was trying to access support. So then I created my own little bubble of support that people could come to. And I've actually made some great friends from that who were 20s dementia, their mum's got dementia, or they're concerned their mum or dad has dementia. What do they do? And it's kind of created a platform where people People feel that they can be open.

Maybe they can't talk to their friends about it, they don't understand, they're supportive, they don't quite get it. There's someone online that can reply to them, giving kind of positive steps that they can take.

Jim: Back home, Lizzy's Mim, Barbara, was getting support from her local Admiral Nurse.

Lizzie: [00:16:00] So when Dad was diagnosed, Mum got given tons of leaflets.

One of them was Admiral Nurses.

Jim: An Admiral Nurse is a specialist dementia nurse, supported and developed by Dementia UK. They provide free advice and support to families caring for a loved one.

Lizzie: I would say that her Admiral Nurse was her lifeline. She was there for all of the trials and tribulations that came with it, and was able to offer her that neutral support.

She was able to be like, well this is where you're at right now, and this is what you can expect coming up in the next few months. I'm not going to give you the whole timeline, we're going to go at your pace. She would obviously have the two hats on. wife and carer and parent and would want to obviously protect John and I from what was really going on and how bad things might be getting.

But she had Tracy there to be able to support her through that.

Jim: In 2022, Rob was hospitalised for an infection. [00:17:00]

Lizzie: Following that hospital stay, he was bed-bound. He couldn't go up and down the stairs, he could get out of bed with help, to go into a chair, but pretty much was bed bound for the last two years of his life.

There was so many different teams that were trying to implement the best care for Dad through hoists, through different chairs, through different beds, through the flooring we had. Mum's obviously thinking, 'Where do I turn for this?' And Tracy was the one in the middle of that cobweb, kind of connecting the dots and guiding us through.

Jim: And of course Lizzie and her brother John did their best to look out for their Mum.

Lizzie: I think, and I like to hope that I was like this, that we never made her feel like she wasn't there for us. She was there for everything that we go through in our lives. She's there for everything. So for me during this time, it was really What can I do for mum?

When I'm home, is it, you know, the dishes? Is it making dinner? Is it walking the dogs? So really being that part time carer and giving respite so she could go away and not stress and [00:18:00] not be worried that dad's not okay. You know, trying to shift that relationship to being the carer was a tough one. Things that we did was always linked to his passions.

So he loves football. So when we were no longer able to go to the games anymore, it would be watching games with him at home, making sure we had all of the sports, getting Sky Sports, whatever it was, all the sports were available to him. We would also try things like headering a balloon and there's like this beautiful video that I love of Dad and I headering a

balloon for each other for ages and you can see in this video his smile and his genuine affection for the game and he's engaged in it, like fully engaged because he recognises what it is.

So we would always adapt it and I think finding joy in something like that. It's something that I've come to terms with, like, throughout his diagnosis. Not being sad that I'm having to engage with [00:19:00] Dad in a balloon format, or whatever it is. It's seeing how happy he is, and seeing that he's content, and he's enjoying life as much as he can.

That's all we can wish for. Not to, to get away from the emotion of it, there were times where I would be so upset and sad and heartbroken that things that we used to do as quite traditional things, we could no longer do. Like, for instance, every Christmas Eve. Dad and I would always go for a walk. It was something we always did before we'd have this big buffet.

And so I remember the first year that we just weren't able to do it. And thinking that that's ended. Throughout his dementia it was these constant grieving milestones that you hit which are very personal to your own relationship with that person. Every time he couldn't do something, you've lost that and it's that repetitive feeling and you constantly have to bounce back and you constantly have to adapt and you put on a good face and you keep going and so it can be very exhausting but seeing him [00:20:00] have enjoyment is ultimately what it's about.

Jim: By Spring 2024, Rob had been mostly bedbound for two years.

Lizzie: We were always told that if he loses his ability to, to swallow and to drink, then you know, that's alarm bells. And we were starting to see that symptom creep in. But also this happened before and he got hospitalised and it was an infection and he came back from it.

And I remember when that happened two years ago that I was thinking, this is it. I was fully mentally prepped for the worst then. So then when it happened this time round, part of me was thinking he'll.

So he did have an infection. He went to hospital. He was then in hospital for two and a bit weeks. They treated him for sepsis, I think pneumonia. He was on oxygen for two weeks, he wasn't really eating, but no one was saying the black and white he stopped [00:21:00] swallowing and eating because of his dementia.

That didn't get said until two and a half weeks in, and then it turned into palliative care, and trying desperately to get him out of hospital and get

him back home so he was in his own surroundings. We'd spent quite a bit of back and forth trying to get that care in place, speech and language teams, the hospice teams.

Again, that, you know, huge army of people there to help, but trying to coordinate them all. So we eventually got him home. He passed away in his own bed, in his home, with us around him, so Like, that's how it should have been.

When he passed away, we didn't know how to feel. I remember my saying it wasn't a joke. Like, this really happened to us. And that kind of, almost fake life that we've been living for the last six years, which seems so bizarre to us, was real. And there's that full stop, and that's done. [00:22:00] And I didn't believe it had happened.

