Chloe and Amy - storyteller episode 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 a 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,

Chloe: I never really second guessed any of that, helping out and assisting mum with anything to me like mum was mum. She did that to me when I was young, so in a way, the [00:01:00] best I could do now or back then was to give that back to her as well.

Kola: Chloe and Amy were just 12 and 18 years old when their mum, Sarah, began to show symptoms of young onset dementia. At the time, Chloe was in secondary school and Amy was working in her first job as a legal secretary.

Over the following four years, the two sisters and their dad Rob became full-time carers as Sarah's dementia rapidly progressed under incredibly challenging circumstances. The three of them pulled together as a team supporting each other to juggle work, school, and looking after Sarah when their mum died in November, 2021, in marked the beginning of a new chapter for Chloe and Amy grieving the loss of their mum and all the life ahead of them that she would miss.

Amy: I am Amy Lambert. I'm 28 years old from Southeast London. [00:02:00]

Chloe: I'm Chloe Lambert, Amy's sister, and I am 22 years old, also from Southeast London. So we grew up with our mum and dad. Rob and Sarah. And then we've got an older sister as well called Becky. And we've also got a dog called Betsy.

Amy: Growing up with our family was always very funny, very hectic. Um, we used to take our Sundays very seriously 'cause that was always our family day, wasn't it? Mm-hmm. Yeah. We'd always, you know, pop out to the shops or go for a walk-in Greenwich or something. As we kind of both got older, mum would take us to go see musicals in the West End.

Chloe: Yeah, we loved the theatre

Amy: and that was always like a massive thing that we always, all three of us kind of bonded over, wasn't it? We'd always like put show tunes on as well in the car when we were like gonna go see like our great granddad and we'd all be singing along. So yeah, I think we can kind of say that we were quite a loud, bubbly family.

Definitely. Definitely. And it was [00:03:00] definitely full of a lot of love.

Chloe: Yes, definitely. We might not be musically talented, but

Amy: we really

Chloe: tried. We were in in that 30 minute car journey. We

Amy: were. Yeah.

I do remember you being born. Holding you for the first time. It was a really weird and surreal moment. 'cause I've always, I always wanted like my little best friend. Yeah. Because I was, you know, about six or seven when you were born. It was just really lovely life changing moment for life, changing moment for me.

I think we definitely have a stronger sisterly bond than hundred percent any other kind of sisters that I know.

Chloe: Yeah,

Amy: I think that's because we've kind of experienced so much together.

Chloe: Yeah,

Amy: and probably 'cause you were so young as well when mum got diagnosed that I did kind of have to step up to be that maternal role for you.

Definitely. Which was definitely a challenge. You weren't the easiest of teenagers, but

Chloe: keeping you on your toes for sure. Definitely

Amy: keeping on my toes. [00:04:00] Yes.

Kola: Chloe and Amy's mum, Sarah, was a teaching assistant at their primary school.

Chloe: I remember walking to school each morning with mum. Those 10, 15 minutes were the best time of the whole entire day, weren't they?

Yeah, just we used to talk about anything and everything.

Amy: Dad used to be a baker, but he actually had an accident when I was about eight years old. Yeah. Um, which left him disabled. So he was retired essentially. Mm-hmm. And mum was his primary caregiver? Yes. For a lot of our childhood. I think that kind of says a lot about who she was as a person.

She was very loving and one thing that everyone like always used to say about her was just how like friendly and funny she was and flappy, and I think everyone used to love her.

Kola: Around 2016, the family started noticing some changes in Sarah's behavior.

Amy: She would kind of go out, not come back with anything.

She would go shopping and [00:05:00] because she didn't come back with anything, she would then have to go back out. Her personality changed quite rapidly, I would say. So I remember like Dad and I kind of keeping a note of like what kind of changes we've noticed. Drive in became, you know, a bit more erratic. 'cause she was always a very safe driver and she would kind of forget how to do things.

I remember when she was cooking, you like chicken nuggets. Once she forgot to turn the oven on, for example. I think the big changes probably came in about 2017, the year before she was diagnosed. We went on a holiday to Dominican Republic. Yes. Where she would kind of go off and just go for walks.

Chloe: Yeah, always go for walks.

And whenever we had like dinner in the evening, there was loads of different restaurants. Yes. On the complex, but mum would always want to go back to the buffet just to get jelly for dinner. And [00:06:00] we tried to explain like, you know, there's so many other restaurants here.

Amy: Yeah.

Chloe: But mum was just fixated on the jelly.

Yeah. Jelly and ice cream, wasn't it? And

Amy: I remember one time it not being there, she was getting herself like quite worked up about it. That was definitely like a, a moment where all three of us kind of thought,

Chloe: thought something's not too right.

Amy: Yeah. Isn't it? Yeah. This is not mum. She wouldn't have done this a couple of years ago ago.

That definitely was like the turning point, and that's when dad and I kind of started exploring options into what could it have possibly been that's caused this. Menopause for example, like I thought it was menopause for quite a few months and I was Googling about that just to see what symptoms, and then I was trying to book her like doctor's appointments to get her like bloods and hormones checked and she would ring up as soon as they're booked to cancel them or just not turn up.

So again, things that are very, very out of character for mum, weren't

Chloe: they? Definitely

Amy: for sure. [00:07:00]

Kola: Chloe and Amy's dad, Rob, had spoken to his best friend about what was happening with Sarah and his friend's wife was a nurse. She was the one who first suggested that Sarah might have young onset dementia, which is when dementia symptoms start before the age of 65.

Amy: And I remember at the time thinking like she's way too young to, you know, even have that diagnosis because

Chloe: mum would probably, at that time was 46.

Amy: 47. 46. Yeah. And I remember that looking at all the symptoms and they just married up completely to what mum had because it made so much sense. Dad then, you know, started the ball rolling on getting mum a diagnosis.

There was a lot of tests kind of involved, but. I don't think she ever really understood, if I'm being honest. Yeah. But

Chloe: I think it was important for all of us to be a team. We just wanted to keep her reassured and keep her relaxed. And also kind of explain to her that we're a [00:08:00] team. We can get through this.

Kola: In June, 2018, Sarah was diagnosed with young onset frontotemporal dementia. She was just 46 years old. Frontotemporal Dementia is an umbrella term for a group of dementias that mainly affect the frontal and temporal lobes of the brain. These are the bits of the brain that are responsible for personality, behavior, language, and speech.

Amy: She was always quite stressed, wasn't she? Yeah. Once she was diagnosed and she was always very anxious after that as well. Definitely. So I think how we kind of spoke to mum was always kind of like in a jokey way or trying to like calm her down or a hundred percent. I would always like give her cuddles and then be like, I'd be annoying to her.

Yeah. So a

Chloe: lots more reassurance in that sense as

Amy: as well.

Chloe: Yes. I

Amy: want it, that kind of security, like you can trust us. I think I was about 19 or [00:09:00] 20 when mum first started showing symptoms and then was diagnosed. You were a

Chloe: lot younger obviously. Yeah, I was deep into like year seven and or and year eight.

Um, but yeah, very young to like kind of juggle with that as I'm sure in your early career.

Amy: Yeah.

Chloe: Having to juggle everything as well.

Amy: Yeah, definitely. Definitely a journey. Definitely hard, especially when you try and explain to people and because you're so young, people don't really expect you to have a parent who is quite that unwell.

Yeah. Having to kind of learn to be open and you know, explain to people about it. 'cause I think I've always been kind of private. That was a really hard moment for me, so I can imagine that was probably very hard for you as well.

Chloe: Yeah, definitely. Especially with like teachers and friends. Everything just happened so fast after that.

Amy: Yeah. Everything after that moment when she was diagnosed, it seemed that she rapidly went downhill. Her [00:10:00] personality definitely changed quite rapidly. Yeah. But I think because we had the diagnosis, we. Could actually attempt to get somewhere with it. We could learn to understand the situation that we were in after that moment.

Definitely a lot more sensitive towards the subject and towards mum.

Kola: Amy remembers there was almost no information online about what frontotemporal dementia even was.

Amy: I do remember seeing it on Dementia UK's website. I remember printing it off and giving it to dad and like our Nan for example, just kind of sharing that.

So we all had like a wider understanding of it. It was a scary time for sure. Scary.

Chloe: Scary and confusing.

Amy: Very confusing. But

Chloe: not only mum, but all of us as

Amy: well. The whole family for sure. For

Chloe: sure.

Amy: Yeah. One thing I remember dad kind of saying as [00:11:00] soon as mum got really unwell was, you know, just, just in case she declines fast or you know, if anything was to happen to get the lasting power of attorney, both in finance and health over herself and him, and I remember being like 19 and dad doing that and thinking like, this is really scary.

No one at that age should kind of be doing that.