I just went out into the forests with the dogs. Mum said to my brother and I, "Do what you need to do today and we'll regroup. Everyone grieves differently, everyone has a different approach." I loved that she said that. So yeah, I escaped. I escaped to a National Trust forest and was there for three hours, and the sun came out, and it didn't go away for about two weeks, and we had that lovely sunshine.

That was really such a healer for me, just to walk it off, in a sense, like, walk through my mindset, what was I thinking, how was I feeling, if floods of tears came over me. They came and I had my partner and my best friend with me and we just let it happen. Following that it was, I had this urge to just go somewhere so we went camping and we just went and just kind of got off the grid, went camping with the dog and I just got to think about dad and think about what's happened and kind of process it in my own [00:23:00] way.

My mum said something beautiful and was like, "We have, we have to look forward at the same time." So we always have to have our foot in the future. In losing dad. I really actually reconnected with who he was before dementia, which I'm so pleased about. Because for the last six years, all we've seen of Dad is him deteriorate, his personality's kind of, you know, disappeared.

His facial expressions have changed, his physical appearance has changed, and the man he was at the very end is definitely not the same. The man he was for the majority of his life. So following his, his death, like my memories of strongly of how he was before. I'm really pleased that that's how it is in my head.

When you're in the midst of it all and you're dealing with something like this and you're caring. I for sure forgot. How it was before, and part of

me was like, have I lost these memories? In the kind of conclusion of his dementia, it's kind [00:24:00] of reawoken, you know, who he was before.

Jim: A big thank you to Lizzie for sharing her dad's story. The experience of young carers often goes under the radar when people think about dementia. But Lizzie is far from alone. You, or someone you know, might be going through something similar right now. So two of Dementia UK's Admiral Nurses, Hilda and Vic, are here to share some advice on the themes from this episode.

Hilda: I'm Hilda Hayo and I'm the CEO and the Chief Admiral Nurse of Dementia UK.

Vic: Hi, my name is Vic Lyons. I'm one of the Senior Admiral Nurses at Dementia UK.

Hilda: We've just heard from Lizzie about the experience her dad, Rob, had, uh, with young onset dementia. Often people with young onset dementia have a different set of [00:25:00] symptoms than you would expect to see for older age dementia.

So what we've just heard from Lizzie is how her dad's behaviour changed. Uh, he began to stare more at people and that made people uncomfortable. Um, they saw a person standing in front of them that looked apparently normal. So when he was staring, they thought there was an intention to that. Actually, this is a condition called young onset frontotemporal dementia.

It always reminds me of a client that I worked with, and they were big churchgoers, and the wife was mortified because her husband stood up in the middle of the congregation and told everybody they were hypocrites, and they talked too much. So very often that kind of gateway that stops you from saying inappropriate things, even if you think it, just isn't, isn't going to work effectively. It's wide open.

Vic: The other thing when, when we were listening to the story is thinking about for young carers, how they can feel almost sometimes, and I don't want to assume this was the case for [00:26:00] Lizzie, but almost a sense of embarrassment, or this isn't, this isn't how I want my dad, my person to behave, how I want them to look and be perceived by the world.

And I've certainly worked with a number of carers in the past who, who've struggled with that, the sense of who dad is, who their parent is

and how they should present. And then you lead into a feeling of guilt as well, because you then start feeling quite guilty that you feel that way. You shouldn't feel that way.

Lizzie also talks about the transitions that she was in, the stage of life that she was in, and around actually what to discuss at work. Deciding how much to share in the workplace is a personal thing to some extent, because you know your workplace environment, you know the line management support you've got, you know what you feel comfortable discussing.

A supportive workplace ideally should have. Programs in place to support people. They should allow flexible working for people. They [00:27:00] should have schemes in place to allow employers to, to manage their, their stress, their anxiety, to, to, to take these concerns to there. And, and in an ideal scenario, you know, you would want someone to be able to have this conversation with their boss and, and talk to their boss about the fact that there was this other side of their life where they had to do some caring or have care responsibilities for somebody else.

So I think there's lots of challenges that are going to be around this and the way to kind of balance these challenges and overcome them is, it always goes back down to communication. It goes back down to having a really open dialogue and talking to people. Obviously, professional help might be something that's needed to really kind of guide you through these things.

And then actually working out what care package is available. Making sure that you're aware of the support services that are out there and, and then talking openly and honestly about the impact that, that this new normal is [00:28:00] having on you and your relationships.

Hilda: Really good points Vic, and I think sometimes people don't actually offer the services and support to people with young onset dementia.

One, because those services don't exist. Don't exist specifically for that age group in some areas of the country, but on top of that, some of the services that are set up for older people, people over the age of 65 won't accept people under the age of 65 and therefore don't give the right advice to those families about, for instance, how to get financial help, how to get help in the workplace, how to get help at school for Children that are still of school age.

So I think with most situations with young onset dementia, it is a little more complex Because we haven't got the system set up to deal adequately with young onset dementia.

Vic: So you end up having to educate yourself largely about it, don't you? And that's why things like the young dementia network is really helpful, and our Consultant Admiral Nurse for [00:29:00] Children, another service that's really helpful because it's a totally different. Dedicated, tailored resources that are there to help families who are living with young onset dementia.

Hilda: Absolutely.

Jim: 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](https://www.dementiauk.org).

You'll also find links to the website and other resources in the show notes for this episode.

Thank you so much for [00:30:00] listening.