Chloe: Yeah, absolutely.

Amy: You were a bit too young, I think, to be a part of this conversation, but, um, I think one of the social workers when we were sorting stuff with them, um, asked the question of like DNR, so, uh, do not resuscitate. And I remember dad not wanting to answer without speaking to me, and that was a really easy but difficult decision because it was a straight up.

DNR. Like, we don't want, like, she's already got enough. We don't want her to, you know, if anything was to happen, yeah. [00:12:00] For her to then wake up and be even worse or even more confused. And that was a big thing, but it was such an easy answer just to be like, no, like we, like we, we definitely want a DNR in place.

Kola: As the whole family began adjusting to this new reality, Amy and Chloe both benefited from counseling. Amy began to see a counselor who offered CBT cognitive behavioral therapy.

Amy: I, obviously, I've always had anxiety, haven't I? So, um, thinking it was that moment where it was kind of like, need to talk to somebody about this and understand kind of Yeah, definitely.

And learn how to deal with it. I remember after that kind of being still angry at the world that, you know, this has kind of happened to

Chloe: us. Yeah. And like why us? Why mum in

Amy: that? Yeah. Because it was always those questions percent between us wasn't there, like why? I remember us crying a lot lot of the time at that time just kind of crying and saying like, why.

But I think CBT kinda helped [00:13:00] me understand how to deal with my own emotions on like an external level. I remember your school. They organised some like counseling for you, didn't

Chloe: they? Yeah, I remember, I think you probably called up the school and just explained like, is it okay if Chloe goes on like the waiting list for a counselor and Oh

Amy: yeah, that was me.

Chloe: Yes, that was you. And there literally two weeks later, I had a session with my counselor. Sometimes I wouldn't even speak to her. I would literally just go in the room and just cry. Having that outlet to someone. Yeah. Who isn't in your like household, but just to have that external person, again, an outsider,

Amy: even listen to you

Chloe: listen, it was like a shoulder to cry on kind of thing.

Kola: Chloe kept seeing the counselor all through school and for both sisters having that outside support was invaluable. Because even though both of them were still so young, [00:14:00] they were rapidly becoming full-time carers for their mum.

Amy: I think it took about a year for her, not even a year, probably about nine months for her to one day be going out by herself.

Going for walks. Yeah. Taking Betsy, our dog. Taking Betsy. Yeah. Um, to then, not because she would getting lost, um, or asking questions on where she's going, even though we've always lived in the house that we lived in. It was quite a rapid change in that kind of like nine months to a year because I was full-time working.

You were obviously at school. I think dad, you know, was at home with her every day kind of doing that side of stuff. Um, and I don't think it was until like COVID uh, where I obviously was like working from home. You had no school, and I think it was from that moment that. I massively saw the change.

There were things that obviously Dad would tell us, [00:15:00] and that was the moment where I was kinda like, I'm actually seeing this like play out in action. COVID in itself was a blessing because we got to spend so much time with mum, hundred percent, and looking after her, we would have to take her, you know, for like walks ourselves or we had quite a big garden, didn't we?

So we would go for walks around our garden.

Chloe: I do remember we did some like painting like

Amy: Yep.

Chloe: Uh, pens and

Amy: she got bored pretty quick of that. Yeah, she

Chloe: did.

Amy: And jigsaw puzzles.

Chloe: Her attention span. Yeah, the jigsaw,

Amy: her attention span got a lot worse. I think it was COVID as well where mum. Became like incontinent and required a lot more of the like, round the clock care.

Uh, for example, like showering her, getting her dressed in the morning, getting her to take her medication, waking her up, putting her to bed. And I remember that being like, we all take a shift. Yeah, definitely. And we all chip in. We all help because we were all at home.

Chloe: Yeah.

Amy: It was no longer just [00:16:00] on one person.

Chloe: One person. We were a team.

Amy: Yeah.

Chloe: We were all playing our part in it. If we didn't all play our part in it, then we wasn't unit No. Like we were, we've always said from the start,

Amy: we do this

Chloe: together. We're all in this. Exactly,

Amy: yeah.

Chloe: All in this together

Amy: and, and we all support each other. If one of us got a bit too overwhelmed.

Absolutely. It was always you walk away, like you walk away from it, you calm down, you don't get upset or anxious. Like you just try to put on like a brave face in front of mum.

Did you ever find it like difficult when mum became like incontinent for the first time or us having to like do more around the clock, for example?

Chloe: To be fair, like I never really second guessed any of that helping out and assisting mum with anything to me like Mum was mum, like she did that to me when I was young.

So in a way, the best I could do now. All back [00:17:00] then was to give that back to her as well. I just didn't really second guess it. I thought, that's my mum, so of course I'll help. Like that's our mum. So a hundred percent. Yeah. That was our job.

Amy: Yeah,

Chloe: that was our role, and

Amy: that was the cards that were handed to us.

Kola: Although Chloe and Amy tried to take everything in their stride by 2020, Sarah's dementia was much more advanced than the family had expected it to be at that point.

Amy: The next big thing for me where I was like, this is again, a huge declining moment, was when I used to have to feed her around the dinner table during COVID as well. Dad would do all of us dinner, but I used to have mine a lot later and I used to come down every day at about five o'clock. 'cause that's where mum wanted dinner.

Um, and I was still working at the time, but I would just say five o'clock is the time I'm helping out with, yeah. You know, my family, I'll log back on at six o'clock, [00:18:00] which is exactly what I used to do. But that's when I used to come down and feed mum just because she. Would choke quite often, wouldn't she?

Yeah. She would eat very fast, get very sick,

Chloe: drink too much,

Amy: drink too much, yeah. And get very sick. Definitely. So having somebody else kind of feed her, I think obviously made him a much less stressful environment to, for the family to eat in. 'cause I think we've always been very big on that. Like families eat together.

Mum instilled that in us a very young age. Sure did. So we all wanted to do that. But um. Yeah, I remember that being a moment where I was like, again, we are declining far more rapidly than what

Chloe: the timeline. The

Amy: timeline kind of suggested.

Chloe: Yeah. This was probably around the same kind of time when mum's speech was also declining as well.

Yes. So you'd ask her a question and sometimes you used to just get a nod. You could probably kind read her eyes. [00:19:00] Yeah. Can you and her face a little bit?

Amy: Yeah. She. Rarely ever spoke towards like the last year and a half. Definitely. I definitely would say. Um, and if she did, it would be yes or no answers.

Yeah, that was again a huge, I agree with you. Huge moment.

Chloe: Huge decline. Yeah.

Amy: Um. But

Chloe: you would always used to get a smile. Wouldn't you? Always

Amy: used to get a

Chloe: smile? Always used to get a smile.

Amy: And she had the kindest eyes. She

Chloe: did. She,

Amy: and you'd always know what she was thinking. If she was up to mischief.

Chloe: hundred percent, she would.

She wants that last custard cream. She get that last custard cream.

Amy: Yeah. She would cause mayhem still. She would, she would absolutely raid the, uh, snack drawer, wouldn't she?

Chloe: Definitely.

Amy: And she knew what she was doing. She had the mischief in her eyes. Yeah. And she would just be like, whatcha gonna do? That was always very funny.

That was, we always had something to like. Laugh and joke about. Yeah. Would you be like, can't do that. You're so naughty. So cheeky. That was my thing for her. Cheeky, cheeky. Cheeky or funky? Yeah, funky being a little bit funky

Chloe: today. Yes, [00:20:00] definitely. Yeah.

Kola: Rob, Chloe and Amy were a remarkable and strong team, but they had been doing everything by themselves.

As Sarah's care needs became more acute, they decided to try experimenting with respite care. That's when a person goes to stay in a residential care setting for short periods at a time. It can give everyone a chance to have a break and an emotional reset too.

Amy: It was getting at that point, very full on.

So she used to have respite care every six weeks and she used to go in for about two weeks and that was just kind of time for, you know, her to kind of get a break from us. 'cause I'm pretty sure we were very full on looking after her and for us to kind of have a break and. You know, have,

Chloe: it's a normality back,

Amy: isn't it really?

Yeah. Spend time as a family, like even going down to like, you know, [00:21:00] Whitstable to have fish and chips after work, for example of school.

Chloe: Definitely something so silly and so little looking back, but it meant the world back then.

Amy: That meant the absolute world. And I remember. One day I had the day off I think, and dad was like, do you wanna go Costco?

And me thinking this is the biggest deal ever. Like this is really exciting. Yeah. Um, which is really silly, like to think about, but it was, we never kind of got that opportunity to spend time as a normal family. Yeah.

Kola: In April, 2021, social Services did an assessment and recommended that Sarah should have paid carers helping out at home too.

Amy: And so we had carers in a few times a day, didn't we? And about

Chloe: it started off about three then soon after, it was about four times

Amy: a day, I think. Four times a day. Yeah. Yeah. And again, that kind of took a lot of pressure off of us. It just kind of gave us a little bit of normality. Like I could focus on work, for example, dad was able to like [00:22:00] go out with his friends.

Yeah. And you know. He used to do his like Yeah. Model train, didn't he? So that was his like little like escape so he could actually focus on doing that. It meant that you could go to school, do your homework

Chloe: and at the weekend on the Saturday, yeah, we used to get a carer in called Bella. We used to get Bella in and she would be there from 10 till four.

And then obviously that meant that. We also had our weekends as well.

Amy: Yeah, we had one day on the weekend. Yeah. Day where we could, we used to actually just go to Greenwich Park.

Chloe: We did, and we kind of brought back our tradition of going to a musical.

Amy: Yeah, we did

Chloe: as well. Obviously mum wasn't there, but yeah, it felt nice to do something

Amy: together again and spend time together and kind of have a little bit of pressure off, I would say.

Kola: The team of carers helping make all this happen became a really important part of family life.

Amy: A few of them actually came to like mum's funeral. Yes. And kept in touch after like they [00:23:00] were absolute angels

Chloe: outstanding.

Amy: They were incredible people. I would say if anyone was considering respite carers, like it's not shameful to ask for help.

I wish we did it a lot sooner.

Chloe: Looking back now.

Amy: Because it didn't mean we didn't spend as much time with her because we were always there.

Chloe: Yeah.

Amy: But it just meant that if we needed to do something, then

Chloe: we needed that break.

Amy: Yeah.

Chloe: We needed an hour away.

Amy: Yeah.

Then

Chloe: we had that.

Amy: Because you can't be running a hundred percent caring for somebody working, studying all the time.

You do need that break, and I think until we started to get the help, we were like, well, we were doing so much. Yeah.

Chloe: So, so much.

Kola: Chloe, Amy, Rob and all their carers all worked together to look after Sarah right up until late 2021

Chloe: on Monday the 22nd of November. We got the [00:24:00] worst news ever. And yeah, we found out that mum had passed away.

And whilst

Amy: in respite care,

Chloe: whilst in respite care, we was meant to pick her up in

Amy: two days.

Chloe: Two days time. Her birthday would've been on the Sunday. I remember dad running up into your room on the phone and I don't think dad said anything. I think he just passed the phone.

Amy: Yeah.

Chloe: Over to you. And I came out of my room.

Amy: You knew. Instantly.

Chloe: Instantly. And I just speechless.

Amy: Yeah.

Chloe: I think all of us were really.

Kola: Sarah died just a few days before her 52nd birthday from a brain hemorrhage that was unrelated to her dementia. Amy was 24 and Chloe was 18.

Amy: Literally just getting that call and then having to like take over and go into full-on like.

Mode of, yeah. Okay, [00:25:00] we'll go see her now. Then we're on our way. Then me having to then tell our grandparents, for example, our grand example, our older sister.

Chloe: Yeah.

Amy: And I think I was the only one that could actually talk. At the time, I think you and dad were in pure shock, and I think that was just being my brain, just going, okay, we need to cope with this.

We need to cope with this.

The day after mum passed away, we had a lot of the family over, didn't we?

Chloe: Yeah.

Amy: Um, where we were kind of just all sitting there in shock, you know, started to talk about like funeral plans and I remember when everyone kind of went home and I think all three of us kind of looked at each other and said like, well what now?

Chloe: Like, what now? Like, what is. What do we do so much before that we had a purpose.

Amy: Yeah, I a hundred percent agree with you on that. I think after that it did feel like we didn't have a purpose, which was weird. And again, I think on reflection a couple of weeks [00:26:00] after, it was kind of like, I have no idea how we even dealt with that, but I think that proves how much of an autopilot mode that we were kind of on.

Obviously dad going from, you know, looking after her every single day pretty much for around four years to then, you know,

Chloe: don't need to,

Amy: nothing.

Chloe: Nothing. Yeah.

Amy: And that was a huge transition,

Chloe: I would say. And that was really difficult. I found it hard to bounce back to what normal life

Amy: Yeah.

Chloe: Was or would've been, and just having loads of free.

Extra time.

Amy: Yeah. I remember sitting there on one of the like afternoons or evenings a couple of weeks after mum passed, and I was literally praying that I could do all over again.

Kola: It was [00:27:00] only after Sarah died that Amy and Chloe truly realised how hard those last few years had been on their mental health.

Amy: I just remember feeling like really burnt out. Obviously I was working full time, obviously caring for mum, looking after you, you know, trying to have some kind of social life on the side.

And I think it wasn't till

Chloe: like looking back.

Amy: Looking back,

Chloe: yeah.

Amy: I didn't realise how burnt out I was. And that was actually the moment that I went onto like medication for anxiety.

Chloe: Mm-hmm.

Amy: And just. Actually being able to take a little bit of time. For me, that point around burnout I think is really common in carers because it's one of those things I think at the time you don't kind of realise until something happens.

Chloe: Yeah.

Amy: And then you kind of reflect on it and you're like, I don't actually know how I was functioning. And I know you probably felt the same as well.

Chloe: Yeah, definitely. I [00:28:00] think it's probably just 'cause you're so involved in a, caring for that person. B, making them like making your loved one feel safe and making sure that they're okay.

You kind of like lose yourself within that and yeah, it's so important to also make sure that you are okay as well because if you are not okay, like how is the team or how is your loved one also going to feel that way as well.

Amy: Yeah, I think that's actually a bit of advice I'd probably give to anybody.

Yeah. Who's

Chloe: like listening

Amy: or. Is going through what we went through.

Chloe: Definitely self-care is important. Yeah. Just as much as the person you're caring for is as well.

Amy: And it's not selfish,

Chloe: not, or shameful

Amy: to ask for help.

Chloe: No, that's why help's there.

Amy: How have you found the last few years since mum's passed? Like how have you dealt with like the grieving process?

Chloe: Yeah, I think. Grieving, it comes in waves. It's very up and down. One day [00:29:00] I could have myself somewhat like emotionally controlled.

Amy: Mm-hmm.

Chloe: And then other days could literally just be crying on the way to work, crying in the shower, crying before bed and stuff.

It's very staggered and it's not like a straight timeline. Obviously having worse days and better days and stuff, but having grief on a person such as mum and like a loved one just proves how much they were loved. There was a really good quote that I like where there is deep grief. There is great love.

Amy: Obviously I've moved out, um, and that. It was really difficult because that was the moment where I was kinda like, mum's not gonna be there for both of our like milestones, big moments and milestones in life. And I think that has kind of happened over the last couple of years as well. Like sometimes a girl just wants her mum.

Chloe: Yeah, [00:30:00]

Amy: I think this year I was expecting to feel really like sad on mum's anniversary date and for this year it just. Didn't come, but the day after I was so overwhelmed with like, anxiety, sadness, and I think because you, I put so much pressure on the day that it just, it didn't come. Yeah. And I actually looked, it like looked that up after, and that was really common of people saying like, it was always the day after where it's that kind of like, oh my God, like that days happened.

Understanding that other people kind of feel the same. That was really reassuring

Chloe: Looking after mum and caring for her and all of the other like years after. It's made me such more of a patient person and just truly understanding that you really dunno what everyone else [00:31:00] is going through on their day-to-day life.

And just respecting that a little bit more and just being more patient, I think.

Amy: I would 100% agree with you. Mm-hmm. And looking forward, I just want her to kind of be proud of me. I want to do life. You know, thinking of her.

Kola: Chloe and Amy are now 22 and 28 years old. Chloe works as a legal secretary at a law firm, and Amy is at a different law firm working in the community impact sector.

Dementia remains an important cause for both of them. They first raised money for Dementia UK by asking for donations instead of flowers at Sarah's funeral in 2021, and they've continued to support the charity ever since.

Amy: I think we raised a considerable amount, maybe like a couple of thousand from the funeral donations alone.

Chloe: I ran the London Landmarks half [00:32:00] marathon last April for dementia UK in mum's memory and roughly, I think, again, I raised. Round two and a half thousand pounds.

Amy: We just kind of wanna help and educate and you know, if there's a family or somebody that needs the help of

Chloe: yeah,

Amy: the charity, then having that available to them.

Hundred percent. Like

Chloe: it's the most important.

Amy: Yeah.

Kola: Thank you Chloe and Amy for telling us about your mum, Sarah, and for sharing your experiences of navigating caring and grief as young people.

If you’re in a similar situation to Chloe and Amy, you may find our next episode especially useful. Dementia UK Admiral Nurses Hilda and Vic dive deeper into some of the themes that came out in the episode, [00:33:00] offering advice from their perspectives as 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 an 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